PREFACE

It’s 10.30 am on a typical weekday morning at the Cerebral Palsy (CP) Clinic at Chris Hani Baragwanath Hospital. The year is 1994 – the year democracy finally came to South Africa. Down one side of the therapy room sits a line of 15 mothers on hard wooden benches, their children sleeping on their laps. They have come for their monthly therapy appointments. Their faces are expressionless. They left their homes before sunrise to catch a minibus taxi to the hospital. There they joined hundreds of other mothers who had various appointments that day in Ward 31 (the paediatric out-patient department) to collect their files. Then they walked nearly a kilometre, their children on their backs, to the CP Clinic, where they waited some more. Many came prepared for the long day and had brought nappies and a container of “mielie pap” or traditional porridge for their children.

The therapists arrive – two physiotherapists, two physiotherapy assistants, an occupational therapist and a speech therapist. All of them have already spent the morning treating acutely ill children in the paediatric wards. Apart from the senior therapists, all the therapists rotate through paediatrics (which includes CP Clinic) every three months.

Each therapist takes a child, searches for the child’s therapy records in the disorganized filing system and finds a mat to work on. For most of the mothers, this will be the third or fourth therapist they have seen in as many months, and for most of the therapists, the children will be new to them as they rarely see the same child for two consecutive appointments.

It’s chaos. The children are tired and hungry. They don’t like being handled by people they don’t know and they start crying. The therapists are frustrated. They either don’t know or can’t remember the children from the last time they saw them. They only have 30 minutes with each child and in this time they need to
assess and treat the child and revise the home programme. The therapists and mothers do not share a common language, so communication is difficult. The mothers are tired of having to repeat the same story and history to yet another new face. They also feel despondent – they don’t understand why their children are not getting better.

As the morning wears on, the line of mothers sitting on the benches never seems to shorten. More mothers keep arriving – some are late as they had problems with the public transport or the clerks could not find their files, some are new and are waiting to make an appointment, some are looking for a school for their child and some have come back to therapy after a long absence.

As I survey this scene before me, I can’t help wondering “Are we really achieving anything here? Is our therapy changing anything in the lives of the children, their caregivers, or their families? In this overcrowded and under-resourced public
hospital environment, is this the best way of delivering a rehabilitation therapy service?” Listening to the noise of crying children, seeing the emptiness on the mothers’ faces and sensing the disconnectedness between therapists and caregivers, the answer seems to be an overwhelming NO. In fact, I can’t help wondering whether we might even be doing more harm than good by holding out hope that our meagre therapy services could be effective in such circumstances.

Five years later ……………..

Again it is 10.30am on a typical weekday morning at CP Clinic. A group of twelve mothers sit on padded chairs in a circle, quietly chatting to each other. Their children sit or lie on mats in the middle of the circle. They are awake and making a variety of happy sounds.

Figure 1.2 Five years on - caregivers chatting to one another whilst waiting for therapy

Two therapists, a physiotherapist and a speech therapist, enter the room and greet each mother by name. They pull out a folder containing all the children’s
therapy records. After welcoming the mothers to the group, they go around the circle giving each mother the opportunity to share what has happened and what has changed in her or her child’s life since the group met a month ago. Concerns are raised and the rest of the group joins in the discussion.

The theme for this month is “Communication”. The speech therapist introduces the topic and gives the mothers a small exercise to do. They have to communicate a message to each other without using words. This activity brings about much hilarity. After a short talk on the basics of communication and how to start facilitating better communication with their children, it is time to practice. The two therapists help the mothers to prepare and position their children in adaptive equipment (specialised seating, buggies, standing frames or prone standers) and then each mother finds an activity or a game to play with her child where she can practice face-to-face communication. The two therapists go around the group giving individual attention to each child.

As I survey the scene, I cannot help smiling – no child is crying, the children are actively engaged in the session, all the mothers are full participants and they look so animated – it is difficult to see who is having more fun, the mothers or the children.

As the group session comes to an end, the mothers have tea together whilst the therapists write up the children’s notes. The mothers are discussing whose house they will meet at over the weekend. Each month, between their monthly therapy appointments, they and their children have decided to meet socially at someone’s house. Birthdays are a special celebration and often combined birthday parties are held for two or three of the children.

Again I wonder “Have we achieved anything here? Are we changing anything in the lives of the children or their caregivers? Is this a “better” way of delivering services to children with cerebral palsy and their families?”
I reflect on how the service had changed over the past five years – children are now treated in groups rather than receiving one-on-one individual therapy; the groups meet at the same time on the same day each month (so if mothers miss their appointment, they know when the next one will be); the mothers now have an informal peer support group; two therapists (a transdisciplinary team) work with the same group over a period of at least 12 months so they know the mothers and the children, and the mothers know them; there is more emphasis on working on functional activities and participation and less emphasis on working only on the child’s impairments.

Is this a more effective and a more appropriate service? Is our intervention making a difference? How could we find answers to these questions?

And so this thesis was conceived. A foray into the literature yielded just a handful of studies (Jelsma and Zhanje, 1999; McConachie et al., 2000; Goldbart and Mukherjee, 2001) that had been conducted in similar resource-constrained settings. Much of the research relating to rehabilitation therapy and outcomes for children with cerebral palsy has been conducted in developed countries. There are many studies examining the effectiveness of different types of therapy interventions and a number of tools and scales have been developed to measure outcome, but the impact of these therapies has rarely been explored in settings like ours.

How could information gained from research in developed countries be utilised here in this setting in South Africa? Could outcome measures developed and used elsewhere be used here? And more importantly, what were the parents’ views and experiences of therapy and how did they perceive the services? So I set out on a voyage of discovery. Only, just like Christopher Columbus five hundred years ago, I did not find the destination I thought I would. Rather I stumbled across something else. And so the story which unfolds in these pages
is not the story I set out to tell. It’s another story – a journey of exploration, where I discovered that the territory had to be mapped before I could start digging for the treasure.

Figure 1.3  Therapy is about caregivers enjoying their children