SPEECH AND LANGUAGE THERAPY SERVICE DELIVERY FOR CHILDREN WITH CEREBRAL PALSY IN THE REPUBLIC OF IRELAND: COMPARATIVE PERCEPTIONS OF PARENTS AND SPEECH-LANGUAGE THERAPISTS

BY

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Dissertation in Fulfilment of the Requirements of the MSc Degree in Speech Pathology at the University of Cape Town, South Africa.

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February 2008

ABSTRACT

Cerebral Palsy (CP) is one of the most severe developmental disabilities in childhood. Children with CP frequently have multiple disabilities due to associated cognitive, sensory, behavioural and digestive problems, which complicate management of the disorder. Limited research in the area of Speech and Language Therapy (SLT) service delivery for children with CP; a chronic shortage of Speech-Language Therapists in the Republic of Ireland (ROI) resulting in many children with CP on waiting lists; and consequently the parental concern and dissatisfaction with the lack of SLT services available in the ROI (evidenced by government debates), indicated the need for a research study to investigate perceptions of SLT service delivery. The research question addressed the perceptions of parents and Speech-Language Therapists regarding SLT service delivery to children with CP. The degree of concordance between parents' and Speech-Language Therapists' perceptions was determined. A descriptive research design was employed to address the research question using quantitative and qualitative research methods. Data was collected by the use of the Measure of Processes of Care (MPOC) and Measure of Processes of Care for Service Providers (MPOC-SP) questionnaires, focus group discussions, and document analysis of official documents. Participants who completed the MPOC questionnaires comprised of 45 parents of children with CP and, for completion of the MPOC-SP questionnaires, 38 Speech-Language Therapists consented to participate in the research study. Eleven of the 45 parents, and 10 of the 38 Speech-Language Therapists were randomly selected to participate in focus group discussions. The data was analysed by employing descriptive statistics and using two raters to identify the degree of concordance between parents' and Speech-Language Therapists' responses on the questionnaires. Qualitative data was yielded by the questionnaires and responses in focus group discussions, and was subjected to thematic analysis involving the researcher and an independent rater. Comparisons were made between participant responses and information contained in official documents of health and education service providers. Results yielded information in terms of the strengths and weaknesses in the following service delivery areas: (i) enabling and partnership, (ii) coordinated and comprehensive care, (iii) respectful and supportive care, (iv) providing general information, and (v) providing specific information about the child. Overall, parents and Speech-Language Therapists expressed particular dissatisfaction over the lack of general information available to parents of children with Cerebral Palsy. Areas of strength and needs within the other service delivery themes were also identified. Twenty-nine key recommendations were made related to the informational needs of parents, relationship between parents and Speech-Language Therapists, communication, the role of parents, supports for families and speech-language therapy service delivery. The outcome of the investigation resulted in an understanding of parents' and Speech-Language Therapists' perceptions of SLT service delivery to children with CP in the ROI. Gaps, in service provision for children with CP, were identified and recommendations were made to relevant stakeholders regarding the service delivery needs highlighted in the study.

KEY WORDS

Speech and Language Therapy

Children

Cerebral Palsy

Parents / Caregivers

Service Delivery

Health and Education Service Providers

Republic of Ireland

Perceptions

ABBREVIATIONS

CP	Cerebral Palsy
SLT	Speech and Language Therapy
ROI	Republic of Ireland
NPSDD	National Physical and Sensory Disability Database
DVD	Developmental Verbal Dyspraxia
DAS	Developmental Apraxia of Speech
HSE	Health Service Executive
AAC	Alternative and Augmentative Communication
RCSLT	Royal College of Speech-Language Therapists
IASLT	Irish Association of Speech-Language Therapists
MPOC	Measure of Processes of Care
MPOC-SP	Measure of Processes of Care for Service Providers

GLOSSARY

Unidisciplinary: An approach to the diagnosis and treatment of developmental disabilities that focuses almost exclusively on the contribution by a single professional discipline or specialty; not a team approach (Rossetti, 2001).

Interdisciplinary approach: This approach reflects a more cooperative and systematic effort among disciplines and moves beyond the notion of working next to one another and moves toward an ideal of cohesion among group members (Rossetti, 2001).

Multidisciplinary approach: This approach represents a parallel model of service delivery. In this model, professionals tend to work next to each other but with minimal exchange of information or interaction among disciplines (Rossetti, 2001).

Transdisciplinary: This approach has been described as a team model in which a conscious effect to pool and exchange information, skills, and knowledge takes place among disciplines (Rossetti, 2001).

Service providers: In disability services in the ROI, service providers are voluntary organisations that get the majority of their funding from the Irish government to distribute as they see fit (The Council, 2000).

Service-users: An individual that is provided a service for which a priority level (i.e. intellectual and/or physical disability) has been assigned (The Council, 2000).

Person-centredness: Guarantees that the expressed needs / choices and valued outcomes of individual service-users are at the centre of service-delivery, planning, and evaluation (Cambridge & Carnaby, 2005).

Person-centred Planning: A system in which the service-user is central to the direction of his / her own service. The process brings together key people in a person's life who support him in defining a vision for the future, setting goals and implementing realistic life plans (Cambridge & Carnaby, 2005).

DECLARATION

I declare that ‘Speech and Language Therapy Service Delivery for Children with Cerebral Palsy in the Republic of Ireland: Comparative Perceptions of Parents and Speech-Language Therapists’ is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

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M. JANSE VAN VUREN

ACKNOWLEDGEMENT

I would like to extend my gratitude to everyone who contributed in one way or another to this research study from its inception to the final document.

I am most grateful to my supervisor, Catharina van der Walt, for her support, guidance and assistance in this study. Her timely reading, encouragement and prayers made the task of preparing and writing this thesis rewarding and enjoyable.

I extend a special thanks to Colin Reilly, friend and Research Psychologist, for all his time, patience, humour and input around the data analysis and ratings.

My gratitude is due to all the parents, Speech-Language Therapists and service providers who accepted to participate in both the pilot and the final study.

I am grateful to my assistant moderator, Laura Barragry, for moderating the interviews and to Marion Jones for her technical support.

My special appreciation goes to my family for their love, encouragement, support and prayers throughout the research study.

Lastly, by most important, I would like to thank my Heavenly Father for his guidance, inspiration, and comfort during the years.

TABLE OF CONTENTS

CHAPTER THREE: RESULTS 58

FIGURES AND TABLES

CHAPTER ONE

LITERATURE REVIEW

1.1 What is Cerebral Palsy?

Cerebral Palsy (CP) describes "a group of disorders of the development of movement and posture causing activity limitation, which are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain" (Rosenbaum, Dan, Leviton, Paneth, Jacobsson, Goldstein & Bax, 2005, p.572). The hallmark of any person with CP is a disorder in the development of motor function (Rosenbaum, Walter, Hanna, Palisano, Russell & Raina, 2002). In addition to the motor deficits characteristic of CP, there are other physical, behavioural, and cognitive-communicative impairments associated with the disorder, and an individual diagnosed with CP can demonstrate many of these associated impairments (Workinger, 2005).

Children with CP have significant neuro-motor impairments that frequently affect their oral-motor system, and as a result, also affect the development of speech and language skills (Dormans & Pellegrino, 1998). The young child with CP frequently grows up understanding more than he/she is able to express through speech or actions as a result of impairment of motor skills (Finnie, 1997). Up to 20% of children with a diagnosis of CP have severe communication impairments and are classified as non-verbal (Watson, Stanley & Blair, 1999). Another common and significant difficulty in CP is the high rate of feeding and swallowing difficulties, with the prevalence of these difficulties estimated to be approximately 40-50% in this population (Reilly & Skuse, 1992). In specific types of CP, such as spastic quadriplegia, the prevalence of feeding and swallowing difficulties has been found to be as high as 85% (Stallings, Charney, Davies & Cronk, 1993). Saliva management and nutritional problems are also common in children with CP (Yorkston, Beukelman, Strand, & Bell, 1999).

Brain lesions that underlie the motor limitations may adversely influence cognitive development in this population (Dormans & Pellegrino, 1998). Cognitive impairments, hearing and/or visual impairments, attention difficulties, orthopaedic and other medical conditions (e.g, seizures, gastro-oesophageal reflux, and respiratory problems), are also frequently associated with CP. Westlake and Rutherford (1961, cited in Love, 1992, p.49) noted that "in no other clinical population is one likely to find such a variety of conditions that can disturb and delay the acquisition of oral language as in the group diagnosed as CP."

Considering the associated conditions, it is clear that CP is one of the most severe developmental disabilities in childhood (Surveillance of Cerebral Palsy in Europe, 2000). Children with CP do not only have difficulty reaching developmental milestones; they also have difficulty acquiring and learning new skills. The hybrid term 'developmental disability' emphasises the interdependence of developmental processes and the acquisition of meaningful functional skills (Dormans & Pellegrino, 1998). Based on all these developmental and learning difficulties, it is evident that CP presents challenges to the individual and his/her caregivers across the lifespan (Workinger, 2005).

According to the Health Research Board of the Republic of Ireland (ROI); 1,470 people (7.5%) registered on the National Physical and Sensory Disability Database (NPSDD) had CP (Galligan & Mulvany, 2004). In the ROI the incidence rate of CP is 1.49 for every 1000 live births (Surveillance of Cerebral Palsy in Europe, 2002). The same research revealed that children with CP also had associated impairments and that 31% had severe intellectual disabilities (Surveillance of Cerebral Palsy in Europe, 2002).

1.2 Speech and Language Difficulties in Children with Cerebral Palsy.

According to Dormans and Pelegrino (1998), 30% of individuals with CP present with speech, language, and/or hearing disorders. 'Speech' is the verbal means of communicating or conveying meaning (Owens, 2001). 'Language' can be defined as a socially shared code or conventional system for representing concepts through the use of arbitrary symbols and rule-governed combinations of those symbols (Owens, 2001). Both speech and language form part of the larger process of communication, which refers to the process that participants use to exchange information and ideas, needs and desires (Owens, 2001).

Many children with CP present with motor speech disorders although no pattern of speech is typical of all individuals with CP (Yorkston, Beukelman, Strand & Bell, 1999). The comprehensive term 'motor speech disorders' includes conditions like

Dysarthria and Developmental Verbal Dyspraxia (DVD) which is also termed Developmental Apraxia of Speech (DAS). Some children with CP have difficulty controlling the muscles of the vocal tract to degrees matching the extent of central nervous system damage and this speech disorder is referred to as Dysarthria (Love, 1992). Dysarthria affects any or all of the processes of speech production, i.e. respiration, phonation, articulation, resonance, and prosody (Strand, 1995). This motor speech disorder is marked by disturbances in muscle strength and tone, plus disturbances in rate, precision, speed, steadiness, and coordination of movement (Love, 1992). DVD or DAS is an impaired ability of the child to voluntarily execute the expected motor gestures and programming of gestures needed for the articulation of speech, in the absence of obvious muscular disturbance of the speech mechanism (Love, 1992). Children with CP may present with both these motor speech disorders, although the prevalence of Dysarthria is higher (Love, 1992). In early studies on motor speech disorders, the incidence of Dysarthria was estimated to range from 31 to 88% (Yorkston, Beubelman & Bell, 1988). Although the precise prevalence of Dysarthria in CP is unknown, it is a very frequent sequel of the neurological disorder (Love, 1992).

For some children with motor speech disorders, it will be possible to develop acoustically acceptable compensatory speech production, while others may need a combination of speech therapy and augmentative systems of communication (Solot, 1998). The latter mode of intervention will be more relevant for children with severe impairments, for whom speech cannot be the primary mode of communication (Solot, 1998).

In terms of management of DVD and Dysarthria, research indicates that there is no single management procedure that is generally recognised to be most appropriate for DVD due to the controversial nature of this disorder (Strand, 1995). One of the primary explanations for the persistence of controversy regarding DVD is that researchers are not consistent in describing the articulatory errors of the behavioural characteristics necessary for diagnosis (Yorkston et al., 1999). There is much less controversy about the nature of childhood Dysarthria (Strand, 1995). Treatment approaches for Dysarthria can include the Neuro-Developmental Treatment (NDT) approach, physiological approaches (i.e. treatment directed toward the component parts of the speech mechanism), and non-speech approaches (oral-motor feeding skills and oral exercises) to improve speech production abilities (Workinger, 2005). The use of non-speech approaches to facilitate speech is a controversial issue, as no controlled studies exist that clarify the efficacy of using non-speech tasks to enhance the production of speech (Workinger, 2005). Although these approaches are widely accepted (Workinger, 2005) for the treatment of Dysarthria, Strand (1995) states that treatment for this disorder has not been widely covered in the literature.

Individuals with CP can demonstrate both receptive and expressive language disorders (Workinger, 2005). These can range from delayed language development and specific language deficits, to language deficits secondary to an inability to explore the environment due to physical and associated limitations (Mecham, 2002). Furthermore, as a consequence of their speech impairment, children with CP may be denied the opportunity to initiate and reciprocate social interaction and they are often isolated from their social environment (Falkman, Sandberg, & Hjelmquist, 2002). The inability to interact with the environment and objects within the environment may restrict the development of communicative intent, vocabulary, and concept development (Workinger, 2005). This could mean that it is more difficult for these children to develop mental representations that aid language development (Falkman et al., 2002), and language delay is therefore, commonly seen in children with CP (Dormans & Pellegrino, 1998). Strand (1995) also suggests that motor speech disorders in children with CP (i.e. dysarthria and DVD) could possibly further adversely affect the development of language.

Establishing functional communication is the most important objective of language therapy (Solot, 1998). Assistive technology can enhance functioning in Activities of Daily Living (ADLs) and is prescribed to address specific impairments in an effort to ameliorate disabilities and to prevent handicaps (Burnstein, Wright-Drechsel, & Wood, 1998). Augmentative and Alternative Communication (AAC) provides a means for individuals who have poor communication abilities to augment their verbal and written expressions (Burnstein et al., 1998). AAC is "an area of clinical practice that attempts to compensate (either temporarily or permanently) for … severe expressive and/or … comprehension disorders" (American Speech and Hearing Association, 1991, p.8). According to Dowden (1999), AAC does far more than just compensate for communication impairments, as it connects children with limited expressive language with their family and friends and empowers them to participate more fully in life at home, school, and in the community. The evidence for the value of AAC intervention is comprehensive, with case studies demonstrating the range of potential applications in a process that evolves with each individual (Iacono, 2004).

1.3 The Role of the Speech-Language Therapist

Speech-Language Therapists work with children and adults who have difficulties with communication, or with eating, drinking and swallowing (Royal College of Speech and Language Therapists, 2006). The Royal College of Speech-Language Therapy (RCSLT, 1996; 2005) recommends that the primary principle of Speech and Language Therapy (SLT) service delivery for people with physical disabilities (including children with CP), is to recognise the right of every individual to have an effective communication system regardless of severity of disability.

The aim of speech and language intervention for children with CP is to maximise their ability to communicate through speech, gesture and/or supplementary means such as communication aids, to enable them to become independent communicators (Pennington et al., 2005). Intervention can focus directly on spoken output, expressive or receptive language development, or helping children to develop conversation skills. Work to develop children's language or communication skills could involve children using any method of communication. Intervention can also involve children's familiar conversation partners such as families, friends, and teaching staff (Culp & Carlisle, 1998). This indirect therapy aims to teach people who are in close contact with children with CP to facilitate the children's communication development by creating opportunities for them to use new skills in conversation, leading to positive changes in the conversational style for both conversation partners and the children (Pennington et al., 2005). Because the problems experienced by children with a diagnosis of CP are so varied, there is no single universally appropriate form of intervention (Pennington et al., 2005). Therapy may be delivered on an individual basis or in groups and involves clinicians or team members from other disciplines. Part of the role of the Speech-Language Therapist is to liaise with families and teaching staff regarding therapy. Intervention can be delivered in a variety of settings (i.e. preschools, schools, day centres, rehabilitation units, and the home environment). Intervention may also vary in duration and intensity. Clinical guidelines of the Royal College of Speech and Language Therapists (RCSLT) (2005) state that intervention should be theoretically driven with long and short-term aims, objectives of therapy, frequency and duration of treatment clearly documented. Speech-Language Therapists also play a role in advising and counselling carers, advocacy, health promotion and prevention work (RCSLT, 2005).

1.4 Crises in Speech and Language Therapy: Resources and Evidence-Based Practice.

Speech and Language Therapy (SLT) for children with CP is often long-term, requiring significant health service resources (Pennington et al., 2005). The field is dominated by conflicting approaches to treatment and strongly held opinions, often unsupported by empirical data, as to the 'correct' approach to management of the child with CP (Love, 1992). Very few of the treatments for CP have been fully researched. The majority of conventional practice is founded either upon 'common sense' or upon clinical observations that have stood the test of time (Scrutton, 2004, p2).

Research by Bryen and Joyce (1985) focused on critically reviewing various language intervention studies for children with severe disabilities. This reference cited, in support of the review, merits a degree of caution since it is over 20 years old. Bryen and Joyce's aims were to answer two major questions: Firstly, to what extent have these intervention studies been successful in increasing the communicative competence of their severely impaired, primarily non-verbal participants; and secondly, to what extent have these studies applied the theoretical models and empirical findings derived from current psycholinguistic research. Their findings revealed that a major gap existed between current psycholinguistic theory and research and its application with persons with severe disabilities. They also found that the majority of the intervention studies were not guided by empirical evidence.

The evidence-base for speech and language service-delivery for children with CP has always been limited (Pennington et al., 2005). A recent systematic review by Pennington et al., (2005) addressed direct SLT for children with CP. They reviewed current research as well as studies dated back to the 1980s. After applying their inclusion and exclusion criteria to various research studies, only seven studies were selected for their review, highlighting the lack of evidence-based literature in the management of children with CP. The researchers recommended that a bank of research evidence is needed including definitions of the methods currently used to treat different areas of communication development for subgroups (i.e. physiological types like spasticity, ataxia, etc. and types of distribution, for example, hemiplegia, quadriplegia, etc.) of children with CP and their conversational partners, gained through surveys and focus groups (Pennington et al., 2005).

Apart from the lack of evidence-based intervention techniques used in children with CP, there is also a chronic shortage of Speech-Language Therapists in the Republic of Ireland (Government Debates, 2001). Research published in the Irish Examiner newspaper in 2007, revealed that children can be waiting as long as 3 years to see a SLT. There is a major shortage of SLTs across the country. There are currently 655 SLTs employed by the HSE, and the Bacon Report (2001) commissioned by the Irish Government indicated there was a need to have 1,285 by 2015. The Irish Association of Speech-Language Therapists (IASLT) thought that was an underestimation of the need. According to the Bacon Report (2001), the concentration of Speech-Language Therapists is approximately 8.1 per 100,000 (cited in Government Debates, 2001). This report advocated an annual increase of 75 training places for SLT to achieve the fourfold increase in the number of Speech-Language Therapists over the next decade (Dáil Éireann, 2003). To date an additional 175 therapy training places in have been introduced for allied health professionals in addition to new SLT courses being offered in University of Limerick (UL), University College Cork (UCC) and National University of Ireland, Galway (NUIG). Waiting lists for SLT are excessively long and have been for some time. For instance, waiting lists of up to four and a half years for speech and language services have been documented in County Galway (Galway Independent, 2007). There is evidence of even longer waiting lists for SLT services as existing clinical staff have to undertake additional assessments as part of the HSE Disability Act (2005) where an independent assessment of need to children aged 0-5 years is a statutory obligation (HSE Service Plan, 2008).

Speech and Language Therapy (SLT) is the most common therapeutic service for people to be wait-listed in the ROI (National Physical and Sensory Disability Database (NSPDD), 2004). The NPSDD (2004) revealed that of the total number of people on their database (n=19,677), only 16.9% (n=3,320) were receiving SLT in 2004 (more recent statistics are unavailable). Furthermore, of this subgroup, 8.8% (n=1,735) of the peoples' speech-language needs are deemed to be unmet. This comprises of 6.6% (n=1301) requiring an initial assessment, 2.1% (n=416) assessed but on a waiting list and 0.1% (n=18) assessed but unable to be seen for intervention. Of the total population, 9.9% (n=1,945) have a diagnosed speech-language impairment (i.e. Dyspraxia, Dysarthria, Dysphasia, etc.).

In the 2001 government debates on the shortage of Speech-Language Therapists in the ROI, the incumbent Minister of Health highlighted the deep-seated problems that exist especially for children with special needs (Government Debates, 2001). Since 2001, the number of universities providing training courses for Speech-Language Therapists has increased with degree courses now available at universities in Cork and Limerick. In the Republic of Ireland, the term 'special needs' is mostly used to encompass diagnoses of autistic spectrum disorders, learning disabilities, physical and sensory disabilities. For the purpose of this study, Cerebral Palsy (CP) is the special needs-subgroup of primary interest.

Documented government debates on the shortage of SLT services, are characterised by parents openly expressing their concern and dissatisfaction with the lack of SLT services in Ireland (Government Debates, 2001). To the author's knowledge, there have been no published empirical studies investigating parental perceptions of SLT intervention and SLT service-delivery to date. However, an analogous study was recently carried out in the United Kingdom (UK) investigating the perspectives of parents towards physiotherapy input (Bower et al., 2001). Findings of parental perceptions of the quality of physiotherapy care demonstrated that parents were least satisfied with the provision of general information even during periods of intensive therapy and collaborative goal-setting (Bower et al., 2001). The researchers concluded that overall, the parents were pleased to be included in the study and expressed the view that important questions were being addressed. Similar research is needed within the area of SLT. This is supported by published research studies (Pennington et al., 2005) indicating the need for qualitative research studies to investigate children and families' perceptions of intervention techniques and evaluate their need for these interventions.

1.5 Service Delivery for Children with Cerebral Palsy

Beyond the usual demands of parenting, families of children with special needs often experience additional worries about the uncertainties surrounding their child's prognosis, the best way to promote their child's development, and how to reconcile the many and sometimes conflicting opinions they receive about the 'best' therapies (Rosenbaum, 2004). The inadequate provision of long-term rehabilitation and support for people with physical disabilities and their carers has been well documented in recent years (Bakheit, Bower, Cosgrove, Fox, Morton, Phillips, Scrutton, Shrubb, & Yude, 2001; Heinen, 2001). In a study in the United Kingdom (UK), it was found that services were frequently provided in an uncoordinated and haphazard way and there are marked variations in the standards of healthcare in different regions of the UK and even within the same health district (Bakheit et al., 2001).

The Health Service Executive (HSE) in the ROI (2005), in their National Service Plan, contended that disability services should be needs-led, person-centred, and underpinned by the principle of equity. They further recommend that the range of services should be provided in partnership with people with disabilities, their families, alongside statutory, non-statutory, voluntary, and locally based community groups.

The team approach to the management of children with CP arose in response to the complex needs and issues that often attend this developmental disability (Pellegrino & Meyer, 1998). The communication problems of the child who has CP cannot be isolated from the rest of the child's problems, and treatment for communication difficulties cannot be given in isolation from other kinds of treatment (Mecham, 2002). It has long since been acknowledged that no one person or one discipline has all of the requisite skills or perspectives to adequately address the complex issues surrounding the evolving nature of developmental disabilities (Pellegrino & Meyer, 1998). This increasing sensitivity in society as a whole to issues of developmental change and developmental disability has highlighted the importance of interdisciplinary care and the concept of family-centred care (Pellegrino & Meyer, 1998).

The interdisciplinary team approach provides integration of various specialised treatments (medical treatment, occupational therapy, physical therapy, SLT, and special education), and for effective treatment, each member of the team must be familiar with what each other member is doing (Mecham, 2002). Unfortunately, few children have the possibility of the 'best' treatment for all aspects of their disorder (Scrutton, 2004). This is partly because no one clinic will have the expertise in all fields, but also because there is often so much that could be done that treatment would be disproportionate and dominate the lives of the child, parents, and siblings (Scrutton, 2004). Family-Centred Service (FCS) is a philosophy and method of service delivery that recognises parents as the experts on their child's needs, promotes partnership between parents and service providers, and supports the family's role in decision-making about services for their child (King et al., 2002). In a FCS model the child is no longer the sole focus of interest to the service provider (Rosenbaum, 2004). This approach acknowledges and incorporates the needs of parents and families and recognises that the well-being of parents and families is important to the well-being of children with special needs. It thus includes parent and family perspectives and needs in all aspects of assessment and management of the child's condition (Rosenbaum, 2004). When delivering a FCS, a number of key behaviours are fundamental for facilitating collaboration between clinicians, team members, and parents. These behaviours include encouraging parental decision-making; providing information as a basis for parents to make informed decisions; and assisting parents to identify both their children's and their own needs and strengths. When families find this process difficult, service providers should help and support them in reaching decisions the family will find acceptable (Rosenbaum, 2004). It seems clear that, to the greatest extent possible, efforts should be made to provide coordinated services for families of children with CP, since it is exactly these families who are at risk of stress, burnout, and dissatisfaction with the services on which they depend for their child's development (Rosenbaum, 2004).

Traditionally Speech-Language Therapists have relied on an impairment-based model of decision making when addressing speech and language difficulties in children (McLeod & Bleile, 2004). Families and teachers have less input into the goal setting in the impairment-based model since it relies heavily on the expertise of the professional who typically conducts the assessments and analyses, and determines goals based on areas of impairment (McLeod & Bleile, 2004). In recent years, many Speech-Language Therapists have adopted a social model of decision-making where the emphasis is on the communicative impact of the client's differences rather than the client's deficits (McLeod & Bleile, 2004). The social model further necessitates extensive support from the family, teachers and the children themselves as the 'experts' (McLeod & Bleile, 2004) and ties in with the principles of FCS. However, McLeod and Bleile (2004) documented, that both impairment and social models can be valid in treating children with CP. Regardless of the model of service delivery that service providers adopt, it is vital to connect the processes of service delivery with the outcomes of family well-being and satisfaction. Service providers need to be aware that the way we work may be as important as what we actually prescribe, and may in fact enhance or detract from the best advice we, as clinicians have to offer (Rosenbaum, 2004).

1.6 Rationale for the Present Study

Cerebral Palsy (CP) is a multi-disabling condition affecting all areas of a child's development. It has been documented as one of the most severe disabilities in childhood. Apart from the motor disorders of CP, children may also experience disturbances in cognition, communication, sensation, and / or behaviour, and / or by a seizure disorder (Rosenbaum et al., 2005). Research in the area of SLT service delivery for children with CP has always been limited. A gap exists not only in the literature, but also in the clinical practice of Speech-Language Therapists when they provide a service to children with CP. Pennington et al., (2005) recommend that, in order to increase the bank of research evidence, studies using surveys and focus groups are needed to define SLT methods currently used to treat different areas of communication development and to also qualitatively investigate families' perceptions of intervention techniques. Furthermore, there currently exists a chronic shortage of Speech-Language Therapists in the ROI with many children with CP on waiting lists (Release, 2004). Speech-Language Therapists are under severe pressure to provide a good quality of SLT service under limited resources, while parents continue to openly express their concern and dissatisfaction with the lack of SLT services available in Ireland (Government Debates, 2001). Apart from all these challenges that Speech-Language Therapists have to face, they also have to adhere to the service providers' philosophies and model of service delivery that can sometimes be in conflict with how they practice and what is deemed 'best SLT practice' for children with CP. Further research is thus needed to evaluate the perceptions of both Speech-Language Therapists and parents of children with CP on the nature and quality of SLT service delivery specifically to children with CP in the ROI. This information should then be disseminated to the relevant stakeholders (e.g. other Speech-Language Therapists, service providers and parents).

CHAPTER 2

METHODOLOGY

2.1 Research Question

This study attempted to answer the following research question:

What are the perceptions of Parents and Speech-Language Therapists of Speech and Language Therapy (SLT) services for children with Cerebral Palsy (CP) in the Republic of Ireland (ROI)?

2.2 Aim

The aim of the investigation was to ascertain the comparative perceptions of parents and Speech-Language Therapists of SLT service delivery for children with CP in the ROI.

2.3 Objectives

Primary Objectives:

a) To describe parents' perceptions regarding the nature and quality of SLT service delivery to children with CP.

b) To describe Speech-Language Therapists' perceptions regarding the nature and quality of SLT service delivery they provide to children with CP.

c) To describe the degree of concordance between parents' and Speech-Language Therapists' perceptions of SLT service delivery.

Secondary Objective:

d) To describe how these perceptions align with the official policies of Health and Education Service Providers in the ROI that employ Speech-Language Therapists who work with children with CP in order to create an awareness of current service provision and to identify gaps in service delivery.

2.4 Research Design

A non-experimental, quantitative, descriptive research design was adopted to describe the nature and quality of SLT service-delivery while using qualitative research methods to add descriptive depth to the quantitative results.

The reason for selecting a descriptive research design is because it allows accurate observations of phenomena as they truly exist, focusing on the validity and reliability of the observations (Durrheim, 2002). Quantitative research yielded accurate data related to the research questions and included the measurement and analysis of observations in a numerical way (Bowling, 2002), while qualitative research was used to enhance and expand on the quantitative survey data by incorporating the lived experience of therapists and parents into the study (Krueger & Casey, 2002).

Multiple (triangulated) methods of investigation were used to enhance the validity of research findings and minimise the error contained within each individual approach (Bowling, 2002). Triangulation (Terre Blanche & Kelly, 2002) entailed collecting data in various ways (i.e. questionnaires, focus groups, and documents) and from various sources (Parents, Speech-Language Therapists and Service Providers). This helped to home in on a correct understanding of perceptions on SLT service delivery in Ireland by approaching it from different angles.

2.5 Study Population

Two groups of participants were targeted to accomplish the primary objectives of the research and to answer the questions regarding perceptions of service delivery:

- The first respondent group comprised of parents who have a child diagnosed with CP.
- The second group comprised of Speech-Language Therapists working in Ireland with children with CP.

The secondary objective of the research was accomplished by examining the documents of Health and Education Service Providers in the ROI responsible for establishing a service to children with CP. Official documents, position statements, and policies were examined to gain insight into philosophies, core values, and models of service delivery to children with CP and their families. Denscombe (1998) states that documents can be treated as a source of data in their own right. The general purpose of these documents is to enhance accountability by making these publicly available and providing a systematic picture of things that have happened in the organisation over time (Denscombe, 1998). These documents were the source of information to investigate whether parents' and therapists' perceptions of SLT were concordant with information in the documents.

2.6 Recruitment Procedure and Study Sample

2.6.1 Parents of children with CP

A purposive sampling frame was employed in recruiting parents of children with CP in the ROI. Although the first sample comprised of parents, it was not the parents, but their children (i.e. the service-users) that were considered against inclusion / exclusion criteria before their parents were selected to participate in the research study. Contact was made with all health and education service providers in the ROI providing a service to children with physical disabilities. After seeking ethical approval from the prospective service providers, the service providers were asked to compile up-to-date lists of all children with CP for the purpose of surveying their parents. Registers and databases were the basis for the recruitment process.

Inclusion Criteria:

1) Service-users attending an Irish Health and/or Education Service Provider where a Speech-Language Therapist is employed.

2) Service-users with a primary diagnosis of Cerebral Palsy, diagnosed by a paediatrician or medical director, as children with CP are the focus of this research study.

3) Service-users aged 0 – 18 years, as this forms part of a paediatric population and service delivery to this age group differs from service delivery to adults.

Exclusion Criteria:

1) Children with Cerebral Palsy as a secondary diagnosis. Service-users with CP as a secondary diagnosis (i.e. children with specific syndromes, children with a primary diagnosis of an intellectual disability, etc.) because service delivery to children with a physical disability (i.e. Cerebral Palsy) differs from service delivery to children with more significant learning needs (i.e. intellectual disabilities).

For the focus group discussions, prospective participants were all parents who returned their completed questionnaires and consented to participate in the focus group discussions. A stratified sampling frame (Cohen, Manion & Morrison, 2000) was prepared of those who consented to participate in the focus group discussions. Stratified sampling involves dividing the population into homogenous groups, each group containing subjects with similar characteristics (Cohen, Manion & Morrison, 2000). A maximum of sixteen parents were randomly selected through fishbowl selection from the stratified sample with six to eight (Krueger, 2002) parents selected to form each focus group. This sampling technique allowed the researcher to carefully select the potential informants with a minimum prospect of redundant material (Denscombe, 1998). For the purposes of this particular project, the research was better served by getting information from fewer informants that provide more in-depth insight into the topic i.e. that are "information rich". This kind of detailed information from only a few informants is justified (Denscombe, 1998) by the data based on their personal experiences as parents with children with CP.

Within the sampling frame, parents were grouped together according to the following criteria:

(a) *Geographical location.* Two focus groups were conducted in the country's two largest cities (i.e. Dublin and Cork) to allow for easy access for all parents to the focus group discussions.

(b) *The Health or Education Service Providers* their child is receiving a service from. All the various service providers have different philosophies, team approaches, policies and procedures when providing a service to children with CP. It was important to get parents of children from different service providers together to examine the various models of service delivery.

(c) *Age levels of their child.* Since the paediatric population ranges from birth to eighteen years of age, or until they leave school, the children were divided into the following age groups: (i) 0-5 years of age (or all preschool children) (ii) 6-11 years (or all primary school children) (iii) 12-18 years (or all secondary school children).

2.6.2 Speech-Language Therapists

Speech-Language Therapists across the Republic of Ireland (ROI) were recruited through obtaining the most current directory of Irish Association for Speech-Language Therapists (IASLT) members. A purposive sampling frame (Bowling, 2002) was employed to select all those therapists who are currently working with children with CP. The dearth of Speech-Language Therapists in Ireland working with children with CP represented a significant constraining factor for the sampling process and thus necessitated selection of all possible participants who met the selection criteria in order to maximise the study sample (Bowling, 2002). Consequently an exhaustive sample (Bowling, 2002) of all Speech-Language Therapists currently working with children with CP was targeted to complete the questionnaires.

All therapists who returned their completed questionnaires and consented to participate in the focus group discussions were selected for participation in focus groups. Two focus group discussions were held in different parts of the country and the therapists were grouped together according to the following criteria:

(a) *Geographical proximity* – whether they were based in the Counties of Dublin, Cork or Galway.

(b) *Health or Education Service Providers.* Therapists affiliated with different Service Providers have different philosophies, policies and team approaches when working with children with CP and for the purpose of the study it was advantageous to examine the various service delivery models.

2.6.3 Health and Education Service Providers in the Republic of Ireland.

The internet, a learning and resource library, and the Irish Association of Speech-Language Therapists (IASLT) directory (2003, 2005) were used to recruit all Health and Education Service Providers in the ROI providing a service to children with physical disabilities or CP. Convenience sampling was used for recruiting all service providers who provided SLT services to paediatric service-users with CP.

2.7 Ethical Considerations:

This study was approved by the University of Cape Town Health Sciences Faculty Research Ethics Committee (REC REF: 029/2006) and by Enable Ireland Learning Disability Services Ltd. (REC Reference: 21).

2.7.1 Morality of the study

The present research study was designed to be non-maleficent and to ensure respect for the psychological well-being and autonomy of all participants (Bowling, 2002). Central to its objectives was to be just to all respondents. It aimed to be beneficial to children with CP, their parents, Speech-Language Therapists, and Service Providers. It was also important to highlight to the participants participating in the focus group discussions that the moderator / researcher or the service provider he/she is affiliated with will not gain anything from the findings of the study.

2.7.2 Informed consent

As is customary for research of this nature, informed consent was sought from all participants prior to their involvement in the study. Participants were assured, verbally and in writing (See Appendix G, H and I for Information Sheets and Consent Forms), that having freely joined the study they could withdraw at any subsequent stage without repercussions (Bowling, 2002).

2.7.3 Anonymity / Confidentiality

The assurance of participants' anonymity was central to this research study. Any identifying names (service providers, participants, etc.) were substituted with codes. All efforts were made to ensure participants were not harmed in any way by the research, for example by an identified individual's views becoming public knowledge. Data were collated in aggregate form and in such a manner that no quotes/information was traceable to any individual or Service Provider. All data collected as part of this research study was kept confidentially. The data was securely stored in a locked cabinet in the researcher's office in the SLT department. (See Appendix J and K for Confidentiality Agreement of Researcher / Moderator and Assistant Moderator). Data will be stored by keeping the documents at this location for ten years as recommended by the University of Ulster, United Kingdom.

2.7.4 Proficiency of Investigator

The moderator was a senior Speech-Language Therapist with a minimum of 3 years experience in working with children with special needs and appropriate post-graduate training and experience in research methodology, including focus groups methodology. Biographical information of the moderator / researcher, including the service provider he/she is affiliated with (preferably not a service provider providing a input to the target group of this study) were disclosed to the participants during the focus group interviews to ensure objectivity (Denscombe, 1998) throughout the focus groups.

2.7.5 Publication / Dissemination of Results

The governing body of all Irish Speech-Language Therapists, the IASLT was informed of the research study being undertaken since some of their members were requested to participate in the study. The executive summary of this research study was sent to the chairperson of the IASLT. In writing up the information for this dissertation, and in addition to any subsequent publications, the participants' identities will be protected within the presentation of basic demographic data about age, sex, etc., and their responses will be hidden within collated formats or presented as variations on a theme (Stevens, 1999).

2.8 Materials for Data Collection

2.8.1 Questionnaires

Parents' perceptions of the nature and quality of the Speech-Language input their children receive or received (*i.e.* children who are currently not receiving SLT input due to staff shortage, or who have just completed a block of SLT) were elicited through the use of the Measure of Processes of Care (MPOC) – questionnaire (Appendix A).

The MPOC is a well-validated and reliable self-report measure that aims to assess parents' perceptions of care that their children receive from children's treatment centres (Woodside, Rosenbaum, King, and King, 1998). It is a means to measure parents' perceptions of important aspects of care on a specific behavioural level and is a useful tool for program evaluation. The MPOC is also a theoretically sound measure of family-centred service provision (Woodside et al., 1998). This scale has been used in a number of studies in North America and Europe (King et al., 1995; Woodside et al., 1998; King et al., 2002).

The MPOC comprises of a 56-item questionnaire and for each item, parents respond to a given question using a Likert scale with respondents rating each item according to a 7-point response scale. A respondent's data will yield 5 scores, one for each of the factors/scales and each scale score is obtained by computing the average of the relevant items' ratings. At the end of each question, a few lines were inserted to allow respondents to provide additional qualitative information or explanations for the ratings given. The questionnaire typically takes between 15-20 minutes to complete (Woodside *et al.*, 1998).

In addition to the MPOC, parents were asked to complete a short questionnaire with detailed background information of their child's medical and developmental history. This questionnaire included details of medical diagnoses, associated conditions, and developmental and communication history. See Appendix C for Background Information Questionnaire.

Speech-Language Therapists' perceptions of the nature and quality of Speech-Language care they provide to children with CP were ascertained through the use of the Measure of Processes of Care for Service Providers (MPOC-SP) - questionnaire. (Appendix B).

The MPOC-SP is a self-assessment questionnaire for paediatric Service Providers who provide services to children with chronic health or developmental problems and their families, and is typically used to contribute to programme evaluation and research in the field of health service delivery (Woodside et al., 1998). The MPOC-SP can be paired with the parent questionnaire, the MPOC, allowing researchers to gain multiple perspectives on service delivery in a clinical setting (Woodside et al., 1998).

The MPOC-SP is based on the MPOC and comprises 4 scales and 27 items. For each item, service providers respond to a pertinent question using a Likert scale. A respondent's data yields 4 scores, one for each of the factors/scales and the scale score is obtained by computing the average of the relevant items' ratings. The MPOC and MPOC-SP questionnaires were slightly adapted, after permission was sought by the authors, by inserting a few blank lines to allow respondents to explain the rating assigned to each question. This amendment to the questionnaires was made to provide the researcher with additional qualitative information. The questionnaire takes about 10-15 minutes to complete.

The MPOC and MPOC-SP can also be used in programme evaluation studies and total quality management activities, directed either at a program or a centre as a whole, or at specific services offered by a program. The publishers of the questionnaires highlighted the importance of being "explicit to the respondent about the target service or program to which the MPOC responses are to apply" (King et al., 1995, p.58). For this reason the questionnaires were adapted by replacing words like 'the target service' or 'the program' with the words 'Speech and Language Therapy' and 'treatment centre' to 'your organisation'. The authors of the scale consented to the amendments made to the scales (Rosenbaum, 22 November 2006).

2.8.2 Consent Forms

Information sheets along with written consent forms about the nature of the research study were sent out to all the participants. The information sheet included a short overview of the research study with the research question highlighted. This information included aspects about the importance of the research study and what the study involved (i.e. the data collection process with explanations about the measures and/or methods used), along with reassurance about confidentiality and anonymity. The consent form gave respondents the opportunity to voluntarily agree or decline to participate in the study with check boxes provided to consent over the different aspects (i.e. completion of questionnaires, participating in focus groups, etc.) of the research study. See Appendix G, H and I for all information sheets and consent forms.

2.9 Data Collection Procedure:

A pilot study was conducted prior to this research investigation. Both the pilot study and data collection for the current research investigation commenced once approval from the University of Cape Town Health Sciences Research Ethics Committee and St Michael's House Research and Ethical Committee was granted. St Michael's House is a community-based voluntary service provider and one of the ROI's largest providers of services for people with an intellectual disability and their families.

2.9.1 Pilot Study

Prior to the study, the various questionnaires were piloted on a convenience sample to test operational procedures and time required for the assessments to be completed. One of the special needs subgroups, children with Down's syndrome, was targeted for the purposes of piloting. The service provider where the primary researcher is currently affiliated participated in the pilot study. Ethical approval from the Organisations' research board was sought prior to the pilot study. Ethical approval was granted on the basis that the only purpose of the pilot study was for refining of the data collection procedure, to test the operational procedures and to rule out any ambiguity or vocabulary difficulties in the questions posed to the readers. It was also stated that the findings were not to be documented, published, or included in the final data analysis.

Convenience sampling was used to select three potential participants. The sampling frame consisted of all parents of children with a diagnosis of Down's syndrome attending Early Services at St Michael's House. Informed consent was obtained from the parents before inviting them to complete the MPOC-questionnaire. The three Speech-Language Therapists who were part of the Early Services Team were invited to complete the MPOC-SP-questionnaire after informed consent was obtained.

The outcome of the pilot study was to clarify a small number of questions posed in the MPOC and MPOC-SP. The participants agreed that the replacement of the words 'people' with 'Speech-Language Therapists' and 'Treatment (Rehabilitation) Centre' with 'Organisation / Service Provider' helped them focus their attention of the particular study population.

2.9.2 Main investigation:

a) Completion of the MPOC and MPOC-SP Questionnaires

A survey, in the form of postal questionnaires, was conducted to include parents of children with CP and Speech-Language Therapists working with children with CP. This method was used in order to have wide and inclusive coverage (Denscombe, 1998) of all the participants selected for the research study. A limitation of postal questionnaires is that there is not any personal contact between the researcher and the respondent, which can lead to a low response rate to the questionnaires (i.e. approximately 20% of questionnaires are returned (Denscombe, 1998)). To overcome this limitation, all parents with children with CP across Ireland and all therapists working with this population were invited to participate in focus groups to help gain more in-depth qualitative information.

The sampling frame compiled by the respective service providers was used to survey the study population (in this case, the parents of children with CP). To protect the names and contact details and assure anonymity of the prospective participants, the Research and Ethical Committee for Disability Services Ltd recommended that a list of all children meeting the inclusion / exclusion criteria was compiled and prepared by an employee of the respective service providers. This employee addressed and sent out the sealed questionnaires, information letters, and consent forms to the parents on the list informing them of the proposed research study and inviting them to participate.

For completing the MPOC-SP, Speech-Language Therapists working with children with CP were identified through the sampling frame based on IASLT members' directory and identified service providers providing input to children with CP. A letter was sent to the Speech-Language Therapists requesting their participation in the research study based on the following questions:

- Do you work with children (0 –18 years) with Cerebral Palsy with / without an associated intellectual disability?
- Are these children receiving any input (direct or indirect) from your Speech-Language Therapy Department?
- Do you have children with CP on a waiting list awaiting input from your department?

Once the Speech-Language Therapist consented to the study, information about the study was forwarded to each therapist. Therapists were also informed about voluntary participation in a series of focus groups through the written informed consent and information sheet included in the questionnaire.

b) Focus Groups

The responses of parents and therapists elicited during the completion of the questionnaires served as a guide for focus group discussions. Focus group discussions with parents and Speech-Language Therapists provided more detailed and richer data that could have been missed due to the limitations imposed by structured questionnaires. Face-to-face interaction during focus groups, involves direct contact between the researcher and respondents. The face-to-face contact offers some immediate means of validating the data since the researcher can sense if he/she is being given false information in the face-to-face context in a way that is not possible with questionnaires (Denscombe, 1998). Focus groups were conducted with the first and second sample of participants. The first series of focus group discussions included all Speech-Language Therapists currently working with children with CP. The second series of focus groups comprised of parents of children with CP.

The focus groups were carefully composed and balanced in relation to the characteristics of the target respondents (e.g. grouped according to geographical location, different Service Providers, age levels of service-users). The focus group discussions followed an interpretive approach where the aim was to analyse how people understand their social worlds (Bowling, 2002). One advantage of this unstructured approach is to enable more complex issues to be probed. Answers can also be clarified, and a more relaxed atmosphere may be obtained for the discussion of more in-depth and sensitive information. Guidelines for setting up and implementing focus groups, as documented by Krueger (2002), were followed throughout the focus group discussions.

Approximately eight to twelve open-ended questions were asked during each focus group interview. Data consisted of notable quotes used by the participants, key points and themes for each question.

Questions for parents with children with CP addressed their perceptions about SLT care received, as well as their knowledge about the SLT intervention approaches used. See Appendix D for Focus Group Questions for Parents. The following topic areas were discussed during the focus groups:

1. Scope of practice of Speech-Language Therapists working with children with CP.
2. Parental involvement during SLT (i.e. decision making, therapy, information sharing).
3. Perceptions of service delivery (i.e. SLT, Service Provider, Family-Centred Services)
4. Aspirations for ideal service delivery from (a) Speech-Language Therapists (b) Health and Education Service Providers (c) national policies for children with CP.

Questions for Speech-Language Therapists addressed models of service delivery, their perceptions about SLT care provided as well as an overview of SLT intervention approaches used. Questions for the former two topic areas consisted of one to two unstructured open-ended questions to incorporate the lived experience of the therapist. Questions on SLT intervention approaches were based on Bryen and Joyce's (1985) recommendations of what constitutes successful speech-language intervention approaches. After identifying the broad topics for the focus group discussion, the researcher in accordance with the Royal College of Speech-Language Therapists (RCSLT) guidelines for working with children with physical disabilities (RCSLT, 2005), narrowed the topics to those considered of most interest to the present research study. See Appendix E for Focus Group Questions for Speech-Language Therapists. The following topic areas were discussed during the focus groups:

1. The model(s) of service-delivery followed by Speech-Language Therapists (i.e. family-centred vs. child-centred; social model vs. impairment based model).
2. Knowledge of the service provider's official policies and procedures.
3. Speech-Language Therapists' perception of care they provide to children with CP.
4. The nature of the caseload.
5. Prioritisation of caseload.
6. Aspects of SLT that are addressed (e.g. feeding, oral motor skills, speech, language, communication, etc.).
7. The intervention techniques used for the various diagnoses (i.e. motor speech disorders, language and communication impairment).
8. The type of service-delivery provided (i.e. direct or indirect therapy, team approaches).
9. The context in which intervention takes place (i.e. setting, location, frequency, intensity).
10. Measures of outcomes in intervention.
11. Parental involvement in SLT (i.e. decision making, information sharing, goal setting).

12. Aspirations for ideal service delivery from (a) Speech-Language Therapists, (b) Healthcare and Educational Service Providers, (c) national policies for children with CP.

All the questions had optional sub questions (e.g. prompts/probes) in the event of insufficient elaboration on particular themes/questions.

Each discussion was audio- and videotaped for analysis. Video recording helped to identify the speakers instead of just the audio information. Consent for video recordings was included in a consent form that was sent to the participants. In addition to the recordings, an assistant moderator (i.e. SLT Assistant or Support Worker) took field notes throughout the discussion. The moderator's role included welcoming the participants, providing an overview of the topic of discussion, informing participants of the ground rules (Krueger, 2002) including the rights of each participant, the confidentiality of the information discussed and anonymity of participants. The moderator also introduced the various questions to be discussed during the focus groups. Personal involvement (Denscombe, 1998) of the moderator was limited and served to empower the informants by providing definitions and general examples of the topics being discussed. Pauses, probes, and checks (Denscombe, 1998) were used as required, (i.e.: "Could you give an example? Could you explain further? Tell me a little more about it, etc.") to ensure sufficient elaboration and that confusion of responses/opinions was limited. Group dynamics were monitored to ensure that everybody had an equal opportunity to contribute in the discussion. Data can be affected by the personal identity of the researcher and the way informants perceive the person asking the questions (Denscombe, 1998). This interviewer effect (Bowling, 2002) was addressed by the researcher making an effort to be polite, punctual, receptive and neutral during the interviews in order to encourage the right climate for participants to feel comfortable and provide honest answers (Denscombe, 1998). To ensure saturation of ideas, a copy of the focus group questions were provided to the participants beforehand.

c) Review of Services Providers' Documents and Policies identified

The respective documents and policies of those service providers identified as providing a service to children with Cerebral Palsy were reviewed to investigate certain aspects of service delivery. The investigation of various organising principles (Council, 2000) guided the data collection process. Organisational principles are the basic organisational action strategies that facilitate outcomes for families receiving services and supports (Council, 2000). These organisational principles are used in Irish (e.g. Sisters of Charity, St Michael's House, etc.) and American (e.g. United Cerebral Palsy Associations, American Association on Mental Retardation, etc.) organisations as the basis for quality enhancement in human services and included the following best and promising practices (Council, 2000): (See Appendix F for Organisational Principles for Health and Education Organisations / Hospitals)

- Leadership
- Systems
- Quality Management and Planning
- Practice Guidance

Data consisted of qualitative information such as inducting the themes and organising principles that 'naturally' underlie the material (Denscombe 1998).

Heads or directors of the respective health and education service providers were contacted in writing and requested to furnish any published documentation, policies, procedures and/or guidelines relating to service delivery for this client group in addition to any documentation pertaining to speech-language service-delivery. A copy of the executive summary was sent along with information letters and consent forms pertaining to the study. Informed consent was obtained and the heads or directors of the services were assured of confidentiality and anonymity of the service provider's name and relevant personnel named in documents. These documents were used to draw comparisons between the responses of parents and therapists regarding the nature and quality of service delivery and how these perceptions align with official policies of health and/or education service providers. Each document was numbered so that it could be distinguished from others and located if necessary. Serial numbers, to ensure anonymity, were used to identify the service providers and its geographical location.

2.10 Research Qualities

2.10.1 Reliability and Dependability

The questionnaires used in this study have been documented to have good reliability (King et al., 2002; Woodside et al., 1998). Studies by King et al., (1995); Woodside et al., (1998) & King et al., (2002) demonstrated that the MPOC-questionnaire has good internal consistency (Cronbach's alpha ranging from .63 to .96) and test-retest reliability (coefficients ranging from .78 to .88). Validity has been evidenced by (a) positive correlations between MPOC scale scores and a measure of satisfaction, and (b) negative correlations between MPOC scale scores and a measure of the stress experienced by parents when dealing with their child's treatment centre (Woodside et al., 1998). Various studies of MPOC-SP's reliability and validity as a discriminative measure have been conducted (King et al.,1995; Woodside et al., 1998 & King et al., 2002). These analyses demonstrated good internal consistency (Cronbach's alpha ranging from .76 to .88), test-retest reliability (ranging from .79 to .99) and validity (i.e. including cross-disciplinary scale score comparisons and real-ideal comparison testing) (Woodside et al., 1998).

Reliability refers to the degree to which results are repeatable (Terre Blanche & Durrheim, 2002). If the study is reliable, the same set of results (i.e. the participants' scores on questionnaires and the outcomes of the study as a whole) will be obtained repeatedly in replications of the study. Findings from the focus groups do not have the same reliability as the findings from the questionnaires as the researcher is not investigating a stable and unchanging reality. On the contrary, the researcher should expect that participants and organisations would behave differently and express different opinions in changing contexts (Terre Blanche & Durrheim, 2002). In place of the criterion of reliability, findings should be dependable (Terre Blanche & Durrheim, 2002). Dependability refers to the degree to which the reader can be convinced that the findings did indeed occur as the researcher says they did (Terre Blanche & Durrheim, 2002). This can be achieved through rich and detailed descriptions that show how certain actions and opinions are rooted in and develop out of contextual interaction.

2.10.2 Validity and Credibility

Various studies of MPOC and MPOC-SP's validity have been conducted (King et al., 2002; Woodside et al., 1998). Validity refers to the degree to which the research conclusions are sound (Terre Blanche and Durrheim, 2002). Using tried and tested measures, like the MPOC and MPOC-SP, can ensure that accurate conclusions can be drawn from the research results (Terre Blanche and Durrheim, 2002). Qualitative research (like the findings obtained through focus group interviews) is usually evaluated according to its credibility (Terre Blanche and Durrheim, 2002). Credible research produces findings that are convincing and believable and can be achieved by the researcher continually looking for discrepant evidence to the hypotheses she/he is developing as a means of producing a rich and credible account (Terre Blanche and Durrheim, 2002). Many different research methodologies (triangulation) were used to find out whether this provides discrepant findings.

2.10.3 Generalisability and Transferability

Generalisability was ensured through the use of representative samples in the surveys to ensure that descriptions of samples can be used to describe populations (Terre Blanche and Durrheim, 2002). Terre Blanche and Durrheim (2002) define generalisability as the "extent to which it is possible to generalise from the data and context of the research study to broader populations and settings" (p.63). Transferability was achieved by producing detailed and rich descriptions (obtained through focus groups and document analyses) of contexts that will give readers detailed accounts of the structures of meaning which develop in a specific context (Terre Blanche & Durrheim, 2002). These understandings can then be transferred to new contexts (e.g. children with intellectual disabilities) in other studies to provide a framework with which to reflect on the arrangements of meaning and action that occur in these new contexts (Terre Blanche and Durrheim, 2002).

CHAPTER 3

RESULTS

3.1 Introduction

This study consisted of 3 phases. Phase 1 included document analysis, phase 2 the quantitative and qualitative analysis of questionnaires, and phase 3 was mainly the analysis of qualitative information from the focus groups.

3.2 PHASE 1: Document Analysis

Documents were analysed by two raters and themes were included if they were agreed upon by both raters. These themes included the following objectives and core values for service delivery:

3.2.1 Objectives for Service Delivery:

1. Service delivery happens within a team-based ethos and approach. Service providers strive to work towards an Interdisciplinary (ID) and Transdisciplinary (TD) model of service provision. The service providers support team coordination, monitor performance and develop effective team working.
2. Service-users receive a co-ordinated service based on the person-centred planning approach. Service-users have an individualised person-centred plan in

place. The person-centred plan is developed in partnership with service-users, parents/caregivers and professionals, and has clearly identified goals. There are mechanisms for monitoring and review of service delivery in place.

3. Service providers adopt a partnership approach. Service-users are ensured access to all relevant information and receive information on services.
4. Service providers promote and support integration into local community. The focus is on the needs of the whole family including siblings and parents.
5. Service-users have access to support and training. This includes access to Assistive Technology (AT) needs being assessed. Service-users and parents/caregivers are facilitated to make informed choice regarding AT.
6. Services adhere to international best practice and relevant legislation.

3.2.2 Core Values

Along with the objectives, the service providers highlighted certain core values for service delivery. These include the following important points that can be categorised under nine headings:

1. Social Model of Disability
    - Recognise and accommodate individual needs
    - Uses holistic approach – focuses on all aspects of individual's life in context of community and society
    - Dignity and respect

- Activities focused on supporting and facilitating service-users to access and be included in the community and society.

2. Rights-Based
   - Equal rights
   - Equal access and opportunities to participate in education, family life, society, community, employment.
   - Compliance with relevant legislation

3. Person Centredness
   - Unique and diverse needs and preferences are acknowledged.
   - Activities are organised and delivered in ways that accommodate this diversity.
   - People are at the centre of all decision-making that affects them.
   - Ask what supports they require and identify their priority needs by using Person-Centred planning, personal development plans.
   - Privacy and confidentiality are respected.
   - All resources and activities are directed and support what really matters.
   - Recognise and embrace diversity.

4. Independence
   - Rights of individual to self-determination in relation to matters of personal life choice.

- Facilitate people to help them make informed decisions and choices through provision of knowledge / skills /information.
- Support and empower people to achieve goals and aspirations

5. Equality

- All people have equal opportunities and fair access to services and information.
- Apply systems and processes to our activities in a consistent and fair manner within available resources, directed at supporting the needs of the individual.
- Organise / develop / locate activities in such a way that they take account of individual needs.
- Offer equal opportunity for personal and professional growth and development.

6. Integrity

- Honest / trustworthy / impartial / stand by values
- Make decisions and evaluate outcomes based on core values
- Encourage honesty and openness to support reflective practice and improve services.

7. Quality

- Excellence
- Promote culture of continuous improvement
- Regularly monitor and review all activities

- Research findings – ensure activities are in line with best practice
- Comply with national standards of disability services
- Uses the European Foundation for Quality Management (EFQM) Excellence Model as framework to evaluate and monitor service delivery.

8. Transparency
    - Visible / clear / easy to understand
    - Policies and procedures available and accessible
    - Decision-making processes clear and open

9. Accountability
    - Advocate for and represent views of stakeholders
    - Use of resources to achieve best outcomes
    - Monitor and review all aspects of performance
    - Responsible for actions and decisions

The service providers are held accountable for its service delivery by adhering to the EFQM standards (Tuominen, 2000). The EFQM is a model of excellence. It is a non-prescriptive framework which recognises that there are many approaches to achieving sustainable excellence in all aspects of performance. This model helps to identify the service providers' goals and gives guidance on how to achieve them. It also supports the quest for improvement by recognising that is a continuous process.

3.2.3 Service Delivery of the Service Providers

For children in Early Services (0-6 years)

- Interdisciplinary Team
- Assess / individual intervention / parents and family advice / group parent support / home intervention and support / team and family meetings / advice and direct support regarding school placement
- Ensure achieve maximum potential in all areas of development
- Day-to-day management of children services are the responsibility of the director of services / children service manager
- Assessment / individual programme
- Parents informed of purpose and goals of therapy programme
- Team act as source of information and support for family
- Periodic review meeting where team looks at progress made and make plans for immediate future.
- Provides framework for parents to meet and get to know each other
- Help family come to terms with child's disability. Team there to listen, give information and support.

School-aged children in Mainstream Education (5-18 years)

- Support services
- Clinical support services from members of Interdisciplinary team

- Assessments / individual intervention / parent support groups / sibling support groups / school visits / support and advice to mainstream teachers and other school issues including transitions from primary to secondary school.

School-Based Services in Special National Schools

- Interdisciplinary team time
- Assessment / individual or group intervention / classroom or non-classroom based / direct liaison with teachers / team meetings / involvement with parents.

3.3 PHASE 2: Quantitative and qualitative analysis of questionnaires

3.3.1 Demographic Information

3.3.1.1 Demographic information of respondents completing the **MPOC-quesionnaires**

(i) Number of respondents

A total of 50 parents from the main agency providing SLT input to children with CP across 6 locations in the Republic of Ireland participated in the research study. Of the 50 questionnaires, 5 questionnaires were excluded for the following reasons:

- "Our child has very mild CP and has never used the services of a Speech-Language Therapist."
- "Never required SLT."
- "Our child was a late talker due to CP but once he spoke at 3 and a half years of age, he no longer needed SLT."
- "Speech-Language difficulties have resolved and haven't seen a Speech-Language Therapist in more than 2 years".

One service-user had an acquired brain injury at the age of 7 and based on the definition of CP was excluded from the research study. The demographic information of the 5 participants who were excluded, was not used.

A further 4 questionnaires out of the 50 completed questionnaires were deemed invalid since more than 50% of the items were marked 'not applicable'. Reasons offered by participants included:

- "My child hasn't needed Speech and Language Therapy for some time (last seen a Speech-Language Therapist 1 year ago)"
- "Only guidelines around feeding issues"

In 2 cases, parents who wanted to highlight the extent of the lack of services from Speech-Language Therapy, marked most questions as a 0-score / not-applicable rating:

- "Has had no SLT in the last 2 yrs, yet he needs it!"
- "Not in past year! Finished Speech Therapy at age 6."

The biographical information collected from these 4 questionnaires were included as part of the child variables.

In summary:

- A total of 41 MPOC questionnaires were used for data analysis.
- A total of 45 questionnaires were analysed to reveal the following demographic information.

(ii) Counties of Origin of Parents of Children with Cerebral Palsy

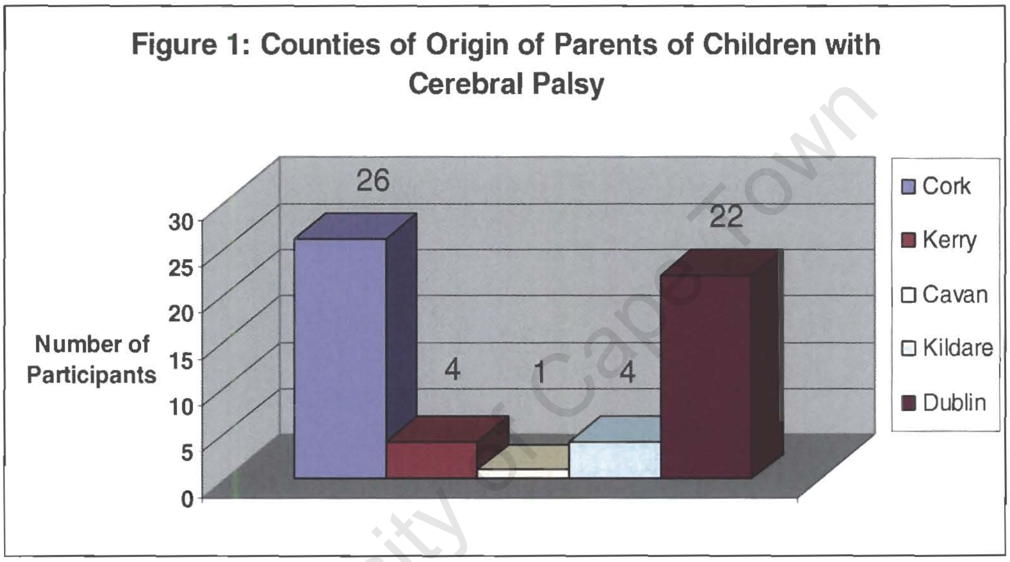

Figure 1: Counties of Origin of Parents of Children with Cerebral Palsy

Parents of children with CP from 5 locations participated in the research study with most (58%) of parents from Cork.

Location 1 (Cork): 58% (n=26)

Location 2 (Kerry): 9% (n=4)

Location 3 (Cavan): 2% (n=1)

Location 4 (Kildare): 9% (n=4)

Location 5 (Dublin): 22% (n=10)

(iii) Ages and Gender of Children

Thirty of the 45 children were male whilst 15 were female. The largest proportion of children came from the primary school-aged population between the ages of 6 and 12 years

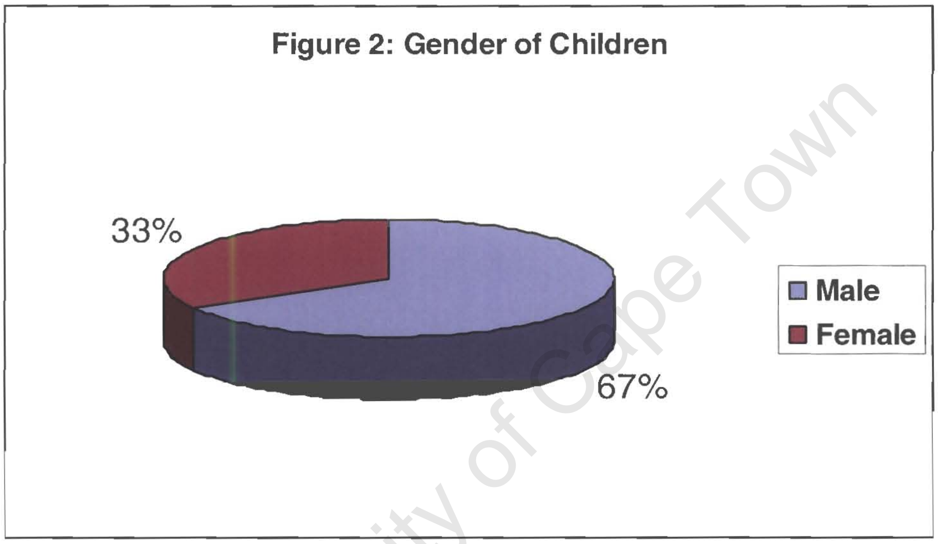

Figure 2: Gender of Children

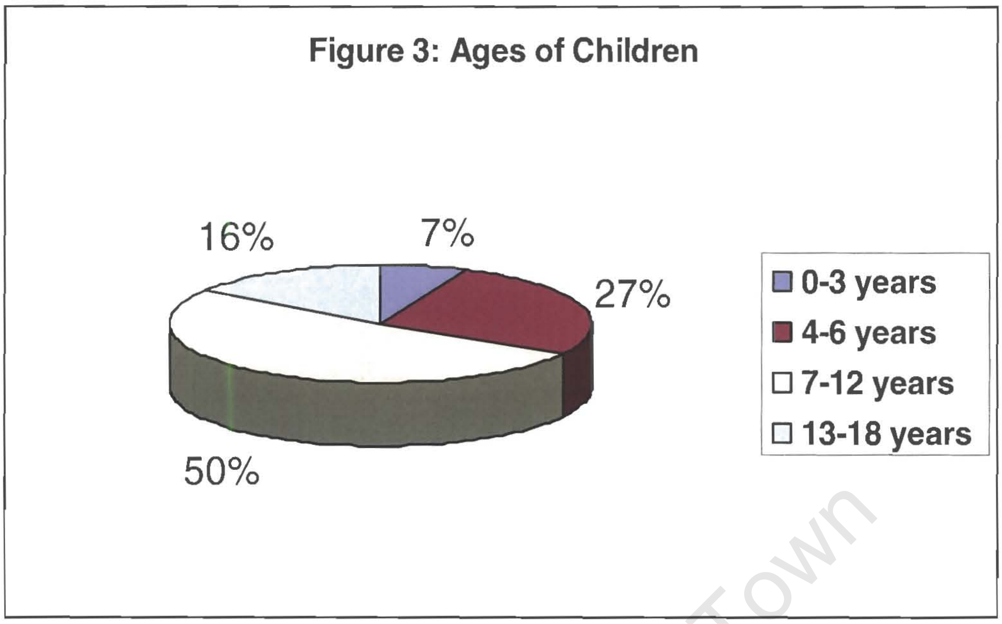

Figure 3: Ages of Children

(iv) Diagnoses

More than two thirds (77.78%, n=35) of the surveyed population had a diagnosis of spastic CP, a further 13.33% (n=6) had dyskinetic CP, and 8.89% (n=4) had ataxic CP. The classification of the children's motor impairment is shown in Table 1. Forty seven percent of the total surveyed population (n=21) had no additional health conditions or other secondary medical diagnosis. Of the rest of the population, 46% of the children had epilepsy (n=11) of which 63.64% (n=7 of 11) children's seizure activity was controlled with medication while 36.36% (n=4) was uncontrolled despite the use of prescribed medication. Twenty percent of the children had sensory difficulties: 13.33% (n=6) had auditory difficulties ranging from hearing losses to central auditory processing difficulties and being hypersensitive to sound, and 6.67%

(n=3) had visual impairments. Other conditions included chronic lung disease (n=2), cardiac conditions (n=2), hypothyroidism (n=1), and microcephaly (n=1).

Table 1: Classification of Motor Impairment

Classification		**Frequency (n)**	**Percentage (%)**
Spastic	Hemiplegia	21	46.67%
	Diplegia	6	13.33%
	Quadraplegia	8	17.78%
Dyskinetic	Athetosis	5	11.11%
	Dystonia	1	2.22%
Ataxic		4	8.89%
Hypotonic		0	0%
Mixed		0	0%
TOTAL:		**45**	**100%**

Fifty-three percent of the total surveyed population (n=24) were fully mobile, and 2 out of these 24 children needed a wheelchair for distance mobility. Twenty-nine percent (n=13) had limited mobility (i.e. used crutches or a walker) and of these 13 children, 4 had wheelchairs for distance mobility. Seventeen percent (n=8) were wheelchair users. Just over half of the children (n=23) had no orthopaedic complications where the rest of the children (n=22) did. Of the 22 with orthopaedic complications, 40.9% (n=9) had muscle contractures, 22.72% (n=5) had scoliosis, 9.09% (n=2) had seating problems, 9.09% (n=2) have had operations for their orthopaedic complications and 4.54% (n=1) had a dislocated hip. Sixty-four percent (n=29) of the children had bowel and bladder control and 35.56% (n=16) did not. When asked about their children's learning abilities, only 31 out of the 45 respondents completed this question. Thirty percent of the parents (n=14) stated that they did not know their child's level of cognitive ability or that their children had not had testing to identify their level of learning needs. Forty-five percent (n=14) of the children whose level of cognitive ability was known, had cognitive abilities in the average range, 6.45% (n=2) had low average cognitive ability, 19.35% (n=6) had a borderline learning disability, 6.45% (n=2) had a mild learning disability, 12.9% (n=4) had a mild-to-moderate learning disability, 6.45% (n=2) had a moderate learning disability, and 3.23% (n=1) had a profound learning disability. Seventy-one percent (n=32) of the total surveyed population had no behavioural difficulties. Of the 13 who had behavioural difficulties, 69.23% had decreased attention span (n=9) and 23.07% (n=3) had difficulties with hyperactivity, and emotional lability.

A third (35.56%) of the population surveyed had difficulties managing their saliva. Twenty-six percent had recurrent chest infections and oral-motor difficulties. Only 11.11% had been diagnosed with dysphagia or were at risk of aspiration, although 17.78% had various diet modifications (e.g. liquidised food or use of thickener in liquids) in place. See Table 2 for a summary of the children's feeding history. Eighty percent (n=36) of the total population were verbal, 4.4% (n=2) had limited verbal skills, and 11% (n=5) were non-verbal. Two children had a diagnosis of dyspraxia. Of the total population, 4 children had Alternative and Augmentative Communication devices and 6 used LÁMH-sign language as their primary mode of communication.

Two of the children, whose parents indicated that they were 'verbal', also used LÁMH-sign language to augment their speech intelligibility.

Table 2: Feeding History

Feeding History	**Frequency (n)**	**Percentage (%)**
No difficulties	17	37.78%
Recurrent chest infections	12	26.67%
Dysphagia	5	11.11%
Oral-motor difficulties	12	26.67%
Drooling	16	35.56%
Diet modifications	8	17.78%
Nutritional difficulties	3	6.67%
Sensory or aversive feeding behaviours	2	4.44%

3.3.1.2 Types of services where Speech-Language Therapists completing the **MPOC-SP** work:

In the Republic of Ireland (ROI), Speech-Language Therapists work in various types of service providers. These include:

- Voluntary Agencies for children with a primary physical disability
- Voluntary Agencies for children with a primary intellectual disability
- The Health Service Executive (HSE) within various Community Care Areas including Language Classes.
- Hospitals

- Schools
- Private Practice

Voluntary agencies for children with a primary physical disability

There are two main voluntary agencies in the Republic of Ireland (ROI) (Directory of Disability Services, 2006) that provide care for children and adults with physical disabilities. Most children with CP attend these specialist services with therapists specialising in the area of physical and/or intellectual disabilities.

Of the two agencies, only one, the largest agency in ROI, consented to participate in the research study. The other agency declined as they will only participate in research projects conducted by staff employed at the agency. Although the agency declined to let the carers/parents of service-users with CP be surveyed, the Speech-Language Therapists from the agency were targeted to complete the MPOC-SP questionnaire and participate in the focus group discussions. The agency has two locations in the ROI and Speech-Language Therapists from both locations participated in the research study.

The Agency that was targeted for the research study provides a service for approximately 3000 children in 14 locations across the country (Neurological Alliance of Ireland, 2005). Of the 14 locations, 6 centres participated in the research study. The following reasons were given by service managers or Speech-Language Therapists for not participating in the study:

- One location had a vacancy for the past 6 months and the service manager did not feel it was appropriate to send out the questionnaires to parents asking them to evaluate a service that they are not currently receiving.
- Another location's parents recently participated in a similar research study about service evaluation conducted by a psychology student.
- One location's parents were recently surveyed for a different research study.
- One location had only one child, a baby aged 8 months with CP.
- Three locations provided no SLT input
- Three locations did not participate in the study – no reason given.

Voluntary agencies for children with a primary intellectual disability

There are also a few agencies in the Republic of Ireland who provide SLT intervention for children with a primary diagnosis of intellectual disability secondary to conditions like Down's syndrome, Prader-Willi syndrome, Cornelia De Lange syndrome, etc. A few children with CP may attend these agencies because they fall outside the catchment area for the agencies that provide services to children with a primary physical disability. Of these agencies for children with intellectual disabilities, Speech-Language Therapists from two locations participated in the research study.

Health Service Executive and Community Care

Children who do not attend any of the voluntary agencies, can avail of SLT input from Primary Community and Continuing Care (PCCC) Team of the Health Service Executive (HSE). Children seen by the PCCC team are usually seen in a unidisciplinary fashion. Children who need input from other disciplines like Occupational Therapy and Physiotherapy will be referred to the necessary disciplines. Case conferences, team meetings, and joint teamwork are limited in these PCCC areas.

Hospitals

Only a handful of children with CP may attend acute hospitals and then mostly as in-patients for eating, drinking and/or swallowing difficulties, medical problems or for initial diagnosis. Hospitals do not provide ongoing management (Hospital Network Manager's Office, 2006).

Special Schools

Most Speech-Language Therapists working in special schools are employed by the Department of Health and work for either the HSE as part of a PCCC team or a voluntary agency. Only a handful of private Speech-Language Therapists are contracted in by the Department of Education and are dedicated Speech-Language Therapists attached to a specific school.

Summary

Of the total number of Speech-Language Therapists in the ROI, 38 participated in completing the MPOC-SP questionnaires and included therapists from the following service areas:

- Voluntary agencies: 19 Speech-Language Therapists (one split post between private practice and voluntary agency)
- Community Care: 15 Speech-Language Therapists
- Hospitals: 0 Speech-Language Therapists
- Special Schools: 4 Speech-Language Therapists
- Private Practice: 1 Speech-Language Therapist (split post between private practice and voluntary agency)

3.4 Qualitative Information: MPOC-questionnaires completed by parents

Using descriptive statistics, means, standard deviations, and ranges, and scaled scores were calculated to provide statistics about the relative strengths and weaknesses of organisations providing care for children with CP. Descriptive statistics could only be computed for the MPOC-questionnaire and not for the MPOC-SP questionnaire. The MPOC-SP manual did not include the minimal number of valid responses required for the 27-item MPOC-SP questionnaire in order to compute scale scores. As the results from the questionnaires were not appropriate paired samples due to having varying numbers of items and participants, inferential statistics such as T-tests could not be utilised as part of data analysis. Both questionnaires were divided into 5 specific service delivery issues or themes. Under each of these 5 themes there are identified items that encompass the various themes. The guidelines of the authors were followed according to which items belonged under the various themes. The following themes or service delivery issues were addressed:

- Enabling and partnership
- Providing general information
- Providing specific information
- Co-ordinated and comprehensive care
- Respectful and supportive care

Table 3: Service Delivery Themes

Themes	M	SD	Scores Within M +/- 1SD		Min	Max	Range
			From	To			
Enabling and Partnership	4.94	0.89	4.05	5.82	3.56	6.05	2.49
Providing General Information	3.67	0.48	3.20	4.15	2.71	4.29	1.58
Providing Specific Information about the Child	4.93	0.35	4.58	5.28	4.49	5.41	0.92
Co-ordinated and Comprehensive Care	5.04	0.55	4.48	5.59	3.25	5.71	2.46
Respectful and Supportive Care	5.89	0.38	5.51	6.27	5.27	6.32	1.05

Respectful and supportive care received the highest mean score of 5.89, indicating that parents perceived this theme as a relative strength of service delivery at the organisations. Parents perceived coordinated and comprehensive care, provision of specific information about their child, and enabling and partnership as satisfactory with mean scores closer to 4. Overall, parents were least satisfied with the level of general information they received from their organisation (mean score of 3.67).

Both quantitative and qualitative information gathered from the MPOC-questionnaire were used to provide item by item information in order to identify areas where improvements can be made by looking at the identified themes.

3.4.1 Enabling and partnership

- **Fully explain treatment choices**:

53.7% said "to a great extent"; 17% said "sometimes"; 29.3% said "nearly never."

More than half of the respondents commented that treatment choices are fully explained to them: "*It is easy to ask questions and she* (SLT) *breaks it down into English*," "*She* (SLT) *tells you what she thinks will work best for him.*" The other respondents had the following to say: "*We don't meet the Speech-Language Therapist very often due to their lack of resources. We are given a programme to do – no choices of treatment you receive", "Seldom any chance with limited service available", "The only contact has been about what device my child should use"*, and *"I feel you must take what you are offered."*

- **Offer positive feedback / encouragement**:

70.7% said “to a great extent”; 9.8% said “sometimes”; 19.5% said “nearly never.”

Most of the respondents (70.7%) commented that they received a lot of positive feedback and encouragement from their SLT: “*I am told every step of the way why and explained what they are doing”*, and “*We are given good ideas to be carried out at home*”. A few respondents (19.5%) stated that they “*find this hard, other than doing things that are common sense,”* and “*Again, only in regard to her communication aid.”* Lack of direct service delivery was mentioned and participants commented that, “*as the child is in school so we can’t attend SLT as much now so we always get a home programme”*

- **Tell you about service / treatment options**:

48.7% said “to a great extent”; 16.2% said “sometimes”; 35.1% said “nearly never”.

More than half the respondents stated that they do not get enough information about services and treatment options: *“Up to parent to seek out information”, “I have just got some equipment”*, and “*Just about what devices are available”*. One respondent stated that she had had a positive experience at her organisation particularly in relation to choosing a communication device: *“I’ve had a good experience on choosing a communication aid”*.

- **Trust you as expert on child:**

90.3% said “to a great extent”; 0% said “sometimes”; 9.7% said “nearly never”.

Parents commented that they (the Speech-Language Therapists) *"make us very aware that our opinion counts"*. Other parents stated that the Speech-Language Therapists *"will listen to some degree"*.

- **Anticipates concerns by offering information**:

48.7% said "to a great extent"; 16.2% said "sometimes"; 35.1% said "nearly never."

Thirty-five percent of the respondents stated that this rarely happens: *"We don't meet the therapist very often", "Not that much"*. Other comments included: *"If she notice something she will say it but mostly I tell her if something's worrying me."*

- **Chance to say what is important to you**:

84.6% said "to a great extent"; 5.1% said "sometimes"; 10.3% said "nearly never."

Respondents mostly felt that they get a chance to say during meetings what is important to them: *"The organisation couldn't be more supportive*". Others who felt that they do not always get a chance to say what is important to them, made comments particularly related to the Speech-Language Therapists' lack of time due to their "*big caseloads*": "*We do not always have time with the Speech-Language Therapist" and "the Speech-Language Therapist is very busy running from one meeting to the next"*.

- **Let you choose when to receive information and type of information you want:**

65.7% said "to a great extent"; 8.6% said "sometimes"; 25.7% said "nearly never."

Respondents made the following comments: *"If I want to know something I ask*" and *"It's usually good."*

- **Tell you about reasons for treatment / equipment:**

90.2% said "to a great extent"; 4.9% said "sometimes"; 4.9% said "nearly never."

Respondents made the following comments about this statement: *"Yes, every step of the way"* and *"Yes, lets us know what it is for."*

- **Provide opportunities for you to make decisions about treatment**:

56.8% said "to a great extent"; 18.9% said "sometimes"; 24.3 % said "nearly never."

Only half of the respondents felt that Speech-Language Therapists "*ask you all the time what you think*".

- **Answer questions completely:**

80.5% said "to a great extent"; 14.6% said "sometimes"; 4.9% said "nearly never".

Most participants felt that Speech-Language Therapists do this *"to the best we can.*"

- **Recognises that the family has final say in decision making regarding treatment**:

81.8% said "to a great extent"; 6.1% said "sometimes"; 12.1% said "nearly never".

Of the 81.8% of the respondents, comments included the following statements: *"Of course"* and *"Definitely!"* where others commented that *"I will make all decisions anyway"*. Some participants highlighted the importance of the whole team's input in the decision making process: *"It's a group choice: child, therapist, family"*. Once again participants felt that they were *"asking for more services than are available."*

- **Consult with you when discussing equipment and services:**

84% said "to a great extent"; 8% said "sometimes"; 8% said "nearly never".

The majority of respondents stated that Speech-Language Therapists consult them when discussing services and equipment: *"Yes, I'm always involved, it's very important"* and "*Parents usually involved in process"*. Of the 8% of respondents who mentioned that they were nearly never consulted, the reasons given for why this has not been happening was due to a *"lack of SLT services*" or *"shortage of Speech-Language Therapists"* and *"no regular speech therapy sessions available"*.

- **Details of child's speech and language therapy service (i.e. reasons, type of therapy, length of time)**:

70.7% said "to a great extent"; 4.9% said "sometimes"; 24.4% said "nearly never".

The majority of respondents stated that the Speech-Language Therapists "*are always very informative*". Of the 29.3% of respondents who felt that they do not know much about the details of their child's SLT service, the following issues were raised:

(i) Lack of resources: Lack of services

- *"My child has had no SLT in the last 2 years, yet he needs it",*
- *"Not in past year! Finished Speech Therapy at age 6",*
- *"The centre is great in dealings with us on a visit only basis. No resources available to them to provide required services i.e. 3-5 visits a year, sometimes this is not nearly enough, "*
- *"We are satisfied by the centre, would just wish it to have more therapists to offer services."*

(ii) Lack of resources: Time constraints:

- *"I would like however to point out that every Speech-Language Therapist who worked with my child, while being very good at their task did not have the time to work with her as I'm sure they would have liked to – their caseloads were always too full."*
- *"The Speech-Language Therapists who work with my child both presently and in the past have too many children on their caseload and very little time to allocate to each child."*

(iii) Speech and language therapy

- *"I would just like to add that my child has been offered approximately 12 hours of therapy for this year. We have not in the past 11 years been offered any advice on feeding or drinking."*
- *"All therapy is done by family – in addition to care."*
- *"As my child has got older her speech has improved but therapy has decreased, only for communication device now."*
- *"Speech-Language Therapist not in touch with child or parents very often."*

- **Opportunity to explain your treatment goals**:

71.8% said "to a great extent"; 10.3% said "sometimes"; 17.9% said "nearly never".

The majority of respondents felt they had an opportunity to explain their treatment goals for their child: "*Excellent! They always listen to me", "and they explain some things in detail if you don't understand*" and "*I would find this extremely important and always try to grab these opportunities*". Other respondents gave "*lack of time*" as the reason why this did not happen more often.

- **Partner in child's care**:

90.2% said "to a great extent"; 0% said "sometimes"; 9.8% said "nearly never".

An overwhelming 90.2% of respondents felt like they were a partner in their child's care. Of the 9.8% who did not feel like a partner in their child's care, the following comments were made: "*Its all up to the carer*" and "*Sometimes too much – have the impression we're becoming Speech Therapists' assistants ourselves*".

- **Listens to you about child's needs for equipment / services**:

90.2% said "to a great extent"; 4.9% said "sometimes"; 4.9% said "nearly never".

Respondents made the following comments: "*Speech-Language Therapists listen and give suggestions as to what toys to buy that will help*", "*Seems to listen anyway*", and "*Take the time to listen and give feedback.*"

3.4.2 Providing General Information

- **Information in various forms:**

32.5% said "to a great extent"; 21.6% said "sometimes"; 45.9% said "nearly never".

Respondents commented that they received *"some introductory information on the service,"* but felt that *"there could be more information to help. I found parents along the way gave me more information than the centre"*. Others commented that *"mostly they met and spoke to you"* rather than hand you written information which made it *"less impersonal"*.

- **Information regarding types of services offered – in the organisation and community**:

59.5% said "to a great extent"; 10.8% said "sometimes"; 29.7% said "nearly never".

Participants commented that although they received information about types of services offered in the centre / organisation they *"never got any information of them from the community."*

- **Family-to-family gatherings:**

39.1% said "to a great extent"; 34.1% said "sometimes"; 26.8% said "nearly never".

For the respondents whose Speech-Language Therapists provided this service as part of a team, they commented that it was "*great days out fun and relaxing*". Some respondents said that there was *"not enough of that",* whereas most respondents thought it to be the role of the Social Worker: *"Social workers facilitated preschool group parents meetings approximately 4 per annum."*

- **Special guests – topic of interest:**

28.2% said "to a great extent"; 28.2% said "sometimes"; 43.6% said "nearly never".

Respondents felt that there was *"not nearly enough and I think there is a big demand for this especially new families coming in".* A few respondents stated that a *"solicitor spoke on making will and we found such information very valuable".*

- **Support to help cope with impact of disability – advocating:**

40% said "to a great extent"; 28.6% said "sometimes"; 31.4% said "nearly never".

Respondents made the following statements: "*This is usually addressed during the first visit of social worker to your home*", and "*Not enough! much more needed.*"

- **Information regarding the child's disability**:

40% said "to a great extent"; 22.9% said "sometimes"; 37.1% said "nearly never".

Respondents reported that the information received was *"not enough much, more needed"*. One respondent commented that: "*I found [I had] to seek my own information*" and in another case the child's disability was *"never discussed"*. Usually participants received information from the "*social worker to the home*" and commented that the *"social worker calls to check up on you"*.

- **Contact other parents:**

32.5% said "to a great extent"; 32.4% said "sometimes"; 35.1% said "nearly never".

Comments included: *"Not aware that such facility exists"* and *"There is no parent resource library."*

- **Opportunity for entire family to obtain information**:

48.8% said "to a great extent"; 17.9% said "sometimes"; 33.3% said "nearly never".

Most respondents were *"not aware that such a facility exists"* and mentioned that *"they (the organisation) don't really"* have a facility for where the entire family may obtain information.

- **General information regarding different concerns**:

25.7% said "to a great extent"; 20% said "sometimes"; 54.3% said "nearly never".

Most participants were *"not aware of any such source of information*" and stated that they "*would like to find out more information about this*". Other respondents reported that they received "*no information unless to seek social worker who would then help best they could but not handed out information". A few respondents said that they had to "*confess not to have asked*" for information from their organisation.

3.4.3 Providing Specific Information about the Child

- **Explain while watching:**

83.8% said "to a great extent"; 5.4% said "sometimes"; 10.8% said "nearly never".

Of the majority of parents who stated that things are always explained to them while they are watching, one respondent said that "*I'm always involved – very important".* The rest of the respondents commented that "*parents are usually not involved in the process*" because there is *"no regular speech therapy sessions available".*

- **Tell you the results from assessments:**

76.9% said "to a great extent"; 0% said "sometimes"; 23.1% said "nearly never".

Most of the respondents (76.9%) said that they receive written information about their child's progress through *"assessments and reports": "They do assessments every* *couple of months and send you the report"*. The other half of respondents made the following comments: *"Never, because these assessments do not happen", "Hasn't had assessment / evaluation in past year – it'd be over a year ago", "No results ever given. Not aware of any assessments apart from TalkTools assessment*" and *"No assessment for communication devices done."*

- **Written information – doing in therapy:**

63.4% said "to a great extent"; 9.8% said "sometimes"; 26.8% said "nearly never".

Respondents mentioned that there is *"not much written info"*, but *"they (Speech-Language Therapists) will tell me when talking to them"*. Respondents also stated that they "*would like more written information*", where others said that they "*much prefer verbal communication as you can sometimes omit reading information, verbally you ask more"*. Other participants received written information "*only regarding home programmes"*.

- **Written information about progress:**

53.7% said "to a great extent"; 19.5% said "sometimes"; 26.8% said "nearly never".

Participants disclosed that they receive *"not a lot of written information about progress, would like to see more"*. Other participants said that although they do not receive written information, the SLT "*will tell me when talking to them*". Participants also said that they "*much prefer verbal communication as you can sometimes omit* *reading information, verbally you ask more questions"*. Other respondents stated that they receive written information "*only regarding home programmes"*.

- **Notify upcoming case conferences:**

65.8% said "to a great extent"; 9.8% said "sometimes"; 24.4% said "nearly never".

Respondents felt that the organisation is *"getting better at this*", but others expressed a dissatisfaction with the lack of meetings, with "*review meetings only while attending preschool"* and for others *"none are held"*.

3.4.4 Coordinated and Comprehensive Care

- **Therapy plans fit with family's needs and lifestyle**:

61% said "to a great extent"; 19.5% said "sometimes"; 19.5% said "nearly never".

Of the 61% of respondents who felt that Speech-Language Therapists suggest therapy plans that fit their needs and lifestyle, the following comments were made: *"Our Speech-Language Therapist is very flexible on appointments and works full time which I find really important", "Our Speech-Language Therapist will see our child at times when he is out of school and before he went to school, she used to come to the house", "I have no car and the organisation is far from my home, so travel is a problem as he cannot walk far, they help with the cost when they can or use the local health centre to save me the travel"*. Other respondents felt that therapy plans to fit family needs and lifestyle happened only rarely and in a sometimes (19.5% of the time) never: *"All therapy is done by family – in addition to all care needs", "Therapy plans? What therapy plans? It is such a disgrace!", "The Speech-Language Therapists who work with my child both presently and in the past have too many children on their caseload and very little time to allocate to each child", "As my child has got older her speech has improved but therapy has decreased, she is only seen for her communication device now". "Idea: A crèche to mind my other kids while my son is having therapy would be a nice add-on as it can be disturbing to have a toddler around during a therapy session."*

- **Explain things to your child in a child-friendly way:**

82.9% said "to a great extent"; 9.8% said "sometimes"; 7.3% said "nearly never".

An overwhelming 82.9% of parents reported that Speech-Language Therapists explained things to their child in such a way that their child understands: *"He understands the words she uses", "Has a good rapport with my daughter"* and *"Talks to him at his level and not above him".*

- **Take time to establish rapport when there are changes in service:**

83% said "to a great extent"; 2.4% said "sometimes"; 14.6% said "nearly never".

83% of respondents stated that establishing rapport with them and their child happened to a great extent: *"Our Speech-Language Therapist has great involvement in his school for when others follow up her treatment".* The other 17% made the following comments about this statement: *"I put this down to the individual", "We* *have to chase services and each time we discover a change in personnel without being informed beforehand"* and *"Could do with more sessions to establish and build rapport".*

- **Discuss everyone's expectations for your child:**

79.5% said "to a great extent"; 5.1% said "sometimes"; 15.4% said "nearly never."

A high percentage (79.5%) of parents stated that Speech-Language Therapists discuss with them everyone's expectations for their child: *"Regular, family meetings and I can call one if I'm worried which is great*", and *"We have a family and team meeting yearly this gives us hope and a plan".* A few respondents (15.4%) commented that this nearly never happens: *"Don't get any team review for our child unless we pressure / chase it ourselves."*

- **Make sure child's skills are known to all:**

83.8% said "to a great extent"; 0% said "sometimes"; 16.2% said "nearly never.

Eighty-three percent of respondents felt that their child's needs were known to other team members so that the skills are carried across services and service providers: *"The 6-monthly family meeting is a very good opportunity to review progress, confront views and agree on next steps", "Family meetings and joint sessions", "Group meetings every few months".* A few respondents (16.2%) felt that *"We have to push for this to happen".* One parent felt that therapists do not communicate to each other about the child's abilities, skills and method of communication: *"none of the other therapists try to communicate with the child, beyond 'hello' and 'goodbye'"*.

- **Provide ideas to help you work with the health care system**:

42.9% said "to a great extent"; 20% said "sometimes"; 37.1% said "nearly never."

A few participants (approximately 20%) commented that this issue *"Haven't come up" in dealings with the organisation, where other participants "needed more of this"* and suggested that meetings to discuss such issues "*should be every term"*.

- **Recognise the demands of caring for a child with special needs**:

78% said "to a great extent"; 4.9% said "sometimes"; 17.1% said "nearly never".

Most of the respondents (78%) felt that Speech-Language Therapists *"fully understand"* and recognised the demands of having a child with special needs: *"very supportive as he is a twin [and I] also have [a] school going child"*. Others (4.9%) felt that Speech-Language Therapists recognised the demands "*as best they can*". Of the 17.1% of respondents who stated that there was limited recognition, the following comments were made: *"I would go so far as to say – fail to recognise the communication needs of the family with the child and how this adds to care burden."* Lack of SLT service delivery was also mentioned: "*Not enough block sessions for my son's needs*."

- **Needs of whole child met**:

73.3% said "to a great extent"; 9.7% said "sometimes"; 17% said "nearly never."

Once again various opinions were expressed when asked if they felt their child's holistic needs are met. In smaller locations, parents were generally satisfied with the level of input they received from their Speech-Language Therapists: *"Our Speech-Language Therapist is very flexible on appointments and works full time which I find really important". "The Speech-Language Therapist has our daughter to the fore of the picture*", and *"it's all considered – taken into a bigger picture"*. Other parents appreciated the flexibility of Speech-Language Therapists at their organisation: *"Sometimes he may be tired or sick. He has chest infections very regular*." A few respondents mentioned the key worker system: "*We did experience a key-worker for a short period – a physiotherapist dealing with child between ages 2 and 3 years."* From the 17% of respondents who felt that their child's holistic needs are not always considered, the following comments were made: *"Each therapist has own field and sometimes you end up with too many things to do for each and not enough in the day / week / months",* and "*Speech-Language Therapists not in touch with child or parents very often"*.

- **Show sensitivity to family's feelings about having a child with special needs**:

74.4% said "to a great extent"; 20.5% said "sometimes"; 5.1% said "nearly never."

Respondents felt that Speech-Language Therapists do this *"as best they can*".

- **Follow up at next appointment on concerns**:

85.3% said "to a great extent"; 4.9% said "sometimes"; 9.8% said "nearly never."

- **At least one team member is constant**:

53.9% said "to a great extent"; 20.5% said "sometimes"; 25.6 % said "nearly never."

Parents who experienced the key worker role, felt positive about their experience where one person was assigned to coordinate their child's care: *"Did experience key worker for short period – a physiotherapist dealing with child between ages 2 and 3 years."* In general parents felt that due to the high staff turn-over in these organisations, there is not a lot of continuity of care: Parents commented that *"there has been a lot of change in therapists"* with one parent stating that she has had "*4 different therapists in the last 3 years. Severe shortage of therapists at the centre. Thus creating a shortage of therapy sessions"*. Despite the high turnover in therapists, parents feel that the organisation do "*as best they can, but staff changes quite regularly"* and *"they try to but not enough therapists to go around and you get lots of changes"*. Other parents felt disempowered because they felt they are *"not decisionary in this process – a lot of turnover in staff"*.

- **Short-term goals and long-term goals**:

71.8% said "to a great extent"; 5.1% said "sometimes"; 23.1% said "nearly never".

Varied comments were elicited about the presence of goal setting. Most parents stated that goal setting happened as part of the intervention process. Some parents stated that they were *"not aware of the goals"*, while other parents blamed the lack of resources for goals not being identified: *"No goals yet – child gets therapy based on low therapist resources"*. In other centres, parents commented that "*Goals are set out, it just takes time for them to be met"* and parents who attend smaller organisations commented that goal setting happened "*every step of the way"*.

- **Plan together**:

76.9% said "to a great extent"; 10.3% said "sometimes"; 12.8% said "nearly never".

Comments included: *"The Organisation has team meetings once a week*" and *"usually there is a good effort made it is just hard to get everyone together"*. One parent did not feel that all team members planned and worked together: *"No team approach apparent."*

- **Information ahead of time regarding changes in care**:

70.7% said "to a great extent"; 9.8% said "sometimes"; 19.5% said "nearly never".

Parents felt strongly about being informed about changes in their child's care: *"I would definitely expect to be informed"*. Others mentioned that *"change in therapist usually flagged in advance (but had up to 6 changes of therapists to date)."*

- **Aware of child's changing needs as he/she grows.**

68.2% said "to a great extent"; 9.8% said "sometimes"; 22% said "nearly never".

Respondents commented that mostly Speech-Language Therapists *"tell you what level they are at and what they should be at and how they will be getting him to that level"* and that Speech-Language Therapists try their best to stay abreast with current research and therapy approaches: *"Yes always on the lookout for new things*". Some parents felt that sometimes Speech-Language Therapists do not consider the child's changing needs. Usually the focus of therapy remains with the child's basic needs, but as one parents commented *"what about the child's educational needs? Socialising needs? Feelings?"* Another parent felt that the Speech-Language Therapist "*does not see the child often enough and no continuity"* to be aware of the child's changing needs.

- **Make themselves available as resource (support / information / advocacy):**

69.3% said "to a great extent"; 25.6% said "sometimes"; 5.1% said "nearly never".

Respondents commented that only "*some members*" made themselves available as a resource, where others respondents felt that they "*Don't see this as part of the Speech-Language Therapist's role, this service is provided by others".*

- **Information is consistent from person to person**:

75.7% said "to a great extent"; 10.8% said "sometimes"; 13.5% said "nearly never".

Parents felt that *"this depends on staff*". Of interest was the fact that some parents have had the opportunity to move through the various organisations dealing with children with CP. One parent pointed out that the main difference amongst the two organisations was that the one organisation "*identified the child's potential*" where the other organisation "*saw the child's limitations*". Other parents also commented on the fact that they "*have noticed a big difference in feedback / assessments between centres*".

3.4.5 Respectful and Supportive Care

- **Accept your family in a non-judgemental way:**

90.2% said "to a great extent"; 4.9% said "sometimes"; 4.9% said "nearly never.

Most of the respondents participating in the research study felt that they were accepted in a non-judgemental way: *"We have no problem in talking with the therapist"*.

- **Remember personal details**:

90.2% said "to a great extent"; 4.9% said "sometimes"; 4.9% said "nearly never."

Most respondents commented that Speech-Language Therapists will to a great extent remember personal details about their child or family: "*They* (Speech-Language Therapist and organisation) *have a very close involvement", "Very attentive to my child and good at listening to him*" and *"Always is aware who else is at home"*.

- **Caring atmosphere**:

90.2% said "to a great extent"; 0% said "sometimes"; 9.8% said "nearly never".

The majority of respondents stated that "*yes, its always caring*".

- **Treat you as an individual:**

85.3% said "to a great extent"; 9.8% said "sometimes"; 4.9% said "nearly never".

Respondents commented that: *"Yes, I have always found to be treated as an individual."*

- **Treat you as an equal:**

69.8% said "to a great extent"; 25.6% said "sometimes"; 5.1% said "nearly never".

Parents were very positive about this part of service delivery. A few comments highlight their satisfaction: "*They* (Speech-Language Therapists) *have a very close involvement*". The Speech-Language Therapist "*calls you by your name*" and *"I have always found to be treated as an individual."*

- **Feel competent as parent:**

85.4% said "to a great extent"; 0% said "sometimes"; 14.6% said "nearly never".

Parents commented that the Speech-Language Therapist empowers them by *"making us feel that we provide his speech therapy guided by them"* and they (the Speech-Language Therapists) *"provide support if needed*". Other parents felt that they don't feel competent as parent "*where communication with my child is concerned.*"

- **Enough time to talk:**

68.2% said "to a great extent"; 22% said "sometimes"; 9.8% said "nearly never".

Lack of time was overwhelmingly identified as the most important resource that is lacking in service delivery. Parents were fairly understanding of the time constraints that Speech-Language Therapists have to deal with "*They try, but time is much in demand*" However, in smaller centres the parents had "*no problems there, they* (Speech-Language Therapists) *make time for discussions.*"

- **Treat you as a people – not as 'case':**

95.1% said "to a great extent"; 0% said "sometimes"; 4.9% said "nearly never".

Respondents commented that *"Speech-Language Therapists are very good like that thankfully."*

- **Polite and courteous staff:**

100% said "to a great extent"; 0% said "sometimes"; 0% said "nearly never".

All the respondents felt that therapists and staff were *"always very polite, not as available though"*.

3.4.6 Summary of MPOC-questionnaires

Looking at the item by item information, the following areas were identified as areas of strength and weaknesses within the service providers:

(i) Enabling and Partnership

Parents rated the following areas as highly satisfactory: Speech-Language Therapists trust them as an expert on their child, see them as a partner in their child's care, listen to parents about their child's needs for equipment / services and tell them about the reasons for treatment / equipment. Parents stated that although Speech-Language Therapists told them about the reasons for treatment / equipment, they were rarely told about the service / treatment options available in order for them to make an informed decision. Parents also rated 'anticipate concerns by offering information' as a relative weakness in speech-language service delivery.

(ii) Providing General Information

The theme of 'providing general information' was identified as a major weakness in service delivery to children with CP, with all the questions under this heading receiving a rating of below 50%, apart from 'information regarding types of services offered within the organisation and community' receiving a 59.5% satisfactory rating.

(iii) Providing Specific Information

Parents commented that they received significantly more information specific to their child than information about general speech-language concerns. Parents rated specific information that they receive while they are watching a therapy session as an area of strength. Parents were least satisfied with the level of written information they received about their child's progress.

(iv) Coordinated and Comprehensive Care

Parents overall reported that they received a coordinated and comprehensive service from their service provider, with therapists taking time to establish rapport, explaining things in a child-friendly way to their child, following up on concerns expressed and making sure their child's skills are known to all team members, as areas of strength. Parents were least satisfied with the lack of ideas provided to them to help them 'work with the healthcare system'. This weakness also seems to tie in with a lack of information about what services and supports are available within the organisation. Parents also rated the presence of 'at least one team member is constant' as a weakness in experiencing a coordinated service.

(v) Respectful and Supportive Care

Parents rated the theme of 'respectful and supportive care' as highly satisfactory and an important strength in current service delivery. 'Having enough time to talk' and 'treating parents as equals' were identified as slight weaknesses in ensuring respectful and supportive care.

3.5 Qualitative Information: MPOC-SP questionnaire completed by Speech-Language Therapists

3.5.1 Enabling and Partnership

- **Offer parents and children positive feedback/encouragement in carrying out home programmes**:

79.1% said "to a great extent"; 13% said "sometimes"; 7.9% said "nearly never".

Although an overwhelming 79.1% of Speech-Language Therapists said they offer parents and children positive feedback and encouragement, a few Speech-Language Therapists commented that providing positive feedback can be difficult. One SLT highlighted "*we do tend to look out for negatives in SLT but I try to emphasise the positives*". Most of the therapists stressed the importance of providing home programmes: *"Home programs are always given. The families are put in the drivers' seat as far as treatment. That is, they are empowered"*. Therapists also felt that *"enthusiasm for home programmes is more likely to be maintained if given positive feedback."* For children, Speech-Language Therapists stated that *"they frequently review and reiterate to the children why they're doing what they are doing. Review progress from the beginning with them. I find that some children really need the emotional support and discussing their therapy with them, obviously at a suitable level for their age"*. It is also important to *"ensure they (children) understand what they are being asked to do and why."* The Hanen-parent training programme is also offered at some organisations and incorporates a great deal of positive feedback to parents throughout the training course.

- **Tell parents about options for services / treatments / equipment / therapy?**

71.1% said "to a great extent"; 10.5% said "sometimes"; 18.4% said "nearly never".

Speech-Language Therapists stated that they were mostly "*aware of letting parents know all that is available*" because then *"parents can make decisions for their children if aware of all the options available".* Speech-Language Therapists mentioned that telling parents about the available options *"happens to a great extent with parents of children in Early Services"*. Speech-Language Therapists also mentioned that for "*most children over 5 years, most services are already in place*" A few Speech-Language Therapists felt that their "*knowledge in this area [was] not up to date"* and that they "*don't really know what options are out there.*" The Speech-Language Therapists also felt that with regards to information about available treatment and service options "*very little was offered locally".* One Speech-Language Therapist felt that this was not part of their role and mentioned that *"other members do this* (tell parents about options available)" Again, Speech-Language Therapists mentioned that "*parent contact can be limited especially in the school setting, but where possible this* (tell parents about options) *is done*".

- **Trust parents as the experts on their child:**

83.8% said "to a great extent"; 16.2% said "sometimes"; 0% said "nearly never".

Most Speech-Language Therapists felt that "*this is key to all treatment and goal setting particularly in areas like Alternative and Augmentative Communication (AAC)". "Family members are the experts and we listen, inform, and empower". "Parents know their child's strengths and weaknesses and are a valuable resource to the therapist". "Parents opinions on their child will give more information on the child's presentation than the information gained in the clinic setting".* Some Speech-Language Therapists mentioned that *"at times there is a need to discuss parental expectations in relation to actual observations".* One Speech-Language Therapist stated that she "*would say 98% of the time I trust parents as the experts, but I have had 2 children who one would have to argue was not very well 'understood' by their parents and who were way off the mark in their perceptions and plans."* Another Speech-Language Therapist stated that "*sometimes I misjudge the parent's level of accuracy/objectiveness in reporting (both + and – bias on parent's behalf)." "This depends on the parent. Some do not inspire confidence in me".*

- **Anticipate parents' concerns by offering information even before they ask:**

56.8% said "to a great extent"; 27% said "sometimes"; 16.2% said "nearly never".

The following comments were made about this question: *"I would often discuss issues / concerns raised by other parents, e.g., AAC will stop the child talking." "Sometimes I feel I should have waited for their questions instead of giving information that they are not ready for"* and "*I would be very careful. If I feel parents are concerned I would ask them if they have any concerns. I do this at the end of all sessions anyhow. I do tend to follow their pace as I feel this is what people emotionally cope with."*

Other comments included: *"I would be aware that it may be necessary to repeat information as it is hard for a person to absorb everything at once."*

- **Make sure parents had a chance to say what was important to them:**

86.5% said "to a great extent"; 13.5% said "sometimes"; 0% said "nearly never".

Most of the 86.5% of Speech-Language Therapists said that they *"encourage open and frank discussion at times"*. Meeting parents and giving them an opportunity to say what is important to them usually happened *"at that all important first appointment."* Other statements made by Speech-Language Therapists included: *"I make a point of asking whether they believed in the timing of a therapeutic approach etc and what their priorities are at a given time e.g. at family meetings"* and "*regularly ask if they are happy with the way things are going and if there is anything they would like to focus on instead. Also, and if they feel the activities will help."* Making sure parents have a chance to say what is important to them is *"very important"*, as one Speech-Language Therapist pointed out: "*Parents of very sick children have a different focus at different times and need to talk about setting the pace that is right for them"* One organisation's team *"sends questionnaires prior to the individual family service planning (IFSP) meeting"*. Another Speech-Language Therapist stated that "*sometimes my own therapy agenda can get in the way. It also depends on how often we are able to meet"*.

- **Let parents choose when to receive info and type of info they wanted:**

40.6% said "to a great extent"; 35.1% said "sometimes"; 24.3% said "nearly never."

Speech-Language Therapists provided the following information about this statement: *"I would always ask if they have any further questions but I would not always give full choice regarding information." "If you are talking about information relating to language or motor skills, then I let the rate of progress and therapy activities dictate information discussed. I do always make sure that parents clearly understand the specifics e.g. what exactly their child is finding very difficult and why certain approach is recommended, and I hope this generates questions as they are ready to ask them." "Ask them to get in touch. Frequently they do make contact between sessions. They must feel the therapist is approachable and their contact is welcome." "I would respond to requests for information when they arise if the need for further information on a topic arose during the course of therapy I would make parents aware of the availability of this information."* A few Speech-Language Therapists also stated that "parents are invited but not pressured to contact Speech-Language Therapists if they needed information". Speech-Language Therapists also highlighted the importance of coming back to this issue of information giving: *"Sometimes leaving them come to you is not enough. They need encouragement. They may not always know what information is useful or what information they need".*

- **Answers parents' questions completely:**

81.1% said "to a great extent"; 18.9% said "sometimes"; 0% said "nearly never".

Most of the Speech-Language Therapists said they *"try to answer questions honestly and openly"* and *"where clinical knowledge allows"*. Speech-Language Therapists will consult colleagues or the literature and get back to parents if they don't fully know the answer: "*As much as possible, if necessary I may talk to colleagues or access information and report back*" and "*in my ability and as far as my knowledge reaches. I have contacted other professionals if not able to answer questions completely*". Speech-Language Therapists will also ensure that "*parents concerns and queries have been very comprehensively dealt with until they say they are satisfied. Many times this has meant meeting with mum and one other discipline to explore issues and options and then follow up with school/preschool medically or organise full IFSP sooner than originally planned*". Other statements included: *"Would do my best to do the above but we can't always accurately predict prognosis, rate of progress"*, and *"fully answering questions does need to be timed. Very occasionally answers can do more harm than good"*.

- **Tell parents details about their child's service:**

71.1% said "to a great extent"; 21% said "sometimes"; 7.9% said "nearly never".

Most Speech-Language Therapists completing the questionnaire, stated that they directly *"explain ethos and goals of intervention for their child"* where others stated that this "*is discussed at the family meetings*". Other statements included: "*In the school setting contact with the parents is less than is optimal for the above*". *"In Individual Education Plan (IEP) meetings if we are invited, otherwise we try to follow-up with parents over phone or on open days." "This is again addressed at twice-yearly review meetings. Parents are free to ask questions if unclear about anything"*.

- **Make sure parents had opportunities to explain their treatment goals and needs:**

78.9% said "to a great extent"; 15.8% said "sometimes"; 5.3% said "nearly never".

Most of the Speech-Language Therapists commenting on this statement felt that they play a vital role in *"assisting parents in making decisions*". As one Speech-Language Therapist stated: "*Therapy would be a punishment if there was no integration of their (parents') hopes and worries into the child's education or communication goals".* Sometimes goal setting *"is carried out at family meetings*", or "*done in a formal way at Individual Personal Planning (IPP) meetings".* Other comments included: *"Parents' requests are always attended to and needs are met where possible, e.g. supplying feeding profiles, low-tech aids, objects of reference, etc."* One Speech-Language Therapist stated that: *"I feel time may affect this occurring to the level it may require."*

- **Help parents feel like a partner in their child's care:**

84.2% said "to a great extent"; 10.5% said "sometimes"; 5.3% said "nearly never".

Most of the 84.2% of Speech-Language Therapists who said that they ensure that this happens to a great extent made the following comments: *"It is very very important to stress their (parents') role in team"* and *"it's very important to involve parents in treatment". "Programs such as Hanen facilitate this. I always make a point of all the positive things they do in their role as parents" "Always give feedback regarding any input from parents. Often they supply info for treatment and are involved in* *assessments". "Necessary to ensure parental input by empowering them with knowledge and skill. This enables them to assume responsibility and control." "From the beginning I asked how they feel things would work out best and changed some children's therapy to a different term or changed times and activities or the way I did things according to parent feedback.*" Also, *"I spent time making sure parent had practised and was comfortable with what they had to teach or facilitate at each step."*

3.5.2 Providing General Information

- **Promote family-to-family connections:**

42.1% said "to a great extent"; 31.6% said "sometimes"; 26.3% said "nearly never".

Most of the Speech-Language Therapists stated that this is *"something we are deliberately trying to increase"*. In the smaller organisations, family-to-family gatherings are *"formally and informally encouraged by the organisation"*. Most gatherings are in the form of *"coffee mornings, social nights, family days."* At least 16 Speech-Language Therapists stated that *"regular parent groups / family days provide the opportunity for this"* as does the "*Hanen and group interventions". "Family resource centre provides information and training and support for students and families"*. Of the Speech-Language Therapists who have organised *"various social-, information evenings, parent groups for children, siblings groups and parents courses (e.g. Parent Plus, play and communication groups)"* commented that "*families found this a very rewarding experience*". One organisation stated that they are "*beginning to do more focus groups for parents*". One Speech-Language Therapist stated that the "*agency tries, little expressed desire by families*."

- **Provide support to help families cope with the impact of their child's chronic condition:**

50% said "to a great extent"; 25% said "sometimes"; 25% said "nearly never".

Half of the Speech-Language Therapists completing the questionnaire stated that *"this was mostly the role of the psychologists and social workers": "Social workers and psychologists offer counselling."* Other support systems include: "*Social workers, link, respite"* or "*mainly through paediatrician, community nurse (fortnightly visits) and social work department." "Not really Speech-Language Therapist's role, the nurses tend to do that plus liaison nurses". "Families have services of the multidisciplinary team in the organisation. Home visits are done by social workers and care staff."* One Speech-Language Therapist stated that "*I have recommended support systems. I tread cautiously however. One parent said she was overwhelmed with people calling and had no privacy anymore. This mother said she found this intrusive and she could no longer decide to 'go out spontaneously – because someone would be calling'*". In the smaller organisations and in more remote areas Speech-Language Therapists commented that there is "*very little counselling support available*".

- **Provide advice on how to get information or to contact other parents:**

46.1% said "to a great extent"; 19.7% said "sometimes"; 34.2% said "nearly never".

More than half of Speech-Language Therapists felt that providing advice on how to get information or contact other parents were not their role: "*Not Speech-Language Therapists really. Nurse would do this*" or "*This is addressed by our social workers. They contact me if they need information requested by parents.*" Some organisations have websites although as one Speech-Language Therapist said: "*Our website needs improvement in this area*". In the rural areas and in smaller organisations there "*is not a lot available locally*". Larger organisations provide info "*formally and informally, talks, and written information*".

- **Provide opportunities for the entire family to obtain information:**

41.9% said "to a great extent"; 31.1% said "sometimes"; 27% said "nearly never".

Once again, more than half of Speech-Language Therapists participating in this questionnaire stated that they don't see this as their role to provide opportunities for families to obtain information. "*It is usually done via social worker / psychologist*". Some Organisations have "*Siblings groups that run annually*" or "*family resource centre activities which also involve siblings*". A few Speech-Language Therapists felt that their Organisation "*needs to do more for siblings of service-users*" as it "*is an important area e.g. to run sibshops.*" A few Speech-Language Therapists "*have run sibling groups and found it very rewarding*".

- **Have general information available about different concerns:**

38.2% said "to a great extent"; 32.4% said "sometimes"; 29.4% said "nearly never".

Speech-Language Therapists made the following comments: *"Again, this is the role of the social worker and psychologist." "Social work department is mainly involved in this area", "This is covered by professionals on site by psychologists, play therapist, social worker, medical director"*, and *"Information is given by social worker who meets all families regularly."* Other comments included: "*Not available locally, no advice or network sites" "Feel that families have to request this info rather than it being available in our waiting room or website."*

3.5.3 Providing Specific Information about the Child

- **Tell parents about the results from tests and/or assessments:**

89.2% said "to a great extent"; 10.8% said "sometimes"; 0% said "nearly never".

Most of the 89.2% of Speech-Language Therapists said that they *"would always fully discuss assessment findings,"* especially *"regarding feeding and hearing". "Always do – tell what was done and why and how their child did (comparing standard scores usually). Some parents say yes to a written report, some just want the information."* Other Speech-Language Therapists "*will be cautious*" in telling parents the results as *"parents often become upset when confronted with the severity of the impairment. For parents insisting on 'exact results' this is supplied if appropriate*" and "*with caution, I would always tell but would pick my words carefully. I may be dealing with very hurt people who have to drive home after having negative news."* One Speech-Language Therapist stated that *"sometimes if the results are lower than parental expectations, I* *would tell the parents about the severity of the language delay, but highlight areas of potential".*

- **Provide parents with written info:**

78.9% said "to a great extent"; 15.8% said "sometimes"; 5.3% said "nearly never".

Most of the Speech-Language Therapists stated that "*all reports are copied to the parents*" and "*usually, they* (the parents) *receive a copy of my report. Also, I may download or photocopy information for parents*". "*Where clinical time allows, maybe in the form of a note home or report*". Other statements included: "*Homework programmes also frequently mark progress; treatment and progress review appointments are offered generally 6/12 or 12/12.*" "*Mostly in the form of updated programme (monthly to 6-monthly) as appropriate.*" "*Twice yearly reports shared with parents at reviews and available on file*". Some Speech-Language Therapists will only send parents copies of reports "*on request or when child is changing teams etc*". One Speech-Language Therapist admitted that "*I feel I fall down on giving written information on the child's condition however.*"

3.5.4 Coordinated and Comprehensive Care

- **Suggest treatment/management activities that fit with family's needs and lifestyle:**

68.5% said "to a great extent"; 21% said "sometimes"; 10.5% said "nearly never".

More than half of Speech-Language Therapists commented that they would try to offer therapy / treatment / management strategies that, in discussion with parents, fit with their current lifestyle needs. Therapists agreed that *"therapy recommendations will not be effective if they don't fit in with family's needs and lifestyle"*. Therapists "*use and adapt activities that family already enjoy and do"*. *"If treatment fits easily into daily routines it is more likely to be carried out"*. Some therapists gave examples of linking with the children's schools to provide a more holistic approach: *"I've worked with several schools to share aims and some of the SLT homework activities to achieve a more balanced family life and establish SLT needs as part of child's ongoing educational needs."* Therapists also "*change therapy activities in response to the child's motivation and help change family's routines to incorporate learning / fun activities"*. Other therapists mentioned that they *"would be aware if both parents are working"* and have thus tried to incorporate the child's SLT programme into his preschool. Therapists will also link with classroom and preschool teachers about implementing SLT programme during school time. Only one therapist commented that she "*doesn't believe that treatment interferes with lifestyle.*" There was also a strong emphasis on parent training and empowering the parent to implement SLT intervention strategies at home. Parents continue to play a vital role in helping to deliver SLT intervention: "*One client was given therapy for use at home with help of the mother*". School-based therapists and Speech-Language Therapists in residential facilities mentioned that they had "*relatively little contact with families*" or that "*parent-contact is limited and/or irregular*".

- **Take time to establish rapport with parents and children**:

89.5% said "to a great extent"; 7.9% said "sometimes"; 2.6% said "nearly never".

Most of the 89.5% of Speech-Language Therapists felt that establishing rapport is "*particularly important with this population. Relationship built up over a period of time.*" Time constraints sometimes did not allow for the rapport building: A few Speech-Language Therapists stated that they will try to establish rapport "*where clinical time allows*". Establishing rapport with children was overall seen as "*very important, but when working in a school there is less opportunity for face-to-face contact with parents*". Sometimes rapport-building only happened "*where possible with parents, although to a great extent with children*". One therapist mentioned the difficulty with trying to build rapport with children and their parents when they only see the children "*within group settings*".

- **Discuss expectations for each child with other service providers to ensure consistency of thought and action***:*

76.3% said "to a great extent"; 15.8% said "sometimes"; 7.9% said "nearly never".

Most of the Speech-Language Therapists commenting on this statement stressed the importance of "*working as part of a team*". Fifteen of the 38 Speech-Language Therapists commented that they work as part of an Interdisciplinary Team and 11 said they work as part of a Multidisciplinary team. Team members mostly consist of: *"Nursing staff, teachers, physiotherapists, occupational therapists", "I do this with Physiotherapists, Psychologists, Occupational Therapists, Teachers", "Mostly direct care staff, some with Occupational Therapists, head of unit".* Speech-Language Therapists also have regular team meetings where they discuss expectations of each child with other service-providers: "*We have Physical Sensory Disabilities Team meetings every 6 weeks*" or as a "*member of child development team – often discuss service users*" In one organisation the Speech-Language Therapist stated that there are a lot of discussions with "*Occupational Therapists and Physiotherapists, as the child received all 3 services in one afternoon*". Speech-Language Therapists also stated that discussions about the child's expectations were more "*effective on preschool teams as there is a weekly meeting. It's more difficult in school as teachers don't have team meeting time allocated*". Speech-Language Therapists further said that *"multidisciplinary assessments and joint therapy sessions and discussions about interventions with the rest of the team"* and "*regular multidisciplinary team meetings, reviews, IPP meetings and continuous interaction with care staff is possible*" were all methods to ensure consistency of care across the various team members. Two Speech-Language Therapists from one specific location mentioned that "*this is an area we are currently trying to improve at family meetings etc.*" and another Speech-Language Therapist highlighted that these discussions only take place "*where clinical time allows*".

- **Discuss/explores each family's feelings about having a child with Special Needs:**

40.6% said "to a great extent"; 35.1% said "sometimes"; 24.3% said "nearly never".

More than half of Speech-Language Therapists felt that exploring family's feelings about having a child with special needs is the role of the Social Worker: *"Social worker generally does this"* and "*I don't raise issues as we have a very good social work service."* Some Speech-Language Therapists have *"limited contact with families"* and are *"aware that physiotherapist, home teacher provide this support as they are in touch with the family more often"*. Other Speech-Language Therapists stated that *"if it comes up in the course of my work I would do this*" and "*I would allow them to share if they volunteered personal information but I don't probe"*. Other comments included: "*I do not discuss / explore people's feelings directly. But I note words and attitudes expressed by parents*" and *"if parents have feelings of anxiety this is addressed or referred to relevant professionals"*. Once again the issue of time was raised, as 2 Speech-Language Therapists stated that they will address the family's feelings and attitudes about having a child with special needs "*where clinical time allows"*.

- **Help each family to secure a stable relationship with at least one service provider who works with the child over a long period of time:**

37.2% said "to a great extent"; 25.7% said "sometimes"; 37.1% said "nearly never".

Different organisations had different models of service delivery regarding this statement. In some organisations, they have "*assigned key therapists*" or a "*Key worker system*". "*Children under 6 in our service would have one key therapist, but children over 6 would not have a key therapist*" and "*this is usually done through the director of services or social worker*". In other organisations, there were one or two constant team members that will "*stay with the child for a period of years at a time*". Children tended to have the same therapists as "*families will only change therapists every few years, and they never change social workers or preschool teachers*." If there is a staff change-over, therapists will "*introduce a family to a colleague and would try to stay involved initially*". A breakdown in ensuring that families have at least one service provider who is a constant in the child's life usually happens when "*the child moves teams e.g., Early Services to Support Services*". Other Speech-Language Therapists saw having a service provider that is constant in a child's life as an "*aspiration that is fulfilled on paper but not always actually secured*" although "*not deliberately*" and most of the time "*staffing constraints*" were to blame.

3.5.5 Respectful and Supportive Care

- **Accept parents and their family in a non-judgemental way:**

91.9% said "to a great extent"; 8.1% said "sometimes"; 0% said "nearly never".

Speech-Language Therapists made the following comments about this statement: "*I would always try to do so and am aware of not to pigeon box families*" and "*each family / client is always respected*". One Speech-Language Therapist stated that *"there have been times where I have made judgements on parents' priorities, etc"* and another Speech-Language Therapist highlighted that *"each person does their best, but everyone's best is different".* Not all Speech-Language Therapists were that accepting, as one Speech-Language Therapist stated: *"Unfortunately, families do not have the option to be disorganised if they are using a therapy service, even if this is the natural tendency for their personalities and lifestyle. Personal preferences and beliefs are always taken into account and mostly accommodated but I don't feel families are fully accepted in a non-judgemental way if they are 'awkward', i.e. make it difficult to deliver a good service to them."*

- **Treat each parent as an individual:**

94.6% said "to a great extent"; 2.7% said "sometimes"; 2.7% said "nearly never".

Comments varied depending on the therapist's caseload size. In smaller organisations, Speech-Language Therapists made the following comments: *"Absolutely. Every family is introduced to what I do and I then advise them that the first few sessions are very much a ' getting to know' time for them and their child, so we can get to know each other's personalities and likes/dislikes as well as preferred pace".* Whereas Speech-Language Therapists in larger organisations stated that it is *"difficult to know each parent as an 'individual' in busy clinic but definite attempts are made."* Speech-Language Therapists also highlighted the fact that *"There are so many variables in that no two children or two families are the same"* and *"none of the parents react the same and they all see their child as an individual with unique strengths and weaknesses. I see it as my duty to do the same".*

- **Treat parents as equals:**

89.2% said "to a great extent"; 8.1% said "sometimes"; 2.7% said "nearly never".

Most Speech-Language Therapists said that they "*would use first names*", whereas other Speech-Language Therapists would "*usually address them as Mr, Mrs or first names if they are comfortable with this.*" Speech-Language Therapists felt that they "*consider their* (the parents'*) roles as central to their child's development".* Other statements included: "*View parents as equals but without the expertise that the therapist has in their specialism". "Parents are part of the team and I value their input regarding the child. They are people with lives that involve far more than the child".*

- **Help parents feel competent in their roles as parents**:

76.3% said "to a great extent"; 15.8% said "sometimes"; 7.9% said "nearly never".

Speech-Language Therapists made the following statements: "*Always assure parents of their value as role model, caregiver and communication partner." "Encourage, support and develop their competency." "I regularly put things into perspective and support parents by telling specifically what they have done that has helped their child, but also by putting therapy goals in the bigger picture and reassuring them that sometimes the bigger picture just takes over!"* A few Speech-Language Therapists stated that "*some attempts are made*" and "*time constraints*" were to blame when Speech-Language Therapists were unable to fully support and encourage parents.

- **Treat families as people rather than as a 'case':**

94.7% said "to a great extent"; 5.3% said "sometimes"; 0% said "nearly never".

An overwhelming 94.7% of Speech-Language Therapists stated that they *"always refer to parents and child by name and never by diagnosis"*.

3.5.6 Summary of MPOC-SP questionnaires

Looking at the item by item information, the following areas were identified as areas of strength and weaknesses within the service providers.

(i) Enabling and Partnership

Relatives strengths of speech-language service delivery include: trusting parents as the expert on their child, giving parents a chance to say what is important to them, and answering their questions completely. An area of weakness identified by Speech-Language Therapists was letting parents choose when to receive information and the type of information they want to receive.

(ii) Providing General Information

Similar to what parents reported, Speech-Language Therapists concurred that there is limited general information available to parents of children with CP.

(iii) Providing Specific Information

Speech-Language Therapists rated their ability to provide specific information as highly satisfactory, with therapists providing information about assessments, written information on what they are doing in therapy and on the child's progress.

(iv) Coordinated and Comprehensive Care

Speech-Language Therapists saw their ability to establish rapport with children and discuss everyone's expectations for the child as areas of strength to work towards a more coordinated and comprehensive service. They identified having at least one team member constant and their ability to explore family's feelings about having a child with special needs as areas of weakness.

(v) Respectful and Supportive Care

Speech-Language Therapists were highly satisfied with the respectful and supportive care they provided to families. They viewed their ability to treat parents as individuals, as equals and accepting them in a non-judgemental way as areas of strength.

3.6 Comparison between the MPOC and MPOC-SP questionnaires

Table 4 presents a comparison between parents' and Speech-Language Therapists' perceptions of service delivery.

Table 4: Comparison between the MPOC and MPOC-questionnaires

Themes	Questions	Parents	Speech-Language Therapists
Enabling and Partnership	Fully explain treatment choices	+ 53.7% ~ 17% - 29.3%	
	Offer positive feedback / encouragement	+ 70.7% ~ 9.8% - 19.5 %	+ 79.1% ~ 13% - 7.9%
	Tell you about service / treatment options	+ 48.7% ~ 16.2% - 35.1%	+ 71.1% ~10.5% - 18.4%
	Trust you as expert on child	+ 90.3% ~ 0% - 9.7%	+ 83.8% ~16.2% -0%
	Anticipates concerns by offering information	+ 48.7 % ~ 16.2% - 35.1%	+ 56.8% ~27% -16.2%
	Chance to say what is important to you	+ 84.6% ~ 5.1% - 10.3%	+ 86.5% ~13.5% - 0%
	Let you choose when to receive information and type of information you want.	+ 65.7% ~ 8.6% - 25.7%	+ 40.6% ~ 35.1% - 24.3%
	Tell you about reasons for treatment / equipment.	+ 90.2% ~ 4.9% - 4.9%	
	Provide opportunities for you to make decisions about treatment.	+ 56.8% ~ 18.9% - 24.3%	
	Answer questions completely	+ 80.5% ~14.6% - 4.9%	+81.1% ~18.9% - 0%
	Recognises that the family has final say in decision-making regarding treatment.	+ 81.8% ~ 6.1% - 12.1%	
	Consult with you when discussing equipment and services.	+ 84% ~ 8% - 8%	
	Details of child's SLT service (reasons, type, length)	+ 70.7% ~ 4.9% - 24.4%	+ 71.1% ~ 21% - 7.9%
	Opportunity to explain your treatment goals.	+ 71.8% ~ 10.3%	+ 78.9% ~ 15.8%

		- 17.9%	- 5.3%
	Partner in child's care.	+ 90.2% ~ 0% - 9.8%	+ 84.2% ~10.5% -5.3%
	Listens to you about child's needs for equipment / services.	+ 90.2% ~ 4.9% - 4.9%	
Providing General Information	Information in various forms	+ 32.5% ~ 21.6% - 45.9%	
	Information regarding types of services offered (organisation and community)	+ 59.5% ~10.8% - 29.7%	
	Family-to-family gatherings	+ 39.1% ~ 34.1% - 26.8%	+ 42.1% ~31.6% - 26.3%
	Special guests – topic of interest	+ 28.2% ~ 28.2% - 43.6%	
	Support to help cope with impact of disability – advocating	+ 40% ~ 28.6% - 31.4%	+ 50% ~25% -25%
	Information regarding the child's disability.	+ 40% ~ 22.9% - 37.1%	
	Contact other parents.	+ 32.5% ~ 32.4% - 35.1%	+ 46.1% ~19.7% - 34.2%
	Opportunity for entire family to obtain information	+ 48.8% ~ 17.9% - 33.3%	+ 41.9% ~ 31.1% - 27%
	General information regarding concerns	+ 25.7% ~ 20% - 54.3%	+ 38.2% ~32.4% - 29.4%
Providing Specific Information	Explain while watching	+ 83.8% ~ 5.4% - 10.8%	
	Tell you results from assessments.	+76.9% ~ 0% - 23.1%	+89.2% ~10.8% - 0%
	Written information – doing in therapy.	+63.4% ~ 9.8% - 26.8%	+ 78.9% ~15.8% - 5.3%
	Written information about progress.	+53.7% ~ 19.5%	+ 78.9% ~15.8%

		-26.8%	- 5.3%
	Notify upcoming case conferences.	+ 65.8% ~ 9.8% - 24.4%	
Coordinated and Comprehensive care	Therapy plans fit with family's needs and lifestyle.	+ 61% ~19.5% -19.5%	+ 68.5% ~ 21% - 10.5%
	Explain things to your child in child-friendly way	+82.9% ~ 9.8% - 7.3%	
	Take time to establish rapport.	+ 83% ~2.4% -14.6%	+ 89.5% ~7.9% -2.6%
	Discuss everyone's expectations for your child.	+79.5% ~5.1% -15.4%	+ 76.3% ~ 15.8% - 7.9%
	Make sure child's skills are known to all.	+83.8% ~ 0% - 16.2%	
	Provide ideas to help you work with health care system.	+ 42.9% ~20% - 37.1%	
	Recognise the demands of caring for child with special needs.	+ 78% ~ 4.9% - 17.1%	
	Needs of whole child met.	+ 73.3% ~ 9.7% - 17%	
	Show sensitivity to family's feelings about having child with special needs.	+ 74.4 % ~ 20.5% - 5.1%	+ 40.6% ~35.1% -24.3%
	Follow up at next appointment on concerns.	+85.3% ~4.9% -9.8%	
	At least one team member is constant.	+53.9% ~20.5% -25.6%	+37.2 ~ 25.7 - 37.1%
	Short-term and long-tern goals	+71.8% ~5.1% - 23.1%	
	Plan together	+ 76.9% ~ 10.3% - 12.8%	
	Information ahead of time regarding changes in care	+ 70.7% ~ 9.8%	

		- 19.5%	
	Aware of child's changing needs as he/she grows.	+ 68.2% ~ 9.8% - 22%	
	Make themselves available as a resource (support, information, advocacy)	+ 69.3% ~ 25.6% - 5.1%	
	Information is consistent from person to person	+ 75.7% ~ 10.8% - 13.5%	
Respectful and Supportive Care	Accept family in non-judgemental way	+ 90.2% ~ 4.9% -4.9%	+91.9% ~8.1% - 0%
	Remember personal details	+ 90.2% ~ 4.9% -4.9%	
	Caring atmosphere	+ 90.2% ~ 0 % - 9.8%	
	Treat as an individual	+ 85.3% ~9.8% -4.9%	+ 94.6 ~ 2.7% - 2.7%
	Treat you as an equal	+69.8% ~ 25.6% - 5.1%	+ 89.2 ~ 8.1% - 2.7%
	Feel competent as parent	+ 85.4% ~0% -14.6%	+76.3% ~15.8% - 7.9%
	Enough time to talk	+68.2% ~22% -9.8%	
	Treat you as people – not a 'case'	+95.1% ~0% -4.9%	+94.7% ~5.3% - 0%
	Polite and courteous staff	+100% ~0% - 0%	

Key to symbols:

Low rating <50%	Concordance =/<15% difference	Discordance >15% difference	+ Satisfied to a great extent	~ Sometimes	- Nearly never satisfied

Agreement was reached between the researcher and an independent rater regarding the magnitude of the difference between parents' and Speech-Language Therapists' perceptions that was significant. The level of discrepancy was set at 15 with any discrepancy greater than 15% being significant. This scale of 15 was only applied to the 'satisfied to a great extent' rating.

(i) Enabling and Partnership

There was discordance between parents' perceptions and Speech-Language Therapists' perceptions of enabling and partnership service delivery issues: Speech-Language Therapists reported that they tell parents to a great extent about service and treatment options. Parents felt that although Speech-Language Therapists consult with them about service / treatment and tell them the reasons for recommending a treatment / service, the various options are not explained and discussed with them. There was also a variation in parents' and Speech-Language Therapists' perceptions of letting parents choose when and the type of information to receive, with parents reporting this to happen more often than Speech-Language Therapists.

(ii) Providing General Information

There was a high degree of concordance between parents' and Speech-Language Therapists' perceptions on the lack of general information available to parents of children with CP.

(iii) Providing Specific Information

There was a high degree of discordance between parents' and Speech-Language Therapists' perceptions on the level of written information available to parents, although there was concordance about the sharing of results from assessments with parents.

(iv) Coordinated and Comprehensive Care

There was discordance between parents' and Speech-Language Therapists' perceptions about showing sensitivity to family's feelings about having a child with special needs. Parents were satisfied with the level of emotional support they received from their Speech-Language Therapists. However, Speech-Language Therapists felt that they did not explore the family's feelings about having a child with special needs because of time constraints. A few Speech-Language Therapists felt this to be outside the remit of Speech-Language Therapy.

(v) Respectful and Supportive Care

There was a high degree of concordance between parents' and Speech-Language Therapists' perceptions on the respectful and supportive care therapists provide to parents.

3.7 PHASE 3: Focus Group Discussions

Sixteen of the 45 parents, who completed the MPOC questionnaires, were randomly selected for the focus group discussions. Of the 16 parents, 11 parents consented to participate in the focus group discussions. The other 5 parents declined participation due to family or work commitments, but sent their completed focus group questionnaires back to the researcher for additional qualitative information.

3.7.1 Focus Groups: Parents

3.7.1.1 Scope of the Role of Speech-Language Therapists

The focus group discussions started with an open-ended statement about the parents' understanding of the role of the Speech-Language Therapist. All of the parents had a good understanding of the aspects Speech-Language Therapists address during intervention which included feeding, speech, language and communication.

- *"This is vital therapy for children with CP to help them with feeding and communication in order to lessen frustrations."*
- *"Speech and communication – depending on each child, they're all so different in each way."*
- *"All really (speech, language, communication and feeding)."*
- *"Assessments of language, how he says his words. They also look at him eating and drinking."*

One of the parents also stated that Speech-Language Therapists have a lot of administrative responsibilities that can interfere with direct Speech and Language intervention.

- *"Speech-Language Therapists have to do a lot of other things too, they have to phone and check up to see who haven't received what, I think their time should go to doing actual therapy".*

The issue of level of input was also introduced by parents who stated that although they have received a good service from Speech-Language Therapists in the past, the level of input has been very limited.

- *"Very little services available due to a lack of staff and money at the Organisation."*

3.7.1.2 Parent Involvement

The parents' involvement during intervention was discussed by looking at their ability to make decisions about the goals and the aspects of Speech-Language Therapy they would like to be addressed during intervention. Parents mostly acknowledged the fact that Speech-Language Therapists are experts in the area of communication and that they would listen to the advice given by Speech-Language Therapists. However, most parents felt that they were always given the opportunity to state their goals and what aspects of intervention they would like the SLT to target. For most parents this was a joint process where parent and therapist worked alongside to fulfil the child's potential.

- *"Well, we tend to listen to experts and inform them of his good points and any worries we have."*
- *"To sit down and decide which the best is for your child and to set realistic goals, each one is a bonus."*
- *"I am willing to speak up to the girls (the Speech-Language Therapists) and tell them I want them to work on the 'you's' and pronouns."*

Parents also highlighted the importance of the assessment process to help identify and set goals.

- *"The assessments are happening, which is good, because they'll tell you whether it is CP or a swallowing difficulty or an educational issue."*

One parent highlighted the importance of parent sitting in on the Speech-Language Therapists sessions, not just to see how the work is being done, but also as an opportunity to meet other parents, to learn from other parents and to be a support for each other.

- *"Parents should be involved in deciding what aspects of speech therapy should be addressed and parents should be involved in a group so that they can support each other. So that other problems can be figured out."*

One parent pointed out that at times they (the parent and SLT) can "*be singing from the same hymn sheet where other times there may be a conflict of interests*". This can be a difficult situation especially when there is no consensus about the primary mode of communication a child should use.

- *"I am pushing for LÁMH and the therapist is pushing for an AAC device, the Mighty Mo. So I find that although we may have the same goal we might have different views."*

When parents and Speech-Language Therapists work jointly on goals and agreed aspects of therapy, it is important that the Speech-Language Therapist gives the parent positive feedback and encouragement. One parent highlighted the positive impact it had on her when she was given such positive feedback from the Speech-Language Therapist.

- *"I find with the schools I am getting praise for all the hard work I've put into my child and that keeps me going."*
- "*It was a great chat. They said that I was doing a marvellous job. He doesn't talk 100% properly, and his vocabulary wouldn't be great but I think he is a miracle.*"

For some parents with school-aged children goal-setting happened as part of an Individualised Education Planning (IEP) meeting. IEP meeting usually happens every 6 months to a year and during the IEP meetings a few long-term goals (LTG) are identified. Long-term goals are then further identified in short, measurable and attainable goals as identified by the therapists and teachers working directly with the child.

- *"We have an IEP once every 6 months. During the IEP we identify 3-4 different Long-term Goals (LTG) usually looking at my child as a whole with all the therapists present. Each LTG is then divided into specific stages e.g. that my child will learn 6 LÁMH signs and then 10 LÁMH signs, same for my child's communication device. Initially they were working on stories, before making two choices and then making four choices. Sometimes the goal is not to move on from the previous goal and this is good because it gives my child time to consolidate all the information and get used to the goal before moving onto the next goal."*

Only two of the 11 parents were not involved in setting goals with the Speech-Language Therapist. Although the parents were not involved by stating their goals and highlighting the aspects of intervention they want to be addressed, they had the opportunity to join in on the therapy sessions and watch the Speech-Language Therapist targeting her various goals.

- *"I wasn't involved in goal setting, it's the therapists. I could sit in on sessions but for obvious reasons, like having other children, I couldn't sit in on all sessions."*

- *"I would like to be the one to suggest it (the goals) not the therapist."*

Parents also stated that resources should also be shared between parents and Speech-Language Therapists in order for parents to learn more about what resources are available and thus be able to be part of the decision-making process.

- *"Sharing resources – Speech-Language Therapists can hold on to their resources and catalogues and I wish they could share it with us parents. For instance, they may just recommend an AAC device, and we, as parents, have no input in the choice of the device, or a catalogue to look through to see the different devices that are available. I know the Speech-Language Therapist is the one with all the knowledge and she might have her reasons for suggesting a particular device but it is important for us as parents to participate and be involved in the decision making process."*
- *"Same for catalogues of toy companies and toys for children with special needs."*

Parents also gave an overview of their experience of SLT with specific reference to the type of intervention they have received, the frequency and intensity of intervention and the location of where intervention occurred. Most of the parents had experiences where their children were seen during clinic appointments. Children who attended a special or mainstream school were seen during school hours. Parents highlighted the need for more naturalistic environments like the home or in the classroom.

- *"Assessments happen in the clinic, but an assessment at home, on the phone, in the classroom would be best."*
- *"In the clinic mostly, but we work on any homework he might have."*
- *"Therapy should take place in the clinic, classroom and at home – every bit helps, no matter how big or small."*

Some parents had difficulty attending SLT appointments because of other responsibilities, work commitments, or other children and suggested that Speech-Language Therapists should be a bit more flexible to try and accommodate them as parents.

- *"I had two premature children, so I was missing appointments. I got a session of 12 appointments and managed to make 8. She (the SLT) sent me a very aggressive letter stating that he's been taken off the list and that it was a waste of their time. So then I just continued on my own."*
- *"I am very lucky because I work at my child's school, but I think for working parents it must be difficult to attend all appointments".*
- *"Speech-Language Therapists can try to accommodate parents and their lifestyles. This means looking at therapy in the evenings and if possible to give parents six – eight weeks notice so that they can plan ahead if they are working."*

- *"Sometimes we receive only one day notice for appointments. We need a lot more notice "*
- *"They (SLTs) don't take the family situation into consideration. I might have had a really difficult week with hospital appointments and it would be great to be able to say: 'Listen I cannot do it this week but next week I can' so to have that flexibility, or even just to be told well in advance when therapy is starting so you can plan your life around it. They just don't do it like that – it's either do or die."*
- *"Looking at accommodating parents through evening/morning blocks. You might offer the child's first block in the morning and the next in the evening."*

When asked about the type of intervention, parents have experienced mostly direct therapy where the Speech-Language Therapist worked on a one-to-one basis with the child. Parents also received home and / or school programmes and guidelines as part of SLT intervention.

- "*Direct therapy, programmes and guidelines. Work one-on-one with therapist and 1 group session a week."*
- *"Direct – his therapist and himself."*
- *"On his own, with mother present at the moment."*

There was general consensus amongst the parents in favour of more group intervention.

- *"Blocks, if possible, as only a few sessions can be given by therapists."*

The frequency and intensity of SLT intervention varied dramatically from a total lack of input to continuous SLT input.

- *"My child hasn't received any SLT input in more than 2 years. It is such a disgrace!"*
- *"My child was seen for a block of sessions, 10, I think; once a week for about 20 minutes to half an hour and that was it."*
- *"My child is currently on a waiting list. At moment there is a 6 month long waiting list"*
- *"He didn't get as much to think there was anything being done. Like that, I got agitated towards the end of the sessions and demanded to get literature from them."*
- *"It's been a while, it's been 12 months at least, but that was it. 20 minutes once a week for 10 weeks that was it. He is deaf and has cerebral palsy."*
- *"Every day in the class and at home. Sessions with therapist twice weekly: 1 one-to-one and 1 group."*
- *"From the age of four months my child started receiving intervention from the Early Services Team. My child received therapy once a week from the whole team (Occupational Therapists, Speech-Language Therapists and Physiotherapists) until he reached school age and from school age onward he was seen by the Speech and Language Therapist twice a week. He has been in*

school for almost 2 years now and that's been happening for the past two years."

- *"They say an hour a week but each child will be different some may need more, others less and for that reason you have to assess the situation."*

3.7.1.3 Information

The topic of information was discussed with special reference to parents' experience of Speech-Language Therapists providing them with information, feedback on therapy, and feedback on their child's progress. Information sharing amongst team members was also discussed. When the topic of 'information sharing' of various Speech-Language topics, was discussed, only two parents were able to say that they have received a lot of information from their Speech-Language Therapist.

- *"I have received a lot of information regarding communication devices, TalkTools, etc."*
- *"The SLTs are generally good at providing information."*

Most of the parents stated that they get a lot of their information from other parents of children with CP and welcomed more training courses from professionals as a source of information.

- *"We don't get any training courses. I had only one training course, the HANEN course, two years ago."*

- *"Most information I get I get from other parents."*

Most of the parents stated that there was very good communication between them and the Speech-Language Therapists. Where this was the case, information was provided through daily contact sheets or a diary which informed the parent what was happening in therapy. Other parents had regular meetings with the Speech-Language Therapist where they were informed about their child's progress and the therapist's goals during intervention.

- *"Great communication between us as parents and the therapist"*
- *"Notes in homework diary and I would meet with the therapist every 2/3 months to talk about goals and how things are going and if changes are needed."*
- *"Via the diary. After each session the Speech-Language Therapist completes a diary entry telling the parents what happened during therapy."*
- *"When I make suggestions in the school, the school always follows through on it. When I asked them to write in a diary everyday about what he has done, his therapy etc. They did it! And it is brilliant knowing what my child has been up to in school. I sit down with my child and we read his diary together and he is probably thinking: 'wow, she knows what I'm up to in school' and that's important because I want my child to know I am part of his education and his learning."*

Parents welcomed the idea of information on general topics especially in light of a shortage of Speech-Language Therapists in the country and children being placed on waiting lists. The parents felt that the information provided to them by the 'experts' would give them a few ideas to start intervention at home.

- *"My child had a stammer. They did treat it but said that it was down to the family situation and stuff. As soon as I realised that that was how it affected him, his stammer kind of went. It was more to do because I did not give him a lot of attention. It was not very difficult to do but I needed to be told that. So that was good so he didn't receive treatment as such, she saw him once or twice more and she said she couldn't believe the change in him. It's all about getting the information."*

It is a fine balance between giving parents too much and too little information. One parent felt that sometimes Speech-Language Therapists can give too much information too soon in the grieving process which can be very upsetting to parents.

- *"Sometimes I find that Speech-Language Therapists can run away with information. They give too much information and you might not be able to take on all that information. Sometimes Speech-Language Therapists need to be a bit more sensitive. They can be a bit full-on. It's difficult when you sit and hear the news. Especially when you are alone with no one to support you and then you have to get into your car and drive home alone after hearing such news."*

Information can also vary from professional to professional and there is a need for more information sharing amongst professionals so that they do not give parents conflicting information.

- *"The type? They keep changing it. First they said it was on his right side now they say it is in his legs."*

Other parents wanted more specific information related to their child's difficulties in order to implement an intervention programme at home.

- *"I can do speech therapy myself. I watch what they do and I read up. I had to find out information myself and it worked. That's frustrating finding out information for yourself especially if you think, 'Oh god, he is deaf, he's never going to talk' but I've spent 2 years worrying about that and I had no Speech Therapist telling me that."*
- *"Home programmes are extremely important to be followed through at home, to work on repetition."*

Parents received both written and verbal information about assessment findings. Parents stated that they usually receive an assessment *"yearly"*. One parent mentioned that her child is *"still in the assessment phase, as my child hasn't seen a Speech-Language Therapist in more than 2 years"*.

3.7.1.4 Perceptions of care

Parents had an opportunity to state their perception of the care they have received from their Speech-Language Therapist and from their organisation or healthcare provider. Most of the parents have had very positive experiences in attending and working with Speech-Language Therapists.

- *"The care I have received has been very positive. Especially the TalkTools. You can take some of the stuff home and you have the option to get your child reassessed and see progress."*
- *"Good, considering the waiting list"*

The high turnover of Speech-Language Therapists in the area of disability affected some parents' perceptions of the care they received.

- *"Over the last 4 years he has had 6 Speech-Language Therapists."*
- *"I have had six to seven different Speech-Language Therapists in six years. They have either gone on maternity leave or left the organisation."*
- *"Usually about a maximum of two years then the Speech-Language Therapist is gone. Your child only just gets to know her and then they leave again."*

However, parents acknowledged the fact that there is a shortage of Speech-Language Therapists and that they all have big workloads ranging from large caseloads to additional duties and responsibilities.

- *"The Speech and Language Therapist, I'm sure, would probably like to do a lot more."*
- *"Waiting lists are just getting longer and longer and I am scared for my community."*
- *"Poor Speech-Language Therapists, sometimes I think they are just cracking up with parents coming in and shouting at them 'make them talk, make them fucking talk!' Because the government laws say you can't say anything to the parents, I think that a load of bullshit. I've only received good treatment from the therapists"*

One parent brought up the issue of intervention that is not always needs led or based on what the child needs but rather determined by guidelines recommended by the health board. She referred to a specific example where her child had no feeding difficulties, yet a Speech-Language Therapist assessed his feeding skills as part of an assessment 'protocol'.

- *"My child has completed his block last September and I was asking when he will be seen again. Then suddenly the Speech Therapist phoned me asking about his feeding and if she could see him while he is eating in front of her.*

But I didn't want that, I wanted the speech therapy. But she said he has CP and that feeding difficulties are part of their difficulties. I told her that he is grand. But she said it is the protocol, they have to complete their lists and tick all the boxes, it is not them it's the protocol. That was it then from the Speech Therapy. The HSE's protocol can be so stringent with their little lists and assessments because it has to be send into somewhere."

The parents' perceptions of care from their organisation or healthcare provider were varied. In general the parents stated that the care they have received from their Organisation / Healthcare Provider has been "*good*" and "*okay*". However, some parents openly expressed their dissatisfaction at the level of input they have received from their Organisation / Healthcare Provider:

- *"I have three premature sons. They are all left with difficulties ranging from mental and physical they've had lots of surgery and stuff. Now the speech therapy that I have received was to the minimum for all three of them and I have found that other therapies have been the same. It's not there. The education support is not there, the financial support is not there. The support is not there."*

A few parents stated that their perception of the care they have received from their organisation / healthcare providers was directly related to SLT issues.

- *"Just because there has been so many different Speech-Language Therapists that's the only downfall otherwise I am happy with the organisation."*
- *"OK, a lot of funding issues. One therapist – hundreds of kids"*

Other wider issues included that when a child attends a voluntary agency, the child is not entitled to make use of a service from their community healthcare provider even if the child is on a waiting list for SLT intervention or in cases where there is a staff vacancy. Children are allowed to access private SLT if their parents can afford it.

- *"As far as I know about speech therapy, my son is in this 'service' and because he is in this service he cannot get services from the community. At the moment here he is basically getting only swimming. I can't understand it for the life of me, it's a joke. If you have a private place here in Cork it will all be well and good but then there will be the financial burden on people."*
- *"If my child is not getting SLT from his organisation, I should be in the position to apply to my community but they said, I'd still be waiting about 2 years before I'm seen. The waitlists are so long."*
- *"Because my child has a diagnosed physical disability he can stay in the service with no service here for him and he is not allowed to get services from the community. I would like to bring my other children here (the organisation) as well so that they could be part of this."*

Parents welcomed the idea of a more coordinated service for school-aged children where a speech-language therapist, occupational therapist, physiotherapist and nurse should be on-site.

- *" There are other children that might need the more intensive sessions because of their difficulties with learning things, and that is not happening. All schools should have a nurse, a physiotherapist, and a Speech-Language Therapist – the hospitals would then be empty."*

Parents expressed their concern about the lack of support for children in mainstream schools. In the ROI, according to the EPSEN Act of 2004, there is a strong emphasis on inclusion of children with disabilities in mainstream education provided they have the necessary support and resources to help them cope with the national curriculum (Government of Ireland, 2004).

- *"Inclusion is important and the child's specific needs should be addressed and taken care of before and while they are at school."*
- *"My boy is in mainstream, they knew about his specific needs yet still he has not received the care to help him with his class work and learning. He didn't get a lot of speech therapy, so now in school he cannot communicate that well and he is carrying that burden. It is not the teachers' fault, it's not the therapists' fault, it's the fault of the government. But the only one who is really suffering is my child."*

Parents also felt that there was an overall reluctance from the Organisation to arrange meetings where parents can meet each other and discuss mutual concerns.

- *"I find that the organisation don't want parents to talk to each other."*
- *"There is no forum for parents with children with difficulties. Sure if all the parents have to come together there would be uproar. They should close the school down and let the parents in to have their say. The HSE is top heavy, and there are not enough therapists on the ground. My way of saving myself is to be friendly with all the people I need to get things from, because my child has very specific needs. Which can be quite a hard thing in itself to do."*

Parents also felt that the Organisation / Healthcare Provider could do more to advocate on the child's behalf.

- *"Kids are a package and they can be very complicated. We have to fend for our children otherwise they'll be left; especially in this country."*

Parents were further asked to describe their perceptions of the continuity / consistency of care they have received from their Organisation and Speech-Language Therapists. Most of the parents stated that they have to constantly advocate for more services on their child's behalf.

- *"I, as a parent, have to push for services"*

- *"You have to keep chasing things to the point that I have them annoyed but that is how you get things done."*
- *"I must fight for everything."*
- *"My experience is that everything comes in dribs and drabs. There is no such thing as continuity of care in the HSE. No one person that I can contact to say if I need something."*

Two parents stated that they have "consistently and continuously" received a very high level of service from their Speech-Language Therapist.

- *"Our therapist is always prepared. She has exactly the correct instruments for our child."*
- *"I see a lot of preparation that goes into the sessions. It's good"*

When asked about their perceptions of the coordination of care they have received from their Organisation / Healthcare provider, parents in general felt that disability services can be very uncoordinated and disjointed. Parents stated that they would welcome a more coordinated service during important transition periods for example when children start school or transfer from primary to secondary school.

- *"I think it is important for the Speech-Language Therapist to liaise more with children during the first week or two of going into the special school. They know the children best and having a familiar adult in the classroom or visiting the classroom might make it easier for the children as well."*

- *"Also for major transitions from Early Services into school there was only one meeting where the parents had the opportunity to meet the teachers and principal and quiz them, but no therapists were present. It would've been really nice if the therapist who worked in the school would also attend this meeting."*

Parents also stated that they lacked general information about changes in service delivery during important transitions.

- *"In Early Services the Therapist was so involved, also at preschool but to a different extent. I thought my child wasn't getting therapy anymore and I went to the teacher who informed me that he gets seen in the classroom and that the therapist fetches him during school hours. I would've liked to have known about this change, because there I thought he was not getting SLT anymore."*
- *"Maybe we could've had a meeting to be informed that the service delivery model was changing and that therapy was happening. Obviously the parents' involvement was reduced and it would've been nice to be informed that things are changing and that the service delivery model was going to be different, and introduce the different team members."*

Parents felt that the medical teams and therapists did not always communicate with each other to provide a more coordinated service.

- *"Unfortunately I have several different people, several times a month. And there I am I having to explain it to all of them. Things are not happening the way it should be happening, it would be better if you can meet everyone at the same time. So that I'm aware that they are all aware of things."*
- *"Same with SLT, the same with grommets, no coordination of care. It can take a year to get this grommet thing sorted, [to get an appointment] with [the] GP, then with the audiologist and then the grommets appointment and in the meantime he can't get work done on the speech because he can't hear because he needs the grommets. They don't work together. That's very frustrating."*

Parents also commented that services could be more coordinated if they were kept informed about any changes that may happen in the near future.

- *"My child received therapy from one Speech-Language Therapist who had been working with him for two years and then one day another Speech-Language Therapist started joining in on sessions and then one day without saying anything she was gone, my child's therapist. I was not informed that another Speech-Language Therapist will be taking over."*
- *"Parents have to fend for their child, because how can a non-verbal child communicate to his mother that he just got a new Speech-Language Therapist."*
- *"It might only take two minutes but the fact that the therapist took the time to phone that's what really matters."*

In a few organisations / healthcare providers parents have had a keyworker or one service provider that they could contact if they needed something.

- *"I can now, at this organisation because I am a personal friend but that's because I've come to know the teachers and some of the therapists. So yeah, I do have someone or somebody I can go to."*

In most organisations this seems to be the role of the social worker.

- *"As my child got older he did not have a social worker that was as involved, she worked only part time and when she went on maternity leave there was no one to replace her. Only emergencies will be dealt with by other social workers when one is on leave."*

In the case where there is no social worker assigned to the family, the burden lies with the parents to follow things up and advocate for services.

- *"I constantly have to be on my toes, and I have to do all the chasing otherwise things get put on the long finger. Sometimes you feel that all you do is chasing and chasing."*
- *"I must fight for everything."*
- "*They (the therapists at the Organisation) worked out a plan with all the things he needs, his goals. I had great worries about potty training and that became a goal. There were other goals on the paper that didn't happen, like*

speakers for the classroom, they never came. Now I have to go back to the visiting teacher for the deaf who is on the 'missing list' for the past eight months who is getting paid for looking after him, but I am the one doing the chasing and the follow up."

Transparency was another major issue that came up during the discussion of coordination of care. Parents wanted more information on how services are divided amongst the various service-users. Parents felt that they do not always receive an equitable service from their organisation / healthcare provider.

- *"Respite, that's another issue. Just like SLT. It is not an equitable service. Some people get more respite than others just like SLT. The system is not always explained to parents. If there was a system with guidelines, parents wouldn't become so resentful when they see other parents get more. It is not explicitly stated why some get more blocks of SLT. Not very transparent."*
- *"Things need to be levelled out, there should be guidelines for various levels of priority so you know your child is entitled to a specific amount of sessions, and you would know and appreciate the difference then between the different priorities."*
- *"Parents get stressed out when they see things are not transparent and equitable."*

Parents also stated that their lifestyles and other commitments and responsibilities were not always considered and certain guidelines could be put into place to ensure a more coordinated service for the whole family.

- *I have three children; two of them have groups on different days so now I have to travel in twice a week to the same place. I would like services to be more coordinated and to take other siblings also into consideration."*
- *"There is not a lot of support for parents. Therapy and intervention are great, but it focuses more on the child and the child's needs rather than taking the parents' needs and lifestyle into consideration."*

3.7.1.5 Family-Centred Approach

Principles of the Family-Centred Approach (FCA) were also addressed during the focus group discussions. Parents' experiences of the organisation's perception of the impact of having a child with a disability were discussed as well as the family's emotional and informational needs. Only one parent stated that she felt that her organisation has " *always been supportive and sensitive*" to her emotional and informational needs. A few parents stated that these subjects have not been addressed by their organisations / healthcare providers: *"It hasn't been discussed yet"*.

A major criticism from parents was that there was very little support for them available. This included both emotional and informational support.

- *"This is one of my complaints there is no counsellor for us parents to explain things like CP. Also, when you hit the downs, there is no one to help."*
- *"I feel there is a huge need for counselling in this particular population."*

Parents also stated that during team meetings and IEP meetings the child's holistic needs were not always addressed. Apart from the child's needs, parents felt that their own needs are central to their child's well-being and that issues like their mental health and other difficulties they might face also needed to be addressed during these meetings as they can have an impact on the care they are able to provide for their child.

- *"My son, he has his physical problems and his learning problems, but they are causing my child to have mental problems. The doctors don't worry about his mental state, they look at his legs, his health, his speech and hearing but not his mental state."*
- *"It is very important and we worry a lot about the medical issues. During IEP meetings they address just basic stuff: is your child in good health, his vision/hearing etc. but not very specific queries e.g., my child has a protruding chest bone. There is no medic available to sit down and explain this particular condition/ difficulty – to talk you through the difficulties or the impact it might have on his life or organs later on."*
- *"Again on the IEP thing, just like you said there, no medical issues are addressed. It's more goal setting and reviewing of goals, rather than health and health concerns. It would be great if that could be part of IEPs."*

- *"Parent's needs should be part of IEPs too e.g, respite care."*

When asked about their experience of service-providers and the organisation's perceptions of having to cope with a child with a disability, one parent stated: *"It's down to the person, the individual. In a lot of areas in the country, say even your public health nurse should be brought back and these things explained to them by parents."*

Once again the issue of very limited parent-to-parent meetings were addressed. Parents were all in favour of such meetings as a source of information and support for each other.

- *"You can never get enough information, but they have been good at providing."*
- *"There are no opportunities for parent-to-parent meetings or opportunities for parents to meet other parents with children with similar conditions or in similar situations."*
- *"I had a friend who was offered psychology for her child and because of her ignorance she snapped because she knew her child wasn't mad but I had to tell her that psychologists look at the learning side of things too and that he was referred not because he was mad. I would like basic information like that, looking at the roles of professionals. I had to sit down for an hour and explain these things to her, see people are different, they might have had a poor*

education or can't read and how will they know that psychologists do these things."

3.7.1.6 Aspirations for ideal Service-Delivery

As part of the focus group discussions, parents had an opportunity to state their aspirations for the ideal service.

Parents stated that they would like a SLT service where they receive more information about: the care their child is receiving; changes in service delivery; general and specific speech and language information.

- *"Same as above, just someone to explain what is happening, future plans, what you are entitled to and just feedback more often than yearly".*
- *"A lot of information you find out is through other parents. That's where I get a lot of knowledge on different things. Health care is okay."*
- *"To have the opportunity of videotaping SLT sessions in the class or clinic and inviting parents and teachers where they can watch what is actually happening in therapy."*
- *"I would have assumed that preparing the parents and giving parents information is part of their role. It helps them deal with the child and the situation better."*

Parents were in favour of more group SLT.

- *"More group therapy in the classroom, including all children with various disabilities, verbal and non-verbal, using his Big Mack. Able-bodied and disabled all sitting together on the floor playing turn taking games. This I think will be great for children to learn from each other and to reduce their frustration levels."*
- *"What they do in the community clinics is that they have several children together in a group. It is good and it did help him to bring him on."*

Parents wish to see more continuous SLT and fewer blocks of sessions.

- *"Continuous therapy, not blocks of therapy. That's what I've had. Ticking a box that's what it is, giving them just a little bit of input to keep the parents quiet and happy. I found that strenuous because although it's free this block costs me money because I have to get a babysitter."*

Parents suggested a baby-sitting or childcare facility for siblings while the parents are attending sessions with therapists.

- *"There's no place where you can leave your kids. Sibling meetings are also just twice a year. They don't do enough for the other children in the family."*

Parents suggested more parent training sessions from Speech-Language Therapists.

- *"What it has taught me is that parents spend a lot of time worrying about finding the right therapist where they could be at home teaching the child* *themselves. Speech-Language Therapists have a duty to train the parents and if there is a shortage of Speech-Language Therapists, then time should go into training the parents. Or even this one-on-one thing, that's all well and good but I just assumed it would happen in a classroom full of people like yourself training parents and giving them what they need to help their children. It's common sense teach the parents once a week. That's what I did, I just pulled them in the corridor and asked them to show me what they do so that I can do it too, and it worked quite easily, it's sometimes quite common sense but you need to be told. It's easier, it's information but for some reason in this country they are backwards with things like that. I have a list the length of my arm of what they haven't received and what they have received is ineffective, it's just time consuming and money consuming."*

Parents suggested more support and resources for children in mainstream education.

➢ *"Our schools are falling apart around children, no support for them in mainstream, such like resources and Special Needs Assistants (SNAs). My child has special needs and is in mainstream[education] and his teacher said that if he had say a specific diagnosis like being deaf he'd get resource (teaching) but now he gets nothing he has just the learning problem that's bigger than his physical difficulties. My son has a Personal Assistant (PA), but I feel that that's not what he needs at the end of the day he needs to be looked at more holistically as does our family unit. But it's the healthcare system it is shocking. I've heard horror stories of people waiting months for wheelchairs* *and shoes, and when they get it, they've grown out of it. It's costing the state a fortune."*

Parents suggested specialist SLT services.

- *There are disabilities and then there are diseases and they are all very different. I think there should be a SLT for deaf children, there should be a SLT for the hearing impaired and then there should be SLT for the different types of CP."*

Parents suggested that national policies should be implemented.

- *"As a parent, it would be great to see the National Policies put in place and to inform the parents as this does not happen."*

Parents highlighted the need for more general information about other services / service providers.

- *"I would really like more information on links with other services in our community."*
- *"What services, information, are available to people with CP in adulthood."*

Parents suggested a forum for parental support and information groups.

- *"The thought always goes through your head even if your child is only young. I would like to meet other parents of similar children with disabilities. All children are different but it would be really nice to see a child with e.g. spastic quadriplegia in mainstream or one going to a special school and see children* *who are not wearing nappies anymore, it gives parents hope to know that he might not always be in nappies."*

- *"Family meetings. I would like to meet other people and just get the therapist to make the link with the family who has had a positive and negative experience with say LÁMH / AAC. I think it is a good way to get support and ideas from meeting other parents. It also gives us hope."*
- *"It would be wonderful to link with parents of different service providers if you have a problem with your own. Also, to get ideas and support and to see different children. To see that there is light at the end of the tunnel. To see other four to five year olds from mainstream or Special Schools."*
- *"One parent couldn't get a diagnosis for her child but I am no doctor but I could look in this child's eyes and see that he was fine up there. But that's what I'm saying, there is nowhere for us parents to go to. In the organisation they didn't do a lot. She asked for a walking frame and guess what she was told: "Walking isn't everything." She says she is still crying. I told her just to keep trying, to keep talking to him and to keep loving him and now look at him, he is standing now. We need each other. She needed somebody to tell her that because she felt afraid and alone."*

Parents wanted less stringent protocols for levels of service delivery.

- Therapists need "*to give the child what he needs and NOT what hours they have made available to him."*

Parents suggested more information from their Service Provider / Organisation.

- *"I think our organisation can do more in providing basic information. The Social Worker is great but you have to ring them if you want to get any information, no information packs or information evenings. Entitlements too. Maybe an information evening."*
- *"I would like information on the types of services available in the community. Information on swimming, horse riding, gyms, restaurants etc. for children with special needs. The Government need to set up more for children in the community, maybe there is stuff but I haven't heard of it."*
- *"A booklet would be a great idea. It will give reassurance. A booklet from the GP and public health nurse to say what to look out for so that they can start going to a SLT. I can't understand why they are not doing it because they would save themselves a lot of money."*
- *"There is no support for people who don't live in the city. There's no support or information out there."*
- *"Information booklets and leaflets would be great! Even just a few ideas on general things, speech sounds and attention. It's important because not everyone is privy to that information, so the government has to have information out on the education system."*

Parents suggested that professionals should address the child's and family's mental health and health queries.

- *"Have professionals that listen to us. I had only 1 doctor that made all the difference in the world only because she listened to me, the rest of them were only giving me pills and pills saying: 'oh, she is cracking up,' where I wasn't,* *I was just sad, I was just crying for my child and the more pain I was in the more pain they were facing."*

- *"My mental health was not being adhered to."*
- *"Like with the age of technology, I still get doctors not knowing important medical information about my child and then the shock of how he doesn't have hemiplegia, he has now diplegia and just the way I was told these things."*

Parents suggested more team meeting where all the team members are present.

- *"Team meetings are great because they bring everyone who works with the children together because then they can't say: 'I didn't know'".*

Parents suggested that children with CP should be entitled to attend community therapy whilst still maintaining links with the disability organisations or service providers.

- *"That he can still come to the organisation for CP and stay in touch with people like him but that he should receive his therapies from the community. Even though he doesn't get SLT from here because he had his blocks and he still needs therapy, but he can't get it from the community. "*

Parents suggested a forum where Organisations can give parents an opportunity to voice their concerns and together tackle important decisions about service delivery.

- *"To listen to parents and ask what we would like for our child, i.e. 6 month to 3 year plan".*
- *"I say rip the whole lot up and start again and listen to us parents because we have all our stories to tell. Educate the children, educate the parents, educate the community."*

Parents suggested that Government and National Policies should advocate for more inclusion of people with disabilities in the community.

- *"Also, more can be done on promoting more inclusion of children with special needs. For example the scouts club. It also gives the others, the normal children the experience in dealing with children with special needs."*
- *"There are not a lot out there in the community for children with disabilities. You have to find the right place. I stay on the same street and go to the same shop and I cause an interaction to happen that they'd be aware of. It is all to help my child become more independent and part of his community."*

3.7.2 Focus Groups: Speech-Language Therapists

Ten of the 38 Speech-Language Therapists, who completed the MPOC-SP questionnaires, were randomly selected for the focus group discussions.

3.7.2.1 Models of Service Delivery

The focus group discussions started with Speech-Language Therapists providing an overview of the model of service delivery their employers adopt. Most of the Speech-Language Therapists work within a child or client-centred ethos although they naturally adopt a lot of the family centred principles. Most of the therapists also worked within a social model of service delivery with a few therapists working within the impairment based model.

- *"Client-centred planning, primarily, but incorporates family-centred, social model and impairment based model (language classes) depending on each individual case."*
- *"Child-centred, school and clinic based"*
- *"The provision of child-centred service, impairment based model, curriculum and healthcare services provided in the school and Special Care Units (SCU)"*
- *"Social model, child-centred"*
- *"It would be more of a child-centred model, very social model. Although we say child-centred our families would be heavily involved. We do a lot of collaborative work with parents."*
- *"The model of service delivery seems to change at our Organisation. Although our Organisation has a child-centred philosophy, I find it uses a more family-centred approach during the early years say from 0-5. The parents are at the core of decision-making, setting goals and working alongside therapists. This*

unfortunately changes when the child reaches school-age. Everything becomes then more child-centred. They focus then only on the child, his strengths and weaknesses and parents are less and less involved as the child gets older."

3.7.2.2 Policies and Procedures

Speech-Language Therapists were also asked to provide a brief overview of the core values of service delivery as reflected in their mission statement, policies and procedures. Core values that therapists ascribed to included: quality of care, transparency, equity, working in partnership, and working as part of a team. Therapists stated that they work both within a multi- and an interdisciplinary team approach.

- *"Client-centred model, accessible, equitable. Introduction to multidisciplinary team model in Primary Community Care (PCCC), currently in early stages of implementation."*
- *"To provide the highest quality of care and education to pupils, thereby enabling them to achieve their fullest potential and participate in their local communities and society in general."*
- *"Equity, transparency, accountability, equality, good quality of care for all."*
- *"Working as part of an interdisciplinary team, involving parents, and service-users during goal-setting."*
- *"The health board had a 5 year plan during which 8 objectives would be rolled out:*

1) *to show respect for people (person-centred approach)*
2) *appropriate care in the appropriate setting*
3) *provision of a connected service*
4) *accountability*
5) *high performance*
6) *fostering individual's responsibility for themselves and their care*
7) *equity and fairness*
8) *pursuit of partnership working.*

- *"A few words to describe the organisation's policies include: equity and fairness; appropriate care in appropriate settings would be the aim, it is possible but it can be hard, clinicians certainly try to follow through on that. Transparency – that would be true. Partnership with key stakeholders / parents, but not just parents, it would include anybody else working with the child. Very strong interdisciplinary team and quite flexible."*

3.7.2.3 Speech-Language Intervention for Children with CP

Speech-Language Therapists were asked to briefly describe their caseloads including a rough estimate of their caseload size. Most of the Speech-Language Therapists worked with mixed caseloads which included children with CP, children with Learning Disabilities (LD) and / or Children with an Autistic Spectrum Disorder (ASD). Caseload sizes varied from 40 to 130 of which a significant number of children had a diagnosis of CP.

- *"At present all CP children are being managed by* (organisation's name deleted) *or* (organisation's name deleted). *We provide a community based service when required."*
- *"Children with CP, Mild-severe learning disabilities (LD) and autism spectrum disorders (ASD). Approximately 75."*
- *"4-18 year old children having moderate, severe or profound LD and additional physical or sensory disabilities or autistic features."*
- *"Children in special schools (approximately 30 children with mild-moderate LD), Special Care Unit – 10 children with severe-profound intellectual impairment."*
- *"About 20 children with CP and multiple impairments – mostly severe-profound cognitive impairments."*
- *"A lot of children with physical disabilities, for instance Spina Bifida, other syndromes, but just CP, I would say about 30 children."*
- *"I have only one baby at the moment with CP as part of my caseload."*
- *"About 20 children with CP, those who are 'active' on my caseload or currently being seen by SLT."*
- *"About 130 I think, not all of them are like priority ones or high needs, and roughly a third of them would have CP."*
- *"I have 20 children with CP on my caseload. I see them weekly for continuous input. Sessions are generally group sessions focusing on language stimulation and using AAC, both high-tech and low-tech, to enhance communication. All the children get a full communication assessment once a year with an individualised programme to be implemented by their parents or teachers. I*

also see children jointly with other professionals on a one-to-one basis. This is usually when I have access or positioning issues or when I am deciding on an AAC device. I do a lot of meal observations and feeding intervention as well."

- *"I see a few children privately alongside a paediatric physiotherapist. Most of the children we see, attend a local organisation but their parents feel they need more SLT input. I will always endeavour to link with the SLT from the organisation to make sure we are targeting or trying to attain the same goals."*

Speech-Language Therapists were also asked to describe how they prioritise their caseload. A few Speech-Language Therapists used their Organisation's recommended prioritisation scales for assessment and intervention. The Therapy Outcomes Measures (TOMs) were also used as a means to prioritise caseloads. Other Speech-Language Therapists used specific criteria to assign a priority rating to a child. These criteria included: age, level of learning disability, children in a transition period, children with dysphagia, non-verbal children or children requiring AAC input. Other criteria included date of referral in the case of a waiting list.

- "*Early intervention service – allows for all children under 4 years to be seen for intervention in the service. Less than 3 month waitlist. Use Therapy Outcomes Measures (TOMs) to determine case severity. MACS approach used."*
- *"HSE South prioritisation scale"*

- *"By age: junior pupils 4-12 years are high priority. By disability: moderate disability prioritized over severe or profound."*
- *"Primarily by age: younger children get twice more e.g. twice a week in school (individual and class group sessions). Also by need: AAC children in SCU require more time."*
- *"To be honest, we don't have a particular system at the minute. We do have a waiting list at the minute, but up until now we take the referrals chronologically from date of referral and then in terms of prioritising when we have them, we would prioritise our local clients over our regional clients because they would be the ones who would need us for all of their service. But the extent of the prioritise list, I suppose we flag up children at transitional point in their life as well, moving to primary school, moving to secondary school. Waiting list, there is about 20 people on it and I don't know when they will be seen. I guess it would be up to about 6 months before we start seeing them."*
- *"We have an assessment prioritisation list in place, looking at 'bumping' children up the list to be seen quicker, especially late referrals – children who will be making a transition within 6 months, children who have had no SLT input to date, children with no functional communication system, children with a lot of challenging behaviour due to a lack of an appropriate communication system. For therapy we also have a prioritisation scale, assigning a priority rating to each child and deciding whether he/she will be a priority 1 (severe) or 4 (mild). Things that we include are the child and family's readiness for*

intervention, their commitment and support, no functional communication system, transitions, age, previous SLT input, parental anxiety, etc."

- *"Guidelines from the Health Boards and other organisations but not our own prioritisation scale."*
- *"Parents will sometimes say, all children are number one priorities because that is their reality, their child is their number one priority and they can get very cross if you prioritise them according to a rating scale or checklist."*
- *"A prioritisation scale can however help to put things into perspective for parents, to make a service more equitable and transparent. Parents might understand better when they see one child with severe CP and no method of communication gets more SLT than their child with only minor phonological difficulties."*
- *"Non-verbal children with no functional communication system will be a high priority, as is dysphagia."*

Speech-Language Therapists were asked to briefly outline the aspects of speech-language therapy they address most of the time in children with CP. A lot of Speech-Language Therapists' time is spent providing AAC input. A few Speech-Language Therapists indicated that they do not provide Dysphagia input as they were not trained in this area. The Speech-Language Therapists who indicated that they provide a Dysphagia service highlighted the fact that this type of input can be very time consuming.

- *"Low-tech AAC is very time-consuming, we don't have an assistant or admin support and we have to cut, paste, laminate all the communication passports, communication books, etc."*
- *"Communication and AAC. I am not dysphagia trained, so I consult with colleagues about this."*
- *"AAC, preverbal skills, oral-motor and articulation skills, language development, staff/parent training, not yet dysphagia trained."*
- *"We would do a lot of feeding and we would do a lot of AAC particularly in terms of the light tech stuff. The communication boards take hours."*
- *"We spend a lot of time on programming high tech AAC devices, this programming time unfortunately is not built into your day-to-day service delivery and I often have to take a device home for programming."*
- *"Feeding is huge especially the follow-up, report writing, reviews, liaison with other therapists when you have a feeding clinic, order equipment – the list is endless."*
- *"My main focus of therapy is (a) AAC, (b) advising and monitoring feeding / feeding staff, (c) developing oral-motor skills, (d)sensory integration therapy, (e) liaison with OT and PT."*

Speech-Language Therapists also included language stimulation and intervention, training, speech therapy and the development of preverbal skills as part of their daily workload.

- *"Assessment, diagnosis, intervention for all children 0-18 years (not dysphagia). Provision of services to junior / senior language classes. All aspects of fluency, deafness, delay, disorder, dyspraxia."*
- *"Speech clarity, receptive and expressive language, functional communication. In class, preverbal skills (joint attention, initiating interactions, problem solving), social skills."*
- *"We would actively work a lot with schools because we don't have a school attached here so any of the children attending special schools or mainstream schools and we would spend a huge amount of time training and working with teachers, resource teachers and SNAs. And then linking with the parents, going on home visits, sending them home programmes, that kind of thing. Supporting them in their approaches to the Special Educational Officers / SENOs and often write letters to them to endorse software, that kind of thing."*
- *"A lot of the early stuff, pre-AAC skills like cause-effect, joint attention, turn taking, waiting, etc."*

The Speech-Language Therapists gave a brief overview of the context of Speech-Language Therapy service delivery with special reference to the type of service delivered, the setting, location, frequency and intensity of intervention. Most therapists used a combination of direct (in the form of one-to-one or group therapy) or indirect (training, working with the environment, implementing programmes) intervention. Therapists used the MACS approach during group intervention and there was a strong emphasis on working jointly with other disciplines. Intervention was more clinic or school-based and home visits rarely happened. Parent training using the Hanen principles was also favoured by Speech-Language Therapists.

- *"Direct, indirect, school team in the class, early intervention (all relevant disciplines except OT), MACS groups."*
- *"Direct or indirect therapy, joint team approaches".*
- *"Direct therapy and indirect therapy in form of staff/parent training. Team approach including PT, OT, nursing, SNAs, teachers all used in my service delivery."*
- *"Direct and indirect therapy are provided in schools. Home visits are rare at the moment, but possible. Joint working is desirable but not always possible, as other professionals do not provide designated services to schools."*
- *"Direct and indirect through school visits, linking with resource teachers, making applications and writing out home programmes, oh yes, and attending team meetings."*
- *"Parent training evenings following the Hanen approach."*
- *"Interdisciplinary team work where we go on a visit as a team it could be all or one or two depending on what aspect the focus of the visit is."*
- *"We don't use any of the MACS approaches. We don't see them as being appropriate. You can't use something so general with these complex cases."*
- *"We don't do a Hanen course as such. We have offered groups in the summer focusing on early language intervention jointly with the Physios, so looking at a Hanen style type of programme but with a lot of focus on positioning and*

how to manage your physically disabled child and how to make the most of communication opportunities."

- *"We don't offer those out of the main working hours, like some Hanen programmes recommend."*

The context of intervention varied. Most of the intervention was clinic or school based. Speech-Language Therapists based in schools saw children as part of a group in the classroom or used the pull-out approach by seeing them within school hours in a therapy room. A few Speech-Language Therapists working as part of an Early Intervention Team saw children at home.

- "*School: 3 days a week from 9.00am-14.00pm each week. In the clinic or health centre: 3 days a week where we see our regular clients."*
- *"Schools: weekly input, and also in the clinic."*
- *"Intervention happens only in the school, either in the SLT rooms or in the classrooms. The frequency varies from once weekly to fortnightly SLT sessions depending on priority. Therapy is supported daily by teachers/ SNAs."*
- *"Both clinic and home intervention."*
- *"A combination of both home and clinic for the early intervention. Now what we haven't offered is general info to all parents in terms of Hanen style stuff during parent groups. If we have an appropriate group so that we can match them based on their abilities and needs, and where the advice that we are offering at home can be available to all, we will consider doing it, but*

sometimes it is easier to demonstrate at home where communication happens naturally, say for instance 'oh look, the child is looking out of the window - he is waiting for daddy to come home'. That kind of thing."

Session length varied and is mostly client-specific but was approximately 30 minutes long. SLT was provided on a continuous basis for children with no functional communication system until a system was implemented where other children received weekly input. Therapists also used block approaches and on average children received 3 blocks of intervention a year.

- *Children on my caseload are provided with 12/14 sessions per year (this includes intervention and assessments, maybe 1:1 or group)."*
- *"Children are seen individually or in small groups once a week in a pull-out session for 25-30 minutes. Some children are seen again in a class-group once a week for 30 minutes. Some intervention takes place primarily through consultations with staff."*
- *"Frequency and intensity is entirely client specific."*
- *"We have one or two bright, bright children but with severe physical disabilities that we would see quite regularly, maybe even more than once a week and also children with no means of communication. Thus you have to look at all skill areas, technology, access, language. And then after that the majority of our children will be seen once a week. For children with more specific difficulties, speech sounds or language based work, we will see them more in block. Maybe 3 or 4 blocks a year with targets for those blocks."*

Speech-Language Therapists were asked to discuss how they measure the child's progress during intervention. Most Speech-Language Therapists used formal assessments to establish a baseline of communication function and then to measure progress usually every two years. Other means included using goal-setting as an outcome measure. Observation during informal assessments and norm-referenced assessments also rated amongst the resources used by Speech-Language Therapists to measure progress.

- *"Standardized testing, parent, school and clinical observation report."*
- *"Standardised assessments, checklists, criterion referenced measures."*
- *"Targets and objectives achieved in yearly therapy plan with specific aims and objectives. Reassessment on a 2 yearly basis."*
- *"Informally, through observations and reported changes. Formally, through test results if appropriate."*
- *"Again it is quite client specific. Repeats of standardised assessments when it's possible to do and then also informal and specific testing whatever goals we would've set and then I suppose more criterion based listing so that you might've set specific targets and have they been achieved at the end of 6 months for your block of sessions."*
- *"Parents are involved in terms of target setting, the intention would be there."*
- *"Formal assessments every one to 2 years, reviews on request by parents or if a child made significant progress, informal developmental checklists or norm-referenced assessments like the Rossetti / REEL 2, TOMs."*

3.7.2.4 Parent's role in SLT Intervention.

Speech-Language Therapists felt that parents play a vital role in their child's speech-language intervention. Parents are involved in the goal-setting process, attend therapy with their children and implement home programmes.

- *"Parents are involved in choosing goals of therapy and in carrying out tasks at home. They are involved during therapy in leading tasks with their child."*
- *"Parent-therapists meetings are held to discuss goals of therapy and to demonstrate techniques. Children in school have homework books so parents can practise with them during the week."*
- *"Parents play a vital role during therapy. They sit in and join in on all sessions so that they know what do at home in order to reinforce skills and learning goals and help children generalise targets across environments."*
- *"Parents also provide written feedback on request by the therapist after sessions and have the opportunity to identify goals or specific targets that they would like to be included during group therapy."*
- *"Our parents sit in on all therapy sessions. They are responsible for managing the child's behaviour and assisting with AAC devices and hand-over-hand activities. Parents are also asked to give written feedback after a block of sessions and most of the time we ask the parents to identify broad goals they would like us to target during therapy."*

3.7.2.5 Supporting Parents with Children with Disabilities

Therapists stated that they support parents by providing them with information, making themselves available as an emotional and an informational source.

- *"We discuss the child's diagnosis. We ensure at each meeting that the parent is aware and involved in the process. We also advise on other services available and how to access them. Meet with MDT teams / schools with parents. We also provide information on legislation e.g. EPSEN Act. and help in getting access to services."*
- *"Support parents by (a) weekly written updates of therapy progress, (b)SLT available to parents at any time during school day, (c) available for parent-teacher meetings and other school functions where parents attends, (d) available for individual consultation with parents during month of July (after school officially closes for holidays)."*
- *"Giving space for them to talk. Sharing information for example explaining the disability and/or observed behaviours. Discussing various treatment strategies. Providing links with other professionals. Input on school placement in carers of Special Care Unit children."*
- *"We run Hanen parent training evenings, information evenings and group therapy where parents can meet each other and get to know each other."*

Some SLT had input from Psychologists and Social Workers and would see supporting parents as being slightly outside the remit of Speech-Language Therapists.

- *"We are very lucky, we have a full-time social worker and we work quite closely with her. I know that the social worker and a SLT ran a Parents Plus programme at one stage but we can link in with her whenever we need to. If people bring up something that is a little bit outside the remit of SLT we can direct it to a social worker or a nurse for example issues about funding for a car. Our social worker also runs parent groups on an informal level where parents can meet each other."*
- *"The Psychologists and social worker run what is called Sibshops so again if we felt there was a sibling that is kind of sitting on the edge of the therapy process we can feed into that so that they can access support and recognition as well."*

One healthcare provider supported parents in the form of parent support groups.

- *"There is a parent group and a parent support group, but it's fairly informal and they would meet once a month in the clinic. It is there, but it is deliberately quite informal so that people can feel comfortable in pitching up to it. These support groups are directed by the Social Work department."*

3.7.2.6 Perceptions of Speech-Language Service Delivery to Children with Cerebral Palsy

Speech-Language Therapists were asked to describe their perceptions, as Speech-Language Therapists, of the service they provide to children with CP. All therapists felt that they generally provide a high standard of care to children in this population especially under the constraints of time and resources they are facing. Therapists felt that their quality of care is improved by working jointly with other professionals and voluntary agencies.

- *"It is pretty comprehensive. You don't always have as much time as we like but we make best use of the resources that we have. We are lucky that although we are all very busy we do have access to all the different disciplines so you never have to work in isolation. We do joint goal setting with the OT around play and with the PT around positioning."*
- *"Only recently has there been an opportunity for joint working with an OT and PT. Previously it was very isolated. I still feel unsupported and that much of my therapy is trial and error."*

Speech-Language Therapists stated that although they try their best to provide an equitable service, they can sometimes still respond to crises or demanding parents.

- *"Because our caseloads are so big, it can turn into a watered-down fire fighting service. You mostly respond to need, urgent requests, parent who are* *stressed out and pushing for input, and sometimes you feel that you don't provide an equitable service. Sometimes the quiet parents' children get left out, because they don't 'shout' as loud for input."*

Speech-Language Therapists also felt that their workload can be dramatically reduced by employing SLT assistants to help programming AAC devices, order equipment, make resources and provide administrative support to therapists.

- *"Assistants, assistants, assistants!"*
- *"No we don't have any SLT assistants, but we would love one."*

3.7.2.7 Aspirations for the Ideal Model of Service Delivery

Aspirations for the ideal model of service delivery included suggestions for Speech-Language Therapists working with children with CP, suggestions for organisations / service providers and suggestions for national policies.

Suggestions for Speech-Language Therapists

Speech-Language Therapists suggested that there should be a dedicated Speech-Language Therapists working within the educational system to support children in special and mainstream education.

- "*There are many advantages to being 'onsite' and full time in the school setting. This should be a procedure in special schools, with funding obtained* *from healthcare, and/or Speech-Language Therapists employed by Department of Education (similar to the way SNAs are employed by Department of Education.) This should be incorporated into national policies for children with CP in general."*

Speech-Language Therapists requested more consistency of approaches and intervention guidelines used across the various service providers nationally.

- *"To have a clear pathway of care to allow for support and guidance on dealing with CP children. A pathway to indicate specific models of input, amount of intervention and types of intervention. Also, protocols around this pathway to ensure best services for children with CP."*

The therapists suggested a forum for Speech-Language Therapists to meet each other, share ideas, resources and provide support for one another.

- *"It would be great to have the time to network with other Speech-Language Therapists working with CP and AAC. I think there is a willingness to share expertise, but it is difficult to get together."*
- *"More support from other Speech-Language Therapists to share ideas, resources."*

They also suggested more needs based intervention for children with CP where the level of input will match the child's needs.

- *"I think in an ideal world we would back off from this whole idea of blocks and this idea that if you had a block this year you are doing okay and that you had a bit of a service."*
- *"Particularly for children who are in special schools, that you would have collaborative services with education around whatever goals you are setting and that the child will be seen as often or as little as they need to be seen rather than having to fill 6 weeks."*

Therapists suggested that a review of Speech-Language Therapists' workload, as opposed to caseload, is needed.

- *"Smaller caseloads!"*

Suggestions for Education and Health Service Providers

Sufficient funding for resources and equipment

- *"Resources are always an issue. There is always a waiting time before one has the tools and resources one needs. And often we get one item which has to be shared in different settings with different children".*

Better coordination and cooperation between the healthcare and educational system.

- *"To recognise the need for flexibility and for the two (Health and Education) to come together because they can be at opposite ends. There is a lot of legislation that is very positive on paper in terms of the special education needs act with lovely references to teachers accessing Speech-Language Therapists, and that's great and we really appreciate it, but it sort of tripled the workload because your phone is hopping all the time from teachers trying to set IEPs."*
- *" Teachers can be very heavily focused on how many times you have seen the child and not what have you actually achieved."*
- *"Regular contact/meetings with the MDT working with the child, including the school team and family."*

General guidelines nationally for service delivery for children with CP.

- *"There should be rough guidelines across the country for service delivery for children with CP."*

Suggestions for national policies for children with CP.

Therapists felt that *"the national policy should incorporate above mentioned"*. Specific recommendations included:

National AAC loan bank for equipment trials

- *"I would like a library in place where we could borrow devices for trial before you buy. Also staff who were able to advise on how to use the devices, e.g., various mice for computers, AAC devices, software."*
- *"Services need to be joined between all the different aspects for CP particularly in terms of technology for the brighter more physically challenged children to look at the whole child rather than for things to happen in isolation."*

Highlighting the importance of AAC technology

- *"That funding is there for technology and that funding is there across the country."*
- *"National recognition of the trial of such devices / communication systems and that they are expensive but if you trial them and introduce them at an early age your success rate with be so much higher."*

More flexibility around allocation of resources.

- *"Getting back to the educational side of things, that they could be a bit more flexible. They think that because you have a label you are automatically entitled to your 3 hours resource teaching a week and that is just nonsense* *because some children will need considerable more and others will need less and that there should be an allowance for some flexibility."*

Disability awareness

- *"More awareness of children with CP in the community."*

CHAPTER FOUR

DISCUSSION

4.1 Introduction

This chapter discusses the findings from parents' and Speech-Language Therapists' perceptions of Speech and Language Therapy (SLT) service delivery for children with Cerebral Palsy (CP). This discussion aims to answer the research question: what are the perceptions of parents and Speech-Language Therapists of SLT service delivery for children with CP in the Republic of Ireland (ROI)? The discussion will focus on ascertaining the comparative perceptions of parents and Speech-Language Therapists on SLT service delivery for children with CP. In addition, the discussion will also outline how these perceptions align with the official policies of Health and Education Service Providers in the ROI. Analysis of the data identified seven themes relating to information, communication, Speech and language therapy service delivery, role of parents, supports for families, and relationship between parents and Speech-Language Therapists.

4.2 Informational Needs of Parents

Parents attending service providers for their child with CP reported that their informational needs were rarely addressed. Parents expected Speech-Language Therapists and service providers to provide them with general information. As

Cerebral Palsy, and its associated conditions, is one of the most severe developmental disabilities in childhood (Surveillance of Cerebral Palsy in Europe, 2000), parents' need for information has to be addressed by service providers. Parents need to be provided with information that they otherwise may not have access to, as well as simplified versions of complex phenomena and clarifications to any uncertainties (Hargle, Saunders, and Dickson, 1994). Parents reported that they were more often provided with specific information about their own child, but that they lacked general information about Cerebral Palsy, service delivery, and legislation. Beyond the usual demands of parenting, parents with children with special needs often have additional worries about uncertainties around their child's development (Rosenbaum, 2004). A need exists for parents to access more general information regarding their child's disability by inviting guest speakers to speak on a topic of interest. In light of the national shortage of Speech-Language Therapists (Release, 2004), parents also welcomed the idea of more SLT training courses as a source of information as well as information on general SLT issues. Parents reported that there is very limited information about various health, educational, and general concerns available especially in the form of leaflets, brochures, or websites. There is also very limited accessible information regarding the types of services offered within the organisation and the community. Documents from Health and Education Service Providers highlighted the importance of providing families with relevant information that is concrete and specific enough to enable families to make decisions. Based on parents' and Speech-Language Therapists' feedback, Health and Education Service Providers do not fulfil this statement. This finding concurs with the research by Chamba, Hirst, Lawton, Anmad & Beresford (1999) who found that although information has been shown to be one of the most valued aspects of families' contacts with services, a substantial proportion of parents report that their needs for information remain unmet.

Informed choice on the part of families receiving services and supports is based on the availability of information (Council, 2000). Based on outcome measures or quality frameworks, (e.g. European Foundation for Quality Management (EFQM) and Personal Outcome Measures) organisations have a responsibility to evaluate the need for information and education related to the need of its service populations (Council, 2000). However, parents reported that they needed more relevant and accessible information in order to make informed choices. The need for relevant and accessible information for families with disabled children has been highlighted in a number of research studies of families' views of their needs (Beresford & Sloper, 1999; Clare & Pistrang, 1995; Beresford, 1995; Chamba et al., 1999).

Parents stated that they received a lot of information from other parents of children with CP. They saw other parents of children with CP as a source of both informational and emotional support. The ethos Family-Centred service delivery highlights the importance of providing contacts with other parents and informing parents of available support groups in their locality. The provision of information and contacts with parents of other children with a similar disability, together with the assistance of professionals can greatly assist families in the early months after the birth of their child (National Disability Authority, 2003). However, parents indicated that limited opportunities exist for parents to meet other parents of children with CP. Parents felt that there was an overall reluctance from service providers to arrange meetings where parents can meet each other and discuss mutual concerns. Furthermore, there are also very limited opportunities for the whole family to access information. Lack of knowledge of family members about CP and service delivery is significant, as knowledge may be an important precursor to deeper involvement in service delivery e.g. attendance, follow-through on advice and home programmes (Hosley et al., 2006).

Parents who sat in during therapy sessions reported that they always received a lot of information about the therapists' goals and therapy techniques while they were watching the session. A level of discordance existed between parents' and Speech-Language Therapists' perceptions of written information provided. Information about the results of assessments were shared to a great extent, but written information on the child's progress during therapy and what Speech-Language Therapists were doing in therapy when parents did not attend sessions, was limited. Information received about the child's progress and content of SLT session through daily contact sheets or diaries was highly valued by parents.

Both parents and Speech-Language Therapists felt that there was, however, a fine balance between providing too much and too little information depending on where parents were in the grieving process and whether they were emotionally ready to receive all the information. Counselling is part of the Speech-Language Therapist's repertoire of clinical skills (RCSLT, 2005). However, Speech-Language Therapists saw providing informational support to parents as slightly outside their remit of expertise and stated that the onus rested on Social Workers or Psychologists to fulfil this duty. The RCSLT (2005) stated that Speech-Language Therapists may need to use counselling skills to address emotional issues brought up by individuals, providing the issues are related to the communication disorder. Clear guidelines exist in relation to the use of counselling skills as part of therapeutic intervention. It is highlighted that Speech-Language Therapists should only engage in counselling if they have undertaken basic training in counselling, listening and communication skills and if the Speech-Language Therapist felt comfortable in a counselling role (RCSLT, 2005). In general, literature indicated that counselling services tend to be limited for people with CP (Gething, 1997).

4.3 Relationship between Parents and Speech-Language Therapists

Overall, SLT care for children with CP was perceived by parents as being respectful and supportive. Parents felt that their family was accepted in a non-judgemental way, that they were treated as individuals and made to feel competent as parents by their Speech-Language Therapist. Speech and language therapy was generally delivered within a caring atmosphere, with polite and courteous therapists, who remembered personal details about their family or their child. The Health and Education Service Providers' documents outlined that services and supports should be grounded in dignity and respect, as part of the social model of disability. Therapists should strive to demonstrate dignity and respect throughout their interactions with families with privacy and confidentiality respected.

Listening to parents' needs, goals and feedback was also identified as being an important part of nurturing a relationship with parents. Parents in general felt that they had enough time to talk to the Speech-Language Therapist so not to feel rushed, although Speech-Language Therapists' reported that they would like to spend more time listening to parents but due to resource and time constraints they felt that they are always "*rushing*". Parents in general experienced SLT as a joint process where parent and therapist worked alongside each other to fulfil the child's potential. In some instances parents felt they were not treated as an equal especially when there was a "*conflict of interest*" about their SLT goals for their child or the aspects they would like Speech-Language Therapists to address. Speech-Language Therapists commented that they viewed parents as equal "*but without the expertise that the therapist has in their specialism*".

Although most parents stated that they have had very positive experiences in working with and attending SLT, the high turn-over in Speech-Language Therapists affected their relationship. Some parents had up to 6 different Speech-Language Therapists in 4 years with most Speech-Language Therapists in a particular post for no more than 2 years. Parents felt that this affected their relationship with Speech-Language Therapists 'to a great extent' as "*your child only just get to know her then they leave again*". In general, service providers' strategy for hiring, nurturing, and sustaining staff was not evident from the documents reviewed and did not fall under the objectives or core values for service delivery.

4.4 Communication

Open channels of communication should exist between parents, Speech-Language therapists, other professionals, service providers and other outside health and educational service providers. When open channels of communication exist, services can be delivered in a more comprehensive and coordinated fashion. Furthermore, the manner of service delivery should be transparent to all, thus ensuring good quality service delivery that is equitable to all service-users. Due to the complex nature of CP, a team approach to CP is vital to provide coordinated and comprehensive care. Efforts should be made to provide coordinated services for families since these families are at risk of stress, burnout, and dissatisfaction with services (Rosenbaum, 2004). Communication between parents, service providers and all the team members involved in the child's care is vital to ensure the child's holistic needs are addressed. Effective SLT intervention is based on a holistic understanding of the individual, including their social, cultural, economic, political and linguistic context (RCSLT, 2005). It is important that the child with CP's skills are known to all persons working with the child and that skills are carried across therapists and services. Pellegrino and Meyer (1998) highlighted the importance of interdisciplinary team work in order to integrate all aspects of service delivery and various treatment programmes. Parents can become overwhelmed when they feel that they have too many things to do for each discipline with "*each therapist having their own field and sometimes you end up with too many things to do for each*". In general good communication existed amongst team members in the current study and everyone's expectations for the child were discussed so that all the team members were working to the same goals. Parents acknowledged the importance of therapists meeting and planning together as a team to ensure information given to parents is consistent from person to person. Parents also valued the fact that there was generally good communication between them and Speech-Language Therapists especially through diaries, daily contact sheets, and regular meetings.

When breakdown in communication occurred between parents and professionals, it was often reported to have been particularly related to the diagnosis of the child. However, research indicated that parents can often experience grief reactions like denial, anger and rejection when their long-awaited baby is diagnosed as having CP (Gething, 1997), and parents may still be in state of shock and unable to take in much verbal information (Dale, 1996) which can be interpreted as a breakdown in communication.

Parents and Speech-Language Therapists reported that a lack of communication sometimes existed between medical teams, parents, and the therapists. Parents wanted to be kept informed if and when changes were to happen in the future. They recommended that this type of information should be clearly and explicitly stated and that it would enhance the coordination of service delivery. The RCSLT (2005) stated that Speech-Language Therapists should work collaboratively with parents and the team in planning, implementing goals and clinical care. The National Disability Authority (2003) considers that improved coordination and integration of services through collaborative team working is vital for service provision within the social model of disability.

Transparency, in relation to information dissemination, was another issue that came up during the discussion of communication. Transparency was one of the core values identified in service provision. Service providers stated that policies and procedures should be available and accessible to all and information should be visible, clear and easy to understand. Parents wanted more information on how service provision was allocated amongst the service-users highlighting the need for transparency of service delivery decisions. Parents with children with special needs already experience high levels of stress and may sometimes unnecessarily "*get stressed out when they see things are not transparent and equitable*" just because of a lack of communication about particular decisions in service delivery. In general there appears to be a lack of communication between the various Health and Educational Service Providers. This is evident in the lack of consistency in models and ethos of service delivery across the various service providers for children with CP.

The documents of Health and Education Service Providers highlighted the need for services to be delivered within a team-based ethos and approach. Various service providers had different models of service delivery ranging from Multidisciplinary to Interdisciplinary and Transdisciplinary, but what is most important is that a team approach is apparent within the various service providers. Documents highlighted that service delivery should support team coordination and develop effective team working. Although the team-based approach and ethos encompass 'effective communication' amongst team members and are clearly identified in the objectives and core values of service delivery, the theme of 'communication' and the importance of having open channels of communication were not highlighted to the same extent.

Links with other service providers, multi-agency communication, and interagency agreements were also not explicitly stated in service providers' documents. Research by the National Disability Authority (2003) concurred with parents' and Speech-Langauge Therapists' perceptions and stated that in Ireland there are variations across the health boards (or HSE) in the provision of services with poor coordination of disability services with other services. Speech-Language Therapists have a role to work as part of a team, whether it is a multi-, inter-, transdisciplinary team or working within a multi-agency team to encourage coordination and communication between services (RCSLT, 2005).

4.5 The Role of Parents

Parents play an active role in the care of the child with CP (Dale, 1996; RCSLT, 2005) and every effort should be made to include parents at all times in goal-setting, decision-making, and intervention. The central theme in the British Children's Act of 1989 (Dale, 1996) is the importance of partnership with parents. When Speech-Language Therapists work in partnership with parents, they serve the parents by making appropriate expertise available to them for their consideration (Dale, 1996).

The majority of service providers for children with CP adhered to a person or child-centred model of service delivery, although Speech-Language Therapists reported to naturally adopt a lot of the family-centred principles. The model of service delivery can also vary depending on whether a child is in early services or a school setting. Where service providers adopt a family-centred approach to service delivery, the role of the parent becomes paramount to good quality service delivery. Rosenbaum (2004) highlighted that the family-centred approach to service delivery acknowledges and incorporates the needs and well-being of parents and families which are at the core of the child's well-being. Enabling parents and working in partnership with them are important foundations of good quality service delivery within a family-centred model. The results indicated that Speech-Language Therapists acknowledge the role of the parent during goal setting, decision-making, and intervention but that their input was not always adhered to or respected. In general, there were always opportunities for parents to explain what they think are important treatment goals and parents have a chance to say what is important to them. Parents reported that Speech-Language Therapists would always inform them about the reasons for recommending treatment and/or equipment, but rarely tell them about the treatment and /or equipment options available so that they, as parents, can be part of the decision-making process. Although parents were told about the reasons for treatment and equipment choices, Speech-Language Therapists did not always fully explain these treatment choices to parents or provided them with opportunities to make decisions about treatment. Consulting with parents when services or equipment issues were discussed and recognising that parents have the final say in decision-making regarding treatment allows for parents to feel part of the decision-making process. Parents also need to be kept informed about the details of their child's services (e.g. the type, length, and frequency). It is also important to share resources like catalogues and brochures between parents and Speech-Language Therapists in order for parents to learn more about what options are available and to help them make an informed decision.

Parents and Speech-Language Therapists saw and trusted parents as the expert on their child and a partner in their care. Parents can only play a role in service delivery and intervention if he / she are empowered by the therapists delivering the service and working in partnership with the therapists (Dale, 1996). Providing positive feedback and encouragement to parents to carry out home programmes and join in during therapy sessions is vital to keep parents focused and motivated for SLT intervention. Parents stated the importance of sitting in on therapy sessions and learning from the Speech-Language Therapist in order to follow through on the goals at home. Letting parents choose when to receive information and the type of information they want can sometimes be to parents' own detriment as parents "*may not always know what information is useful and what information they need*". Information-giving could be enhanced by Speech-Language Therapists anticipating parents' concerns and offering appropriate levels of information. Due to time and resource constraints Speech-Language Therapists could not spend a lot of time providing and sharing information.

4.6 Supports for Families

SLT service delivery should operate within a family support framework (Hosley, O'Brien, Maheswaran & Larson, 2007) where families' lifestyles and needs are taken into consideration when recommending intervention plans. Overall, most parents reported high satisfaction with SLT service delivery. Parents generally reported lower satisfaction with the level of support they received from their service provider. Parents of children with special needs often experience high levels of parenting stress (Douma, Dekker & Koot, 2006). To support these parents, service providers should aim to provide information, activities, child mental health care and parent counselling (Douma et al., 2006). Parents felt that there was a high need for a counselling service in this population to address their emotional needs and to ensure enhanced mental health. They also mentioned that there is limited support for the whole family available from service providers. Documents of service providers highlighted the importance of focusing on the needs of the whole family, including siblings. There is a need for more service providers to provide supports for the whole family in the form of family fun days out or Sibshops for siblings. Sibshops are opportunities for brothers and sisters of children with special needs to obtain peer support and education within a recreational context (Meyer & Vadasy, 1999). As part of the social model of disability (National Disability Authority, 2003), service delivery should focus on all aspects of the child with CP's life which includes his family, extended family and life in context of community and society. In Ireland there is government commitment to re-orient services towards a social model of service provision (National Disability Authority, 2003). To date there is no national support group for parents with children with CP in existence. Although Speech-Language Therapists made themselves available as a resource to parents by providing information, advocating for services and supporting parents, most Speech-Language Therapists felt that providing support and counselling was outside the remit of Speech-Language Therapists. Therapists try to support families by suggesting therapy plans that fit with families' needs and lifestyles. Parents stated that Speech-Language Therapists recognised the demand of caring for a child with special needs and that they showed sensitivity to their feelings about having a child with special needs. Service providers have a vital role in advocating for their stakeholders and to represent their views

(Council, 2000), yet parents felt that service providers could do more to advocate for services on their child's behalf. Parents stated that they constantly have to 'fight' for services. Parents also expressed their concern about the lack of support for children in mainstream education. Service providers' documents highlighted the importance of promoting and supporting integration into the community and society (Government of Ireland, 2004), yet parents felt that although there was a great emphasis on inclusion, there was not sufficient educational support offered to help children access the mainstream curriculum. Government education policy now aims to mainstream and integrate all students with disabilities (Gething, 1997). The RCSLT (2005) stated that mainstream services should be provided in such a way as to promote access to learning opportunities within the context of the broad curriculum. When children with a limited functional communication system, are introduced to mainstream education, they experience significant difficulties accessing and participating in curricular activities. This breakdown in the child's ability to participate more fully in life at school and in the community, is highlighted by Dowden (1999) who stated that establishing functional communication is the most important objective in language therapy and should be the key focus when preparing a child with CP to be integrated within the mainstream educational environment.

4.7 Speech-Language Service Delivery

Most parents reported high satisfaction with the quality of SLT service delivery their child has received from Speech-Language Therapists. As recommended by the RCSLT (1996, 2005) SLT intervention should be characterised by well-defined short and long term goals, with frequency and duration of treatment clearly documented. Although the frequency and duration of SLT intervention was documented in most cases, it varied throughout the country. Overall parents were dissatisfied with the lack of Speech and Language Therapy available at their service provider. Parents whose children attended service providers that served a smaller population were generally more satisfied with the level of care they have received than their counterparts attending service providers that provide services to larger populations. Therapy varied from 1 block of 10 individual sessions of 20 minutes a year to weekly classroom-based intervention. Waiting lists of approximately 6 months existed, and a few cases were highlighted where children have not received input from SLT for 2 years. This was confirmed by the National Sensory and Physical Disability Database (2004) which stated that SLT is the most common therapeutic service for people to be waitlisted. A few service providers had an early intervention service with children receiving input from as young as 4 months of age. Therapists stated that frequency and intensity of intervention was needs-specific. On average children received 2-3 blocks of intervention a year, with intervention ranging from being continuous to block approaches. Some parents favoured speech and language group therapy within community settings above the intervention they receive from their disability service provider. They saw these groups not only as a source of speech and language therapy information, but also a forum to gain support and information from other parents.

Service providers stated that the various centres endeavour to provide a service of excellence, yet SLT service delivery is characterised by a high turnover of staff and demanding workloads. Therapists stated that their workload affected the amount of direct intervention they were able to provide. A differentiation was made between caseload numbers and workload, as the role of a Speech-Language Therapist extends to more than just assessment and intervention. Therapists indicated that programming communication devices, making low-tech resources, following up and liaison during and after eating, drinking, and swallowing assessments, and administrative duties took up a lot of their time. Regular monitoring and reviewing of therapies and activities are needed to ensure that all input is in line with best practice guidelines and complies with national standards of disability services (Council, 2000).

Parents valued the time Speech-Language Therapists took to establish rapport with their child and how they explained things in a child-friendly way. Speech-Language Therapists also made an effort to provide a coordinated service by following-up on any concerns parents expressed at the next appointment. Providing coordinated care by liaising with families is in line with the RCSLT (2005) best practice guidelines and is an important role of Speech-Language Therapists. Speech-Language Therapists are aware of children with CP's changing needs, however, parents reported a lack of support around major transition periods in the child's life.

CHAPTER FIVE

CONCLUSION

5.1 Limitations of the Study

This study had the following limitations, which need to be taken into consideration when interpreting the findings:

- The size of the sample was small as it involved participants of only those service providers who consented for their parents / caregivers to participate in this research study. This restricts the generalisation of the study findings to other service providers providing a service to children with Cerebral Palsy (CP), although it can be assumed that many of the issues raised in this study are relevant to all parents of children with CP in the Republic of Ireland (ROI).
- It is not possible to ascertain the views of parents / caregivers of children with CP who did not participate in the study but who also receive services from same the service providers of participating parents.
- Only mothers of affected children with CP attended the focus group discussions. It would have given a more balanced picture if fathers also attended the focus group discussions in order to compare and understand their experiences.

5.2 Recommendations

This research study aimed to address the research question: What are the perceptions of parents and Speech-Language Therapists regarding speech and language therapy (SLT) service delivery to children with Cerebral Palsy (CP). The degree of concordance between parents' and Speech-Language Therapists' perceptions was also determined. Relevant literature was reviewed and compared with current provision to identify gaps in the service delivery to children affected by CP. A non-experimental, quantitative, descriptive research design was adopted to describe the nature and quality of SLT service-delivery while qualitative research methods added descriptive depth to the quantitative results. Multiple (triangulated) methods of investigation were used to enhance the validity of research findings and minimise the error contained within each individual approach (Bowling, 2002). Triangulation (Terre Blanche & Kelly, 2002) entailed collecting data in various ways (i.e. questionnaires, focus groups, and documents) and from various sources (Parents, Speech-Language Therapists and Service Providers). This helped to home in on the understanding of perceptions on SLT service delivery in the ROI by approaching it from different perspectives. Data was collected by the use of the Measure of Processes of Care (MPOC) and Measure of Processes of Care for Service Providers (MPOC-SP) questionnaires, focus group discussions, and document analysis of service providers' documents. Participants who completed the MPOC questionnaires comprised of 45 parents of children with CP and, for completion of the MPOC-SP questionnaires, 38 Speech-Language Therapists who provide services to children with CP participated in the research study. Eleven of the 45 parents, and 10 of the 38 Speech-Language

Therapists were randomly selected to participate in focus group discussions. The data was analysed by employing descriptive statistics and using two raters to identify the degree of concordance between parents' and Speech-Language Therapists' responses on the questionnaires. Qualitative data was yielded by the questionnaires and responses in focus group discussions, and was subjected to thematic analysis involving the researcher and an independent rater. Comparisons were made between participant responses and information contained in documents of health and education service providers. Results yielded information in terms of the strengths and weaknesses in the following service delivery areas: (i) enabling and partnership, (ii) coordinated and comprehensive care, (iii) respectful and supportive care, (iv) providing general information, and (v) providing specific information about the child. Overall, parents and Speech-Language Therapists expressed particular dissatisfaction over the lack of general information available to parents of children with CP. Areas of strength and needs within the other service delivery themes were also identified.

Twenty-nine key recommendations were made related to the informational needs of families, the relationship between parents and Speech-Language Therapists, communication, the role of parents, supports for families, and SLT service delivery, and are listed below:

Recommendations for Addressing the Informational Needs to Families:

- General information about services within the child's current service provider and across the various service providers should be available to all parents to ensure consistency of care for children with CP within the ROI.
- More accessible general information about service delivery, disability issues, and general speech and language difficulties, should be available to parents in the form of information leaflets, brochures or via guest speakers.
- A national CP website should be created to provide general information about services, and topics of interest. This website should include a facility for parents to link with each other and professionals who provide a service to children with CP.
- Parents may be aware of services (e.g., respite services or assistive technology interventions), but unsure about whether they can access these services and how such services are delivered in an equitable way to all children. This type of information should be transparent and available to all parents. Therefore, more information about the different services available as well as the process of this service delivery should be provided to all parents.

Recommendations to Improve and Nurture the Relationship between Parents and Speech-Language Therapists:

- Speech-Language Therapists should aim to empower parents to become partners in their child's care, by providing them with adequate information, support, and positive feedback. Speech and language therapy works to encourage individual autonomy and to discourage dependency on the therapist (RCSLT, 2005). Parents need to be empowered by Speech-Language Therapists as a resource for helping their child with special needs, but they also need support, guidance and encouragement to help them carry out their parenting of a disabled child. The information should be provided in the form of regular scheduled contact with parents via written, face-to-face or telephone contact between parents, Speech-Language Therapists and service providers.

Recommendations to Improve Communication:

- There should be open communication between the educational sector and disability service providers to help children with CP access and participate more successfully in mainstream curricular activities. Therefore, more educational and therapeutic support is needed for children with CP and their family around important transition periods.
- A keyworker-system should be introduced to ensure that families have at least one person from the service provider that remains constant in their lives. The keyworker is both a source of support for the families of children with disabilities and a conduit by which other services are accessed and used effectively (Limbrick-Spencer, 2001). The role of the keyworker for children with CP should be to ensure that goals identified during Individual Planning (IP) meetings are followed through, linking with all the team members and

familiarising themselves with the family situation to know when is a good time for intervention.

- Children's holistic needs should be addressed during Individual Education Planning (IEP) meetings. This includes their medical and mental health as well as their parents' mental health needs, and sibling concerns about disability issues. The child's needs cannot be separated from the family process and functioning, and relationships within the family have an interactive effect with each other (Dale, 1996).
- Parents, professionals and team members should be notified well in advance about upcoming case conferences.

Recommendations to Enhance the Role Parents Play during Service Delivery:

- A child-minding facility for siblings of the special needs child should be provided at service providers to ensure parents have the opportunity to participate in IEP meetings and therapy sessions.
- Parents should be central to the IEP process and it may be useful to have a section in the IEP about the families' coping strategies and mental health needs, if necessary.
- Parents should be part of the decision-making, goal-setting process and Speech-Language Therapists should endeavour to support parents by providing them with adequate time, information, and knowledge to make informed decisions.

Recommendations for Improving Support to Families:

- Parent-to-parent gatherings should be established in the form of a support group for parents with children with CP in the ROI. The aim of these gatherings will be to provide emotional and informational support for the whole family.
- The support group should also aim to provide parents with information about different issues related to CP, as well as provide an opportunity for the whole family to access information.
- The support group should endeavour to set up links between families or to provide new families with a contact person to link in with. It may be useful to establish support networks in each region.
- Support groups should also focus on family-to-family gatherings and fun days out to help raise awareness of cerebral palsy in Irish society and the community.
- A counselling service for family members at service providers for children with CP is vital. Throughout focus group discussions and from feedback on the questionnaires, parents stressed the importance of having their emotional needs addressed. A counsellor in the form of a counselling psychologist could help families explore and cope with the impact of having a child with CP.
- Sibling workshops or Sibshops are a great way for siblings to meet other siblings with a brother / sister with CP and can help them cope with having a sibling with special needs.

- There should be coordination between the staff in service providers working with children with CP to ensure that appointments are well spaced out so not to overwhelm parents.

Recommendations to Improve Speech-Language Therapy Service Delivery:

- Parents need to be empowered by their Speech-Language Therapist. This includes providing parents with general and specific information about SLT issues, taking time to explain treatment options and SLT services available in order for parents and Speech-Language Therapists to have consensus when setting goals and making decisions about what aspects of SLT should be addressed. When parents know why and how services are delivered, they should be more conscientious in following through on home programmes.
- The lack of consistency in care pathways and standards in SLT gives Speech-Language Therapists considerable autonomy when providing a service to children with CP. Protocols or guidelines in SLT service delivery for children with CP are necessary for quality control, and continuity of services across the various service providers.
- Parents value the services they receive from Speech-Language Therapists and in order to increase the time that Speech-Language Therapists can devote to working with children with CP, Speech-Language Therapy Assistants should be employed to help reduce the workload of Speech-Language Therapists, especially around AAC programming, making up resources and administrative duties.

- The IASLT should establish a Special Interest Group (SIG) for therapists working with children with physical disabilities to link with each other, and share resources e.g. AAC devices, and therapy ideas.
- Managers of service providers should liaise with Speech-Language Therapists and parent councils in the organisation to help with the prioritisation and distribution of sufficient funding for resources and equipment.
- Parents should receive written reports outlining results and recommendations for intervention from all speech and language assessments. Speech-Language Therapists should meet with parents to explain these reports.
- Parents should be informed in writing of their child's progress during therapy as well as the aim of intervention and goals being targeted.
- Speech-Language Therapists should recommend therapy programmes that fit with families' lifestyles. This includes home visits, giving families a choice about morning, afternoon, or evening appointments, and giving parents at least 8 weeks notice for upcoming therapy sessions.
- Speech-Language Therapists should provide opportunities to meet parents to share resources and discuss appropriate resources.
- Speech-Language Therapists should provide more general training within the school environment to highlight the role and methods of SLT service delivery to children with CP. It has to be stressed to educational staff that intervention should be needs-based and that the level of input should match the child's needs.

5.3 Research Implications

Several areas for further research have been identified as a result of this study. These areas include:

- An investigation of the benefits of intensive speech and language intervention in comparison to blocks of SLT for children with CP.
- Research into the impact of adherence to different approaches to service delivery on the role of the Speech-Language Therapist. These approaches include working as part of a muti-, inter- and/or transdisciplinary team.
- To evaluate the comparative perceptions of fathers and mothers of children with CP on the nature and quality of SLT service delivery for their children.
- To investigate the application of counselling skills by Speech-Language Therapists working with children with CP and similar disabilities.

Through this study, the research question was answered and the outcome of the investigation resulted in an understanding of parents' and Speech-Language Therapists' perceptions of SLT service delivery to children with CP in the ROI. Gaps in service provision for children with CP were identified, and recommendations were made to relevant stakeholders regarding the service delivery needs highlighted in the study. It is hoped that these recommendations, if implemented, will contribute to the quality of life of children with CP and their families.

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APPENDIX A

Measure of Processes of Care (MPOC) - questionnaire

We would like to understand and measure the experiences of parents who have a child with a disability. In particular we wish to know about your perceptions of the care your child has been receiving over the past year from the Treatment Centre.

The questions in this section are based on what parents, like yourself, have told us about the way care is sometimes offered. We would like you to indicate how much the event or situation happens (or doesn't happen) to you at your treatment centre. You are asked to answer each question on a scale from 7 (To a Very Great Extent) to 1 (Not at All) by selecting only one of the options for each question.

The care that you and your child receive from the Centre may bring you into contact with many individuals. The questions on this form are grouped by who these contacts are, as described below.

1. **PEOPLE**: refers to those individuals who work directly with you or your child. For the purposes of the questionnaire it refers to your child's **Speech-Language Therapist**.

2. **ORGANISATION / SERVICE PROVIDER**: refers to **all staff** from the centre, whether involved directly with your child or not. In addition to health care people (occupational therapists, psychologists, doctors, nurses, social workers, etc.) they may include support staff such as office staff, training staff, administrative personnel, etc.

The following is an example of the kinds of questions you will be asked. This example also shows what your answer could mean.

Indicate how much each event or situation happens to you.

TO WHAT EXTENT DO THE PEOPLE WHO GIVE YOU QUESTIONNAIRES ….	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Exten	To a Very Small Extent	Not at All	Not Applicable
… provide you with clear instructions on how to complete them?	7	6	5	4	3	2	1	0

If you circled #7 (To a Very Great Extent), it means that the people who give you questionnaires provide very clear instructions in what they ask you to do.

If you circled #4 (To a Moderate Extent), it means that the people who give you questionnaires are clear in what they want you to do some of the time, and some of the time the instruction are not clear.

If you circled #1 (Not at All), it means that although you have received questionnaires, the instructions are never clear.

If you circled #0 (Not Applicable), it means that you have never received a questionnaire and so you cannot answer the question. It does not apply to you.

We would like you to think about your experiences over the past year at your child's Centre. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own without discussing it with anyone.

For each question, please indicate <u>how much</u> the event or situation happens to you by circling **one** number (from 1 to 7) that you feel best fits your experience. There is also space under each question for you to make further comments if you wish to.

IN THE PAST YEAR **Indicate <u>how much</u> each event or situation happens to you.**

To what extent do the Speech-Language Therapists who work with your child…	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1. Suggest Speech-Language therapy plans that fit with your family's needs and lifestyle?	7	6	5	4	3	2	1	0

Please discuss

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2. Fully explain Speech-Language treatment choices to you?	7	6	5	4	3	2	1	0

Please discuss

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3. Offer you positive feedback or encouragement (e.g., in carrying out a home program)?	7	6	5	4	3	2	1	0

Please discuss

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4. Explain things to your child in a way that your child understands? (If he/she is old enough)	7	6	5	4	3	2	1	0

Please discuss

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5. Take the time to establish rapport with you or your child when changes occur in your services?	7	6	5	4	3	2	1	0

Please discuss

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6. Discuss with you everyone's (other team members) expectations for your child, so that all agree on what is best?	7	6	5	4	3	2	1	0

Please discuss

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7. Make sure that your child's skills are known to all persons (e.g. occupational therapists, physiotherapists, psychologists, etc.) working with your child, so the skills are carried across services and services providers?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate <u>how much</u> each event or situation happens to you.**

To what extent do the Speech-Language Therapists who work with your child…	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
8. Tell you about options for treatment or services for your child (e.g., equipment (communication devices), school-programmes, different types of therapy)?	7	6	5	4	3	2	1	0
Please discuss …………………………………… …………………………………… ……………………………………								
9. Accept you and your family in a non-judgemental way?	7	6	5	4	3	2	1	0
Please discuss …………………………………… …………………………………… ……………………………………								
10. Provide ideas to help you work with the health care "system"?	7	6	5	4	3	2	1	0
Please discuss …………………………………… …………………………………… ……………………………………								
11. Recognize the demands of caring for a child with special needs?	7	6	5	4	3	2	1	0
Please discuss …………………………………… …………………………………… ……………………………………								
12. Trust you as the "expert" on your child?	7	6	5	4	3	2	1	0

Please discuss

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13. Look at the needs of your "whole" child (e.g. at mental, emotional, and social needs) instead of just at physical needs?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate how much each event or situation happens to you.**

To what extent do the Speech-Language Therapists who work with your child …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
14. Show sensitivity to your family's feelings about having a child with special needs (e.g., your worries about your child's health or function)?	7	6	5	4	3	2	1	0

Please discuss

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15. Anticipate your concerns by offering information even before you ask?	7	6	5	4	3	2	1	0

Please discuss

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16. Make sure you have a chance during visits to the centre to say what is important to you?	7	6	5	4	3	2	1	0

Please discuss

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17. Let you choose when to receive information and the type of information you want?	7	6	5	4	3	2	1	0

Please discuss

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18. Remember personal details about your child or family when speaking with you?	7	6	5	4	3	2	1	0

Please discuss

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19. Tell you about the reasons for Speech-Language Therapy treatment equipment?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate how much each event or situation happens to you.**

To what extent do the Speech-Language Therapists who work with your child …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Exten	To a Very Small Extent	Not at All	Not Applicable
20. Follow up at the next appointment on any concerns you discussed at the previous one?	7	6	5	4	3	2	1	0

Please discuss

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21. Make sure that at least one team member is someone who works with you and your family over a long period of time?	7	6	5	4	3	2	1	0

Please discuss

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22. Provide opportunities for you to make decisions about Speech-Language treatment?	7	6	5	4	3	2	1	0

Please discuss

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23. Answer your questions completely?	7	6	5	4	3	2	1	0

Please discuss

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24. Explain what they are doing when you are watching your child in Speech-Language Therapy?	7	6	5	4	3	2	1	0

Please discuss

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25. Recognize that your family has the final say when making decisions about your child's Speech-Language treatment?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate how much each event or situation happens to you.**

To what extent do the Speech-Language Therapists who work with your child …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
26. Tell you about the results from Speech-Language assessments / evaluations.	7	6	5	4	3	2	1	0

Please discuss

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27. Provide you with written information about what your child is doing in Speech-Language therapy?	7	6	5	4	3	2	1	0

Please discuss

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28. Consult with you when discussing equipment (like communication devices) or services?	7	6	5	4	3	2	1	0

Please discuss

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29. Provide a caring atmosphere rather than just give you information?	7	6	5	4	3	2	1	0

Please discuss

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30. Tell you details about your child's services, such as the reasons for them, the type of therapies and the length of time?	7	6	5	4	3	2	1	0

Please discuss

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31. Treat you as an individual rather than as a "typical" parent of a child with a disability?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate how much each event or situation happens to you.**

To what extent do the Speech-Language Therapists who work with your child …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
32. Develop both short-term and long-term Speech-Language goals for your child?	7	6	5	4	3	2	1	0

Please discuss

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33. Treat you as an equal rather than just a the parent of a patient (e.g., by NOT referring to you as "Mom" or "Dad"?)	7	6	5	4	3	2	1	0

Please discuss

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34. Plan together so they are all working in the same direction?	7	6	5	4	3	2	1	0

Please discuss

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35. Make sure you have opportunities to explain what you think are important treatment goals?	7	6	5	4	3	2	1	0

Please discuss

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36. Make you feel like a partner in your child's care?	7	6	5	4	3	2	1	0

Please discuss

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37. Make sure you are informed ahead of time about any changes in your child's care (e.g., therapists, programs, equipment)?	7	6	5	4	3	2	1	0

Please discuss

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38. Help you feel competent as a parent?	7	6	5	4	3	2	1	0

Please discuss

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39. Provide you with written Information about your child's progress in Speech-Language Therapy?	7	6	5	4	3	2	1	0

Please discuss

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40. Seem aware of your child's changing needs as he/she grows?	7	6	5	4	3	2	1	0

Please discuss
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41. Provide enough time to talk so you don't feel rushed?	7	6	5	4	3	2	1	0

Please discuss
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42. Treat you and your family as people <u>rather</u> than as a "case" (e.g., by not referring to you by diagnosis, such as "the spastic diplegic")	7	6	5	4	3	2	1	0

Please discuss
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43. Listen to what you have to say about your child's needs for equipment, input, services, etc.?	7	6	5	4	3	2	1	0

Please discuss
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44. Make themselves available to you as a resource (e.g., emotional support, advocacy, information)?	7	6	5	4	3	2	1	0

Please discuss
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45. Give you information about your child that is consistent from person to person?	7	6	5	4	3	2	1	0

Please discuss
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IN THE PAST YEAR **Indicate how much each event or situation happens to you.**

To what extent did organisation / service provider who work with your child…	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
46. Have information available to you in various forms, such as a booklet, kit, video, etc.?	7	6	5	4	3	2	1	0

Please discuss

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47. Have support staff that are polite and courteous to you and your family?	7	6	5	4	3	2	1	0

Please discuss

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48. Give you information about the types of services offered at the organisation / service provider or in your community?	7	6	5	4	3	2	1	0

Please discuss

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49. Promote family-to-family gatherings for social, informational or shared experiences?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate how much each event or situation happens to you.**

To what extent did the organisation / service provider who work with your child …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
50. Provide opportunities for special guests to speak to parents on topics of interest?	7	6	5	4	3	2	1	0

Please discuss

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51. Provide support to help cope with the impact of childhood disability (e.g., by advocating on your behalf or informing you of assistance programs)?	7	6	5	4	3	2	1	0

Please discuss

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52. Notify you about the reasons for upcoming case conferences, meetings, etc. about your child?	7	6	5	4	3	2	1	0

Please discuss

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53. Have information available about your child's disability (e.g., its causes, how it progresses, future outlook?	7	6	5	4	3	2	1	0

Please discuss

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54. Provide advice on how to get information or to contact other parents (e.g., parent resource library)?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR **Indicate <u>how much</u> each event or situation happens to you.**

To what extent did the organisation / service provider who work with your child ...	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
55. Provide opportunities for the entire family to obtain information?	7	6	5	4	3	2	1	0

Please discuss

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56. Have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, dating and sexuality)?	7	6	5	4	3	2	1	0

Please discuss

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APPENDIX B

Measure of Processes of Care – Service Providers (MPOC-SP)

We would like to understand and measure the actual experiences and behaviours of service providers who work with children with long-term health or developmental problems and their families. In particular, we wish to know about **your** perceptions of the service you have been providing over the past year. The term "service provider" includes clinicians, therapists, social workers, early childhood educators, resource teachers, nurses, etc.

These questions are based on what parents have told us about the way services are sometimes offered to their families. Specifically, each question asks you to indicate to what extent you actually do each of the behaviours described, on a scale from 1 (Not at All) to 7 (To a Very Great Extent). Please note that the zero value (0) is used only if the situation described does not apply to you.

For each question, we would like you to think about **the degree to which you displayed each of the behaviours** described in this questionnaire. The rating you select should NOT represent the frequency with which you engaged in each particular behaviour, but rather your level of involvement and investment in practicing it.

The services that you provide may bring you into contact with many individuals within a family. We have provided a list of who those family members may be.

CHILD: refers to the child with long-term health problem (e.g., cystic fibrosis or diabetes) or developmental problem (e.g., cerebral palsy).

PARENTS: refers to the parents or legal guardians of the child with long-term health or developmental problem.

FAMILY: generally refers to the child with a long-term health or development problem and his/her parents. Family may also include siblings, grandparents, etc.

IMPORTANT INSTRUCTIONS:

1. We would like you to describe your **"actual"** behaviour, rather than what you feel would be "ideal" service. We recognize that professionals may be unable to display behaviour to the extent they might wish, due to caseload size, policies, and other constraining factors. Please be assured that your **confidential** responses will not be viewed as a judgement of you or how you provide services.

2. Please recognize that just because a behaviour is addressed by this measure it DOES NOT mean that it is necessarily an important behaviour for all professions or to all

professionals. Thus, do not feel that selecting a low number is equivalent to giving yourself a poor evaluation.

3. We would like you to think about **<u>your experiences</u>** as a service provider with children with long-term health or developmental problems, and their families, **<u>over the past year</u>**. We are interested in your personal thoughts and would appreciate your completing this questionnaire on your own **without discussing it with anyone.**

IN THE PAST YEAR, TO WHAT EXTENT DID YOU …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
1. .. suggest treatment/ management activities that fit with each family's needs and lifestyle?	7	6	5	4	3	2	1	0

Please discuss

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2… offer parents and children positive feedback or encouragement (e.g., in carrying out a home programme)?	7	6	5	4	3	2	1	0

Please discuss

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3… take the time to establish rapport with parents and children?	7	6	5	4	3	2	1	0

Please discuss

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4… discuss expectations for each child with other service providers, to ensure consistency of thought and action?	7	6	5	4	3	2	1	0

Please discuss

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5… Tell parents about options for servic or treatments for their child (e.g., equipment, school, therapy?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR, TO WHAT EXTENT DID YOU …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
6… Accept parents and their family in a non- judgemental way?	7	6	5	4	3	2	1	0

Please discuss

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7… trust parents as the “experts” on their child?	7	6	5	4	3	2	1	0

Please discuss

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8… discuss/explore each family’s feelings about having a child with special needs (e.g., their worries about their child’s health function)?	7	6	5	4	3	2	1	0

Please discuss

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9… anticipate parents' concerns by offering information even before they ask?	7	6	5	4	3	2	1	0

Please discuss

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10.. make sure parents had a chance to sa what was important to them?	7	6	5	4	3	2	1	0

Please discuss

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11. let parents choose when to receive information and type of information they wanted?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR, TO WHAT EXTENT DID YOU …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Exten	To a Very Small Extent	Not at All	Not Applicable
12… help each family to secure a stable relationship with at least one service provider who works with the child and parents over a long period of time?	7	6	5	4	3	2	1	0

Please discuss

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13.. answer parents' questions completely?	7	6	5	4	3	2	1	0

Please discuss

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14.. tell parents about the results from tests and/or assessments?	7	6	5	4	3	2	1	0

Please discuss

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15.. provide parents with written information about their child's condition, progress, or treatment?	7	6	5	4	3	2	1	0

Please discuss

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16.. tell parents details about their child's services, such as the types, reasons for, and durations of treatment/ management?	7	6	5	4	3	2	1	0

Please discuss

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17. treat each parent as an individual rathe than as a "typical" parent of a child with a "problem"?	7	6	5	4	3	2	1	0

Please discuss

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IN THE PAST YEAR, TO WHAT EXTENT DID YOU …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
18. treat parents as equals rather than just as the parent of a patient (e.g., by not referring to them as "Mom" or "Dad")?	7	6	5	4	3	2	1	0
Please discuss …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………								
19.. make sure parents had opportunities t explain their treatment goals and nee (e.g., for services or equipment)	7	6	5	4	3	2	1	0
Please discuss …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………								
20.. help parents feel like a partner in their child's care?	7	6	5	4	3	2	1	0
Please discuss …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………								
21.. help parents to feel competent in their roles as parents?	7	6	5	4	3	2	1	0
Please discuss …………………………………………………………………………… …………………………………………………………………………… ……………………………………………………………………………								
22.. treat children and their families as people rather than as a "case" (e.g., by not referring to the child and families by diagnosis, such as "the spastic diplegic")	7	6	5	4	3	2	1	0

Please discuss
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

The next set of questions ask, "To what extent did you (or your organisation)…" By "organisation" we mean the facility or agency from or through which you provide services. "Organisation" could therefore refer to a Children's Treatment/Rehabilitation Centre, A Community Care Access Centre, a School Health Support Services programme, Home Care, Community and Social Services, Clinic Programme, Mental Health Service, etc. If you do not work at an "organisation", please answer for your programme, team, or yourself.

IN THE PAST YEAR, TO WHAT EXTENT DID THE ORGANISATION? …	To a very Great Extent	To a Great Extent	To a Fairly Great Extent	To a Moderate Extent	To a Small Extent	To a Very Small Extent	Not at All	Not Applicable
23… promote family-to-family "connections" for social, informational or shared experiences?	7	6	5	4	3	2	1	0

Please discuss
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

24.. provide support to help families cope with the impact of their child's chronic condition (e.g., informing parents of assistance programmes or counselling how to work with other service providers)?	7	6	5	4	3	2	1	0

Please discuss
…………………………………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

25.. provide advice on how to get information or to contact other parents (e.g., through a community's resource library, support groups, or t Internet)?	7	6	5	4	3	2	1	0

Please discuss

....

....

....

26…provide opportunities for the entire family, including siblings, to obtain information?	7	6	5	4	3	2	1	0

Please discuss

....

....

....

27.. have general information available about different concerns (e.g., financial costs or assistance, genetic counselling, respite care, dating and sexuality)?	7	6	5	4	3	2	1	0

Please discuss

....

....

....

APPENDIX C

Background Information Questionnaire

Please circle the information that best describes your child.

Age:

(a) 0-3 years of age (early intervention years)
(b) 3-6 (or all preschool children)
(c) 6-12 years (or all primary school children)
(d) 12-18 years (or all secondary school children up to the school leavers).

Sex:

(a) male
(b) female

Type of Cerebral Palsy:

(a) spastic: (i) hemiplegia (ii) diplegia (iii) quadraplegia
(b) dyskinetic: (i) athetosis (ii) dystonia
(c) ataxic

Other Diagnoses:

(a) epilepsy / seizures: (i) controlled (ii) uncontrolled
(b) hydrocephalus
(c) sensory impairments: (i) hearing (ii) vision
(d) other

Behavioural Difficulties:

(a) yes: (i) hyperactivity (ii) decreased attention span (iii) emotional lability (iv) other
(b) no

Feeding History:

(a) recurrent chest infections

(b) pneumonia

(c) aspiration

(d) dysphagia (any eating, drinking or swallowing difficulties as diagnosed by Speech-Language Therapist)

(e) diet modifications (i.e. thickened fluids, liquidised food)

(f) oral motor difficulties (i.e. chewing, tongue function)

(g) nutritional difficulties (i.e. failure to thrive, allergies)

(h) drooling

Mobility:

(a) mobile (i.e. walking independently)

(b) limited mobility (i.e. walker, crutches)

(c) not mobile (i.e. wheelchair bound)

Orthopaedic complications:

(a) yes: (i) scoliosis (ii) hip dislocations (iii) muscle contractures (iv) osteoarthritis (v) pressure sores (vi) seating problems (v) other

(b) no

Bowel control:

(a) yes

(b) no

Bladder control:

(a) yes

(b) no

Level of Intellectual Disability (ID):

(a) average learning ability (IQ = 90-110)
(b) low average learning ability (IQ = 80 – 89)
(c) borderline – mild general intellectual disability (IQ = 70 –79)
(d) mild ID (IQ = 50 - 69)
(e) moderate ID (IQ = 35 – 49)
(f) severe ID (IQ = 20 - 34)
(g) profound ID (IQ under 20, including physical and sensory components)

Reference: ICD 10

Communication:

(a) verbal
(b) not verbal
(c) limited (less than 50 words for children older than 3 years of age)
(d) communication device
(e) sign language
(f) dysarthria (motor speech disorder, as diagnosed by Speech-Language Therapist)
(g) dyspraxia (motor speech disorder, as diagnosed by Speech-Language Therapist)
(h) other

APPENDIX D

Focus Group Questions for Parents

1. What do you understand to be the scope of Speech-Language Therapy with children with CP?

2. Parent Involvement - What is your role as parent in the following:

(a) Decision-making

e.g. Decision-making in *setting goals*

e.g. Deciding what *aspects of Speech-Language Therapy* (speech, language, communication and/or feeding) are targeted during intervention.

(b) Therapy

e.g. Where therapy takes place (in the clinic, in the classroom, at home)

e.g. Type of intervention your child receives (direct or indirect therapy (i.e. programmes / guidelines / training), on their own, in groups, multi-disciplinary input etc.)

e.g. Frequency and intensity of intervention (daily, weekly, monthly, 6-monthly / continuous input, blocks, etc.)

(c) Providing information (general comments)

e.g. Feedback on Speech-Language Therapy home programmes, AAC devices, therapy

(d) Receiving information (general comments)

e.g. How you are informed about your child's progress during/after therapy (*i.e.* reports).

3. Accessible, Approachable and Available Care – What are your perceptions of the care/services/equipment your child has been receiving from…

(a) your Speech-Language Therapist

(b) your Service Provider / Organisation

4. What are your perceptions as parents of the continuity and consistency of care your child receives (e.g. continuity across appointments/time/settings; therapist's expertise/preparation).

5. What are your perceptions of the coordination of care your child receives (e.g. comprehensive/holistic plan; communication among professionals / contact person or case manager).

6. Family-centred approach to care – What is your perception of therapist's awareness of the impact of ...... on the family.

(a) having a child with a disability
(b) treatment programmes
(c) your emotional / informational needs.

7. Aspirations for ideal service delivery from …

(a) parents

(b) your Healthcare and Educational Organisations

(c) national policies for children with CP.

APPENDIX E

Focus Group Questions for Speech-Language Therapists

A. Models of Service Delivery

1. Describe the model of service delivery that your Organisation follows (*i.e.* family-centred *vs.* child-centred; social model *vs.* impairment based model).

2. Describe your knowledge of the Organisation's official policies and procedures (with special reference to its mission statement, core values and strategic plan).

B. Speech-Language Interventions for Children with CP

1. Describe your caseload (*i.e.* subject characteristics, numbers, severity levels).

2. How would you prioritise your caseload?

3. What aspects of Speech-Language Therapy do you address?

____

____

____

4. Describe the type of service delivery provided *(i.e.* direct or indirect therapy, joint team approaches).

____

____

____

5. Describe the context in which intervention takes place (*i.e.* setting, location, frequency, intensity).

____

____

____

6. Describe how progress is measured (*i.e.* outcome measures).

____

____

____

7. Describe the role that the parent / carer play in your Speech-Language Therapy input.

____

____

____

8. Describe how you support parents with children with disabilities. (e.g. providing information, information sharing, giving feedback, advocacy).

____

____

____

____

C. Perceptions of Speech-Language Service Delivery to Children with CP

1. Describe your perceptions, as a Speech-Language Therapist, of the service you provide to children with CP.

____

____

____

2. Describe your aspirations for ideal service delivery from (a) other Speech-Language Therapists (b) Healthcare and Educational Organisations (c) national policies for children with CP.

____

____

____

APPENDIX F

Organisational Principles for Healthcare Providers / Hospitals / Organisations (Council, 2000)

Organising Principles reflect best and promising practice for organisations committed to supporting outcomes for families and children served. The Organising Principles bring together action strategies related to leadership, systems development and quality management and planning (Council, 2000).

1) Leadership

- The organisation defines its primary customer.
- People served exercise leadership through choice and self-determination.
- The organisation emphasizes the values of listening, responsiveness respect and support for the desired outcomes.
- The organisation links service users and providers to promote individual relationships and increase system capacity.
- The organisation clearly defines expectations from staff competency and performance.
- The organisation has strategy for developing relationships with other agencies/providers in its service area.

2) Systems

- The organisation has a clear statement of its mission.
- The organisation implements a strategy for listening to and learning about each family and child.
- The organisation promotes coordinated systems of services that are responsive to the needs and desires of families.

- The organisation provides service users and other organisations with relevant information.
- The organisation has a strategy for hiring nurturing and sustaining staff.
- The organisation provides opportunities for staff training and personal development.
- Organisational systems promote dignity and respect.
- Organisational systems promote continuity and security.

3) Quality Management and Planning

- The organisation has a process for eliciting and analyzing feedback on services and supports from service users, employees and providers.

4) Practice Guidance

- Family-Centeredness
- Child Assessment
- Service Coordination
- Family concerns, priorities and resources
- Advocacy

APPENDIX G

Information Sheet for Parents

A study that aims to investigate:
Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland

A child with Cerebral Palsy can have delays and/or difficulties in speech, language and communication. The young child with Cerebral Palsy frequently grows up understanding more than he/she is able to express through speech or actions as a result of their difficulties with movement and coordination. Up to 20% of children with Cerebral Palsy have no speech and up to 70% have difficulties with eating and drinking. Speech-Language Therapists play an important role in addressing all the potential problems that a child with CP can experience and this study is aimed at investigating how parents feel about the quality of the service their child is receiving.

Why this study?

The aim of the study is to examine the perceptions of parents on Speech-Language service delivery for children with Cerebral Palsy. This will be done in two ways: Firstly through questionnaires that parents complete on their own; and secondly through group discussion involving parents who agree to participate in such a discussion.

What does the study involve?

You will have the option to be included in the study if your child (a) has been diagnosed with Cerebral Palsy; (b) is aged between 0-18 years, and (c) attending an Irish Healthcare / Educational Organisation or Hospital for services. Parents of the children fulfilling this criterion will be invited to participate in the study.

Once you have agreed to participate, you will be requested to complete a questionnaire called the Measure of Processes of Care (MPOC). The questionnaire typically takes between 15-20 minutes to complete.

You will also be requested to complete a Background Information Questionnaire of your child that will include details of medical diagnoses, associated conditions, and feeding and communication history.

Further to the study, you will be invited to participate in a Focus Group discussion. A Focus Group is a small group of parents (usually 6 or 8) who interact with each other and a group leader through an in-depth discussion on a few topics related to Speech-Language service delivery. If you agree to participate in these Focus Groups, your name will be placed on a list from which only 18 parents will be randomly selected to form these Focus Groups. This is due to the fact that a large number of parents will be participating in the study and it will be impractical to include everyone in a focus group. Every effort will be made to ensure that the focus group is fairly represented.

Do I have to take part?

Participation in this study is voluntary. It is up to you to decide if you would like to take part. If you do decide to participate, you will be asked to sign a consent form (see over). If you do decide to take part now, but change your mind later, you are free to withdraw from the study without giving any reason at any time. If you decide not to participate or withdraw from the study this will not affect the services your child receives now or in the future as your Organisation will not know whether you participate in the study or not. It also does not affect your or your child's participation in other research now or in the future.

What about confidentiality?

All the information collected as part of this study, will be kept confidentially. The information will be stored in a locked filing cabinet at St Michael's House, North Region, Dublin where the researcher is employed and to which only the researcher has access. Individuals will not be named or identified in any reports or publications produced. Names and addresses of those who consented (see over) will only be retained so that the researcher can send you a copy of the written summary documenting the findings of the study.

How do I take part?

If you would like to participate in the above-mentioned research study, please complete the enclosed consent form and questionnaires and return it in the stamped addressed envelope as soon as possible but before _________. If you would like to talk to the researcher first to get more information, please contact Marinet Van at the following number (after 4.30pm): 087 7620 458.

CONSENT FORM FOR PARENTS

Title of Project:

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perspectives of Parents and Speech-Language Therapists

Name of Researcher:

Marinet Janse van Vuren, Senior Speech-Language Therapist, St Michael's House North Region, Dublin.

Please tick each box

1. I have read the information on the above-mentioned study and understand what is required of me ☐

2. I am aware that I have had the opportunity to ask questions about the above-mentioned study whether or not I made use of it. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time. ☐

4. I am aware that my child and I will remain anonymous and that we will not be identified in any way in future publications. ☐

5. I agree to complete the attached questionnaires. ☐

6. I agree to participate in the Focus Group discussions. ☐

7. I would like to be kept informed of the results of the study. ☐

________________	________________	________________
Name of Parent	Signature	Date

APPENDIX H

Information Sheet for Speech-Language Therapists

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perspectives of Parents and Speech-Language Therapists

A child with Cerebral Palsy is at risk for delays or specific impairments of speech, language and communication. The young child with Cerebral Palsy frequently grows up understanding more than he/she is able to express through speech or actions as a result of impairment of motor skills. Up to 20% of children with a diagnosis of Cerebral Palsy have severe communication impairments and are classified as non-verbal.

There appears to be variability between the type of speech and language interventions used for children with Cerebral Palsy. It is thus evident that further research is needed to investigate families' perceptions of the Speech-Language care they receive from Healthcare Organisations in Ireland.

Why this study?

The central aim of the study is to examine the perceptions of Speech-Language service delivery for children with Cerebral Palsy. The objectives are as follow:

1. To evaluate the responses of Speech-Language Therapists to questionnaires regarding the nature and quality of service delivery to children with Cerebral Palsy.
2. To evaluate the responses of Speech-Language Therapists obtained during focus group interviews regarding the quality and nature of service delivery to children with Cerebral Palsy.
3. To provide an overview of the Speech-Language Therapy interventions currently being used by therapists in Ireland.
4. To provide an overview of the models of service delivery Speech-Language Therapists follow.

What does the study involve?

One of the samples will comprise of Speech-Language Therapists working in Ireland with children with CP. The rationale for including Speech-Language Therapists in the research study is to gain insight into the various Speech-Language interventions currently being used when providing a service to children with CP, as well as to investigate the therapists' perceptions of the Speech-Language care they provide to families with children with CP.

Once you, as Speech-Language Therapists, have consented to participate, you will be requested to complete a questionnaire called the Measure of Processes of Care for Service Providers (MPOC-SP). This is a well-validated and reliable self-assessment questionnaire for paediatric service providers, designed to investigate their implementation of different models of service delivery for children with chronic health or developmental problems and their families. The questionnaire typically takes between 10-15 minutes to complete.

You will also be invited to participate in a Focus Group discussion. A Focus Group is a small group of people (usually 6 or 8) who interacts with each other and a group leader while discussing in-depth a few topics related to Speech-Language service delivery. Approximately twelve open-ended questions will be discussed.

Do I have to take part?

Participation in this study is voluntary. It is up to you to decide if you would like to take part. If you do decide to take part you will be asked to sign a consent sheet (see over). If you do decide to participate now, but change your mind later, you are free to withdraw from the study without giving any reason at any time.

What will happen to the results of the study?

The findings of the study will provide insight into Speech-Language Therapists' perceptions of the nature and quality of service delivery for children with Cerebral Palsy. It will also help to provide an overview of the different Speech-Language interventions employed by Speech-Language Therapists in Ireland.

What about confidentiality?

All the information collected as part of this study will be kept confidentially. The information will be locked and stored at St Michael's House, North Region, Dublin where the researcher is employed. Individuals will not be named or identified in any reports or publications produced. Names and addresses of those who consented (see over) will only be retained so that the researcher can send you a copy of the written summary documenting the findings of the study.

How do I take part?

If you would like to participate in the above-mentioned research study, please complete the consent form and questionnaire and return it in the stamped addressed envelope as soon as possible before __________. If you would like to talk to the researcher first to find out more information, please contact Marinet Van at the following number (after 4.30pm): 087 7620 458.

CONSENT FORM FOR THERAPISTS

Title of Project:

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perceptions of Parents and Speech-Language Therapists.

Name of Researcher:

Marinet Janse van Vuren, Senior Speech-Language Therapist, St Michael's House North Region, Dublin.

Please tick each box

1. I confirm that I have read and understood the information sheet dated ________ for the above-mentioned study. ☐

2. I confirm that I have had the opportunity to ask questions about the above-mentioned study. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and that I or my Organisation will not be identified in any way in future publicatio ☐

4. I would like to be kept informed of the results of the study. ☐

5. I agree to participate in the above-mentioned study by completing the MPOC-SP – questionnaire. ☐

6. I agree to participate in the Focus Group discussions. ☐

7. I am an IASLT member. ☐

____________________	____________________	____________________
Name of Therapist	**Signature**	**Date**

APPENDIX I

Information Sheet for Health / Education Service Providers

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perceptions of parents and Speech-Language Therapists

A child with Cerebral Palsy is at risk for delays or specific impairments of speech, language and communication. The young child with Cerebral Palsy frequently grows up understanding more than he/she is able to express through speech or actions as a result of impairment of motor skills. Up to 20% of children with a diagnosis of Cerebral Palsy have severe communication impairments and are classified as non-verbal. The aim of Speech-Language intervention for children with Cerebral Palsy is to maximise their ability to communicate, through speech, gesture and/or supplementary means such as communication aids, to enable them to become independent communicators.

Unfortunately, a chronic shortage of Speech-Language Therapists exists in Ireland. There are approximately 300 full-time Speech-Language Therapists in the country with currently 30,000 people including children waiting for Speech and Language Therapy. In 2004, the National Physical and Sensory Disability Database (NPSDD) stated the Speech-Language Therapy was the most common therapeutic service for people to be wait-listed. The NPSDD also revealed that of the 19,677 people on their database, only 3,320 are currently receiving Speech-Language Therapy.

Furthermore, there also appears to be variability between the type of speech and language interventions used for children with Cerebral Palsy. It is thus evident that further research is needed to investigate families' perceptions of the Speech-Language care they receive from Healthcare Organisations in Ireland.

Why this study?

The central aim of the study is to examine the perceptions of Speech-Language service delivery for children with Cerebral Palsy. The objectives are as follow:

1. To evaluate parents' and therapists' perceptions regarding the nature and quality of SLT service delivery to children with CP.
2. To measure the degree of concordance between parents' and Speech-Language Therapists' perceptions of SLT service delivery.
3. To investigate how these perceptions compare with Healthcare Organisations' official policies.

What does the study involve?

Healthcare and Educational Organisations, Health Boards and Hospitals will be selected from the Irish Association of Speech-Language Therapists directory (2003, 2005) and Health and Educational Services Directory. Managers / Directors of the respective organisations will be requested to furnish any published documentation, policies, procedures and/or guidelines relating to service delivery to children with a Physical Disability (i.e. Cerebral Palsy) in addition to any documentation pertaining to Speech-Language Therapy service delivery.

Documents will be analysed according to various Organizing Principles (Council, 2000). Organisational Principles are the basic organisational action strategies that facilitate outcomes for families receiving services and supports. The Organisational Principles will include the following best and promising practice from Organisations delivering services based on an outcomes approach (Council, 2000):

- Leadership
- Systems
- Quality Management and Planning
- Practice Guidance

Data will consist of qualitative information by inducing themes and organising principles that 'naturally' underlie the material.

Do I have to take part?

Participation in this study is voluntary. It is up to you to decide if you would like to take part. If you do decide to participate you will be asked to sign a consent sheet on behalf of the organisation (see over). If you do decide to take part now, but change your mind later, you are free to withdraw from the study without giving any reason at any time.

What will happen to the results of the study?

The findings of the study will provide insight into parents' and Speech-Language Therapists' perceptions of the nature and quality of service delivery for children with Cerebral Palsy. It will also help to provide an overview of the different Speech-Language interventions employed by Speech-Language Therapists in Ireland.

What about confidentiality?

All the information collected as part of this study will be kept confidentially. The information will be locked and stored at St Michael's House, North Region, Dublin. Organisations, health care providers or individuals will not be named or identified in any reports or publications produced. Names and addresses of those who consented (see over) will only be retained so that the researcher can send you a copy of the written summary documenting the findings of the study.

How do I take part?

If you would like to participate in the above-mentioned research study, please complete the consent form and send it along with the above-mentioned documents related to (i) Organisational policies, procedures, philosophies, and (ii) Speech-Language service delivery, in the stamped addressed envelope as soon as possible before _________. If you would like to talk to the researcher first to find out more information, please contact Marinet Van at the following number (after 4.30pm): 087 7620 458.

CONSENT FORM FOR SERVICE PROVIDERS

Title of Project:

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perceptions of Parents and Speech-Language Therapists.

Name of Researcher:

Marinet Janse van Vuren, Senior Speech-Language Therapist, St Michael's House North Region, Dublin.

Please tick each box

1. I confirm that I have read and understood the information sheet dated _______ for the above-mentioned study. ☐

2. I confirm that I have had the opportunity to ask questions about the above-mentioned study. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

4. I would like to be kept informed of the results of the study. ☐

5. I agree to furnish any published documentation, policies, procedures and/or guidelines relating to service delivery the above-mentioned client group. ☐

7. I agree to furnish any published documentation, policies, procedures and/or guidelines relating to Speech-Language service delivery. ☐

8. I am aware that the Organisation's name or any staff members mentioned in the documents will not be identified in any way in future publications. ☐

Name of Health and/or Education Service Provider / Organisation / Hospital:

____

____________________	__________________	______________
Name of Manager / Director	**Signature**	**Date**

APPENDIX J

Confidentiality Agreement of Researcher/Moderator

Title of Project:

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perceptions of Parents and Speech-Language Therapists.

Name of Researcher:

Marinet Janse van Vuren, Senior Speech-Language Therapist, St Michael's House North Region, Dublin.

Please tick each box

1. I confirm that the above-mentioned research study is non-maleficient and just to all participants, showing respect for their well-being and autonomy. ☐

2. I confirm that informed consent was sought from all participants prior to their involvement in the study. ☐

3. I confirm that all participants were assured in writing (*i.e.* consent forms) that having freely joined the study they may withdraw at any subsequent stage without repercussions. ☐

4. I confirm that the participants' anonymity will be central to the research study. Any identifying names (Organisations, Health Boards, etc.) will be substituted with codes. ☐

5. I confirm that participants will not be harmed in any way by the research, for example by an identified individual's views becoming public knowledge and that data will be collated in aggregate form and in such a manner that no quotes/information is traceable to any individual. ☐

6. I confirm that when writing up the information for this dissertation as well as eventual publications, the participants' identities will be protected within the presentation of basic demographic data about age, sex, etc, and their responses hidden within collated formats or presented as variations on a theme. ☐

7. I confirm that as moderator, I have more than 3 years experience in working with children with special needs, a post-graduate qualification in Research Methodology, and a good understanding of the ethical considerations of the above-mentioned study. ☐

______________________	______________________	______________________
Name of Researcher	**Signature**	**Date**

APPENDIX K

Confidentiality Agreement of Assistant Moderator

Title of Project:

Speech-Language Therapy Service Delivery for children with Cerebral Palsy in the Republic of Ireland: comparative perceptions of Parents and Speech-Language Therapists.

Name of Researcher:

Marinet Janse van Vuren, Senior Speech-Language Therapist, St Michael's House North Region, Dublin.

Please tick each box

1. I confirm that I have read and understood the information sheets for the research study. ☐

2. I confirm that I have had the opportunity to ask questions about the above-mentioned study. ☐

3. I confirm that the participants' anonymity will be central to the research study. Any identifying names (Organisations, Health Boards, etc.) will be substituted with codes. ☐

4. I confirm that all information will be kept confidential and that I will not discuss the information with anybody other than the rese ☐

Name of Assistant Moderator	Signature	Date