THE IMPACT OF THE *"DEVELOPMENTAL RESOURCE STIMULATION PROGRAMME"* ON CHILDREN WITH DOWN SYNDROME

Submitted by

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DECLARATION

I, DOROTHY CHARMAINE RUSSELL declare that the thesis hereby submitted by me for the PhD Occupational Therapy degree at the University of the Free State is my own independent work and has not been submitted by me to another university/faculty previously. I furthermore cede copyright of this thesis in favour of the University of the Free State. I declare that, to the best of my ability, all sources used and quoted have been carefully acknowledged.

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Dorothy C. Russell

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Date

DEDICATED TO

You were ours for a while as slowly you emerged from your cocoon nurtured by love

But gone from us too soon
We held you gentle in our hands
And watched you test your fragile wings so beautiful to see
Then God called softly from above
"Now let him go for butterflies are free"
(Anonymous)

Late Fred, Thabo, Kaatya and Noluthando

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LIST OF ABBREVIATIONS

BCIC	Bloemfontein Child Information Centre
DRSP	Development Resource Stimulation Programme
DSPI	Developmental Sequence Performance Inventory
DS	Down syndrome
ECUFS	Ethics Committee of the University of the Free State
HAT	Head, arms and trunk segments
ICF	International Classification of Functioning, Disability and Health Framework
ICF-CY	International Classification of Functioning, Disability and Health Framework for Children and Youth
OT	Occupational Therapist
OTPF	Occupational Therapy Practice Framework
TIP	Therapeutic intervention process
START	Strive Towards Achieving Results Together

CONCEPT CLARIFICATION & DEFINITIONS

Activity/Activities:

Activities are considered the small units of goal-directed behaviour that make up tasks. It is the execution of a task or action performed by an individual (Radomski & Trobly-Latham 2008:2, 11). Occupational therapists use activities as a therapeutic medium (Kramer, Luebben & Hinojosa 2010:53).

Caregiver:

It is a person (other than a mother or father) who spends a significant amount of time with a child (Case-Smith, Richardson & Schultz-Krohn 2005:13). In this study, the legal parents were involved with the children with Down syndrome.

Client-centred approach:

To accomplish important day-to-day activities the occupational therapist is committed to focus on the client as an active agent and partner receiving a service. The process involves assessing, advising, developing, restoring or adapting the individual's skills to support performance in the local community settings. Organising and using assistance available in natural supports from family and friends. The implementation of interventions follows. It is also referred to as a family-centred approach (Blesedell-Crepeau, Boyt-Schell & Cohn 2009a:218; Dudgeon 2009:183).

Creeping:

Creeping is a familiar terminology used by therapist working in the field of early intervention, specifically used in neuro-developmental techniques. Creeping is the forwards movement of babies in prone without lifting from the floor and not on all four limbs. In lay terms: leopard crawling or crawls on stomach.

Developmental Programme:

Development may be defined as the sequential changes in function that occur with maturation of the individual, the stages of development, as well as the prerequisite skills needed for higher-level skills (Law, Missiuna, Pollock & Stewart 2005:54). A developmental programme is designed to promote these skills.

Developmental Skills Programme:

> *Developmental Skills programs focus on the learning and mastery of a set of normally sequenced motor milestones, with intervention the target is identifying from skills at the next higher level.* (Mahoney, Robinson& Fewell2001:154)

Evidence-Based Practice:

According to Blesedell-Crepeau *et al*. (2009a:219), evidence-based practice refer to the integration of research evidence into the clinical-reasoning process to explain the underlying principle behind interventions and predict probable outcomes.

Framework:

A framework is used to place aspects in perspective. It is a hypothetical description of a complex entity in a process. It is a set of beliefs, ideals or rules that is used as the basis for making judgments and decisions (Hornby 2005:591). In occupational therapy, it is used as a guide within a specific area of practice (Blesedell-Crepeau, Boyt-Schell & Cohn 2009b:431).

Hawthorne effect:

The Hawthorne effect refers to a phenomenon in which participants change their behaviour because of being part of an experiment or study. Quantitative research showed that there was little improvement, and researchers invoked the Hawthorne Effect as the main factor skewing the results. They believed that the extra attention given to the patients, by the doctors, nurses and therapists, was behind the reported improvements in the initial study (Cherry 2008 1/1).

Holistic approach:

The word *holism* comes from the Greek word that means “all, entire or total” and *approach* is the way leading closer to a standard and is greater than the sum of its parts (Hornby 2005:714). The philosophical view on *holism* is that there is a creative influence on the total system (Odendal & Gouws 2009:412). In the context of this study, the total is the idea that the given systems (cognitive, motor, sensory, language and social function) cannot be determined by its component parts alone. The system (child with Down syndrome) as a whole determines how the parts behave. The bio-psychosocial model fits into this thinking. The child with Down syndrome is not seen as ‘parts’, but his/her whole (physical, mental and social) existence plays a part in the approach, with the involvement of the parents or caregivers (Martin1994:308). For the purpose of this study, it is applicable to occupational therapy, which engages a client in all the domains of life.

Intellectual disabilities:

The term *intellectual disabilities* replaced the term *mental retardation*. The individual must present with impairments in both intellectual and adaptive functioning. The DSM-IV-TR regards intellectual function that an individual obtain an IQ (Intellectual Quotient) score of approximately 70 or below or at least approximately two standard deviations below the mean (Alexander 2011:111).

KIT:

The KIT, as integral component of the Development Resource Stimulation Programme, consists of three (3) coloured plastic mugs, four (4) stainless steel teaspoons and a square facecloth.

Model:

A model is a representation of a system that allows for investigation of the properties of the system. It is a simple description of a system, used for explaining how systems work. Models are often used for quantitative analysis (De Vos 2005:36; Hornby 2005:945). In occupational therapy, a model is a statement of an organised and synthesised body of knowledge, which demonstrates relationships between elements within the model and

between theory and practice. This then coordinates the application of relevant approaches and techniques. A professional model, according to Blesedell-Crepeau *et al.* (2009b:431), defines the scope or area of concern for a profession. It articulates the overall beliefs and the knowledge of the profession.

Neuro-developmental techniques:

The treatment approach involves handling the child with the objective of integrating abnormal tone and facilitating automatic reactions, such as righting and equilibrium. This approach further promotes postural stability, which includes training in developmentally appropriate movement patterns and the promotion of muscle strengthening (Castillo 2008:150; Mahoney *et al.* 2001:161).

Occupation:

The term *occupation* in Occupational Therapy and related concepts such as *activity*, *task*, *employment* and *work* are used in the same manner. Occupation is everything people do to occupy themselves. Furthermore, *occupation* comprises coherent patterns of action that emerge through transactions between the child and the environment (Dickie 2009:17–18). Blesedell-Crepeau, Cohn and Boyt-Schell (2009a:217) further explain the concept as the day-to-day activities that people perform that are important and meaningful for their health through engagement in valued occupations.

Occupation-centred practice:

Occupation-centred practice focuses on meaningful occupations selected by the client and performed in their own environment. The clients' occupations and priorities are vital to occupation-centred practice and provide the basis for intervention (Blesedell-Crepeau *et al*. 2009a:218).

Occupational performance:

It is the ability of an individual to perform purposeful daily activities (occupations) satisfactorily. This involves the dynamic transaction among the client, the context or environment, and the activity (Radomski & Trombly-Latham 2008:66). It is part of a

person's sociocultural context and describes what is necessary for a person's well-being (Kielhofner, Forsyth, Kramer, Melton & Dobson 2009:450).

Occupational therapy process:

The occupational therapy process is the therapeutic problem-solving method used to help clients improve their occupational performance (Rogers & Holm 2009:479).

Occupational Therapy Practice Framework (OTPF):

The OTPF was developed to articulate occupational therapy's contribution to promoting the health and participation of people, organizations, and populations through engagement in occupations (AOTA 2008:625). Client factors support the development of performance skills such as motor and communication necessary for everyday occupations. The framework was developed to focus on the application of an intervention process that facilitates dynamic engagement in activity to support participation in life (AOTA 2002:609; Rogers & Holm 2009:483).

Phenotype of DS:

The behavioural phenotype of DS outlines a child's restraints in his/her development with several neuromuscular and musculoskeletal characteristics (Capone 2004:45). A further restraint is the intellectual ability of the child with DS (Alexander 2011:112; Roizen 2013:307).

Parental:

This means the mother and/or father.

Therapist-implemented treatment:

The therapist-implemented treatment approach in this setting is different from the client-centred therapy approach described in occupational therapy intervention (AOTA 2009:649). This is the standard intervention implemented in consultation sessions according to the scope of practice of each discipline (Del Giudice, Titomanlio, Brogna, Bonaccorso, Romano, Mansi, Paludetto, Di Mita, Toscano & Andria 2006:56).

Lautenslager (2000:159) describes a problem-specific physiotherapy programme gross-motor programme (**cf.** 2.6.4). For the purpose of this study, therapist-implemented treatment refers to a problem-specific programme.

SUMMARY

Key terms: early intervention programme, Down syndrome, younger than three years, developmental domains, occupational therapy

The effect of stimulation programmes on children with Down syndrome is necessary especially with a South African impetus. This study was an attempt to investigate the impact of an intensive early-intervention programme, the Developmental Resource Stimulation Programme (DRSP), on Down syndrome children younger than 42 months in the South African context. The DRSP would assist any occupational therapist using one stimulation programme to enable parents to assist their child to develop to their full potential at an earlier age.

Down syndrome is a multisystem chromosomal disorder, which has been recognised to be the single most common cause of intellectual disability occurring in approximately one in 650–700 births. Down syndrome is associated with cognitive limitations and speech as well as motor-developmental problems. Documented studies focused on motor and speech development in older children, with very few studies on babies younger than three years. Adequate early-intervention programmes for babies with Down syndrome with parent involvement do not exist in the South African context.

Contrary to the literature, this study may show the benefits of the role of the occupational therapist in early intervention. The World Health Organization has adopted the International Classification of Functioning, Disability and Health (ICF-CY), a bio psycho-social model that emphasises components of health and reflects participation, activities and function. A holistic approach is essential to the developmental problems of children with Down syndrome to create a long-term difference in their functioning in totality.

The researcher developed the Developmental Resource Stimulation Programme (DRSP) to assist in the management of early intervention of the child with Down syndrome over a period of 20 years. The DRSP is a unique, child-parent specific, one-on-one, integrated developmental programme for children with Down syndrome from birth to 42 months. Each activity of the DRSP is designed to accomplish specific activity performances in

developmental domains, appropriate to the child's ability for different age band groups younger than 42 months. The activities comprise cognitive, motor, sensory and language skills, as well as activities found in everyday living. The Developmental Resource Stimulation Programme was compared to Occupational Therapy Practice Framework.

The aim of this study was to investigate the impact of the DRSP on Down syndrome children younger than 42 months in the South African context. There were four objectives in order to achieve the aim of the study.

A quantitative approach with an experimental and descriptive study design was followed, to confirm results and enhance the reliability and validity of the study. The measurable attributes of the DRSP, including the participation of the parents were the focus. The Bayley Scales of Infant and Toddler Development (3rd edition) and DRSP checklists were used in a pre-test and post-test to measure the effect of the DRSP. There were two groups namely the intervention group, consisting of 32 participants (children and parents) and the control group, consisting of 28 (children and parents) over a period of six months. Evaluation and intervention sessions were video-recorded and moderated.

Informed consent was obtained prior to the study, supported by an information document in the language of choice, namely Afrikaans, English and Sesotho.

A self-administered questionnaire, developed by the researcher, focused on the attainment of information regarding the overall presentation of the area, service and treatment of the participants. The results were analysed, presented in tables and graphs, and discussed.

The results of this study showed that a specifically designed programme with participation of a parent has a positive impact on the development of the child with Down syndrome. Contrary to the literature, there were positive changes in the language, fine-motor and >9-month gross-motor development of children with Down syndrome. The DRSP with specific goals indicated to be an attribute in the early-intervention process. The results emphasised the holistic approach, rendered by an occupational therapist in Down syndrome early intervention.

OPSOMMING

Sleutelterme: vroeë intervensieprogram, Downsindroom, jonger as drie jaar, ontwikkelingsdomeine, arbeidsterapie

Die effek van stimulasieprogramme vir die kind met Downsindroom is noodsaaklik spesifiek in die Suid-Afrikaanse konteks. Hierdie studie was ’n poging om die impak van ’n intensiewe vroeë-intervensie-program, die Developmental Resource Stimulation Programme (DRSP), op kinders met Downsindroom jonger as 42 maande in die Suid-Afrikaanse konteks te ondersoek. Die program mag enige arbeidsterapeut van hulp wees met die gebruik van een stimulasieprogram ten einde ouers in staat stel om hulle kind se volle potensiaal op ’n vroeë ouderdom te ontwikkel.

Downsindroom is ’n veelvuldige-sisteem chromosoomafwyking wat as die enkele mees algemene oorsaak van intellektuele gestremdheid erken word en wat by ongeveer een in elke 650–700 geboortes voorkom. Downsindroom word geassosieer met kognitiewe beperkings sowel as spraak- en motoriese ontwikkelingsprobleme. Gedokumenteerde studies het gefokus op motoriese en spraakontwikkeling by ouer kinders, met slegs enkele studies oor kinders. Daar bestaan nie toereikende vroeë intervensieprogramme waarby ouers betrokke is vir kinders met Downsindroom in die Suid-Afrikaanse konteks nie.

In teenstelling met die literatuur, toon hierdie studie moontlike voordele van vroeë intervensie wat geïmplementeer word deur ’n arbeidsterapeut.Die Wêreldgesondheidsorganisasie het die Internasionale Klassifikasie vir Funksionering, Gestremdheid en Gesondheid vir die kind en jeug (ICF-CY) aanvaar, ’n bio-psigososiale model wat komponente van gesondheid beklemtoon en besin oor deelname, aktiwiteite en funksie. ’n Holistiese benadering tot die ontwikkelingsprobleme van kinders met Downsindroom is onontbeerlik, ten einde ’n langtermyn verskil in hulle algehele funksionering te maak.

Die navorser het oor tydperk van 20 jaar die DRSP ontwikkel ter ondersteuning van die bestuur van vroeë intervensie by kinders met Downsindroom. Die DRSP is ’n unieke, kind-ouer-spesifieke, een-tot-een, geïntegreerde ontwikkelingsprogram vir kinders met

Downsindroom, vanaf geboorte tot 42 maande. Elke aktiwiteit van die DRSP is ontwerp om spesifieke aktiwiteitsdeelname in ontwikkelingsdomeine te ontwikkel, wat pas by die vermoë vir verskillende ouderdomsgroepe van kindersjonger as drie jaar oud. Die aktiwiteite bestaan uit kognitiewe, motoriese, sensoriese en taalvaardighede, asook aktiwiteite wat in die daaglikse lewe aangetref word. Die DRSP is met die Raamwerk vir Arbeidsterapiepraktyk vergelyk.

Die oogmerk met hierdie studie was om die impak van die DRSP op kinders met Downsindroom jonger as 42 maande in die Suid-Afrikaanse konteks te ondersoek. Om die doel van hierdie studie te verwesenlik, was daar driedoelwitte.

'n Kwantitatiewe benadering, met 'n eksperimentele en beskrywende studieontwerp is gevolg om resultate te staaf en die betroubaarheid en geldigheid van die studie te bevestig. Die meetbare eienskappe van die DRSP, insluitende die deelname van die ouers, was die fokus. Die Bayley Scales of Infant and Toddler Development (3rd edition) en DRSP-kontrolelyste is tydens 'n voor- en natoets gebruik om die effek van die DRSP te bepaal. Daar was twee groepe, naamlik die intervensiegroep, bestaande uit 32 deelnemers (kinders en ouers) en die kontrolegroep bestaande uit of 28 (kinders en ouers) persone, oor 'n periode van ses maande. Die evaluering- en intervensie sessies is ook op video opgeneem en gemodereer.

Ingeligte toestemming is voor die studie bekom, met 'n meegaande inligtingsdokument in die taal van keuse, naamlik Afrikaans, Engels en Sesotho.

'n Selfgeadministreerde vraelys, ontwikkel deur die navorser, het op die verkryging van inligting rakende die algehele aanbieding van die area, diens en behandeling van die deelnemers gefokus. Die resultate is ontleed en in tabelle en grafieke aangebied en bespreek.

Die resultate in hierdie studie toon aan dat 'n spesifiek-ontwerpte program met deelname van 'n ouer 'n positiewe uitwerking op die ontwikkeling van die kind met Downsindroom het. In teenstelling met die literatuur, was daar 'n verbetering in die taal-, fyn motoriese en >9-maande groot motoriese ontwikkeling van die babas met Downsindroom. Daar is bevind dat die DRSP met spesifieke doelwitte 'n attribuut in die vroeë intervensieproses is.

Die resultate beklemtoon die holistiese benadering wat deur ’n arbeidsterapeut tydens vroeë intervensie by Downsindroom gevolg is.

PREFACE

Down syndrome – a journey or destination?

(Down Syndrome Association Pretoria/Tshwane 2007)

The journey for the researcher as an occupational therapist started in 1989 when the first child with Down syndrome came to the Bloemfontein Child Information Centre (BCIC) for assistance. This nine-month-old baby girl with her friendly smile and open eyes incited my interest in this syndrome. At the time, not many occupational therapists had the opportunity to work with babies with Down syndrome, as they were not referred to occupational therapy in Bloemfontein (Free State), until they were six months old or even older. According to medical doctors, occupational therapy was not the first choice of intervention, as it was felt that the motor disabilities of a child with Down syndrome should only be assisted by physiotherapy. This often is still the assumption today (Colorado Springs Down Syndrome Association 2011:1/2; Down Syndrome South Africa 2010:1/4; Heyn 2012:1/15; Majnemer 1998:67; MEDSavailable 2012:1/2; New York State Department Of Health n.d.:106; *NHS Choices website*. 2012:2/4). As private practices in occupational therapy started in the Free State in 1985 only, most of the occupational therapists were working in the Public Sector at that time. This meant that no occupational therapist could treat patients without a referral from a medical doctor (Rosa 2009:288).

The BCIC renders a community service to any person with children with special needs and for this reason this child with Down syndrome was referred. It started with a concerned mother that knew her child with Down syndrome could accomplish more than what was predicted by the medical profession. A message of failure of the child with Down syndrome, extensive challenges and possible institutionalisation was relayed to the parents by health professionals. This motivated, but anxious, mother was the beginning of the driving force behind my professional journey.

Confronted by more parents requesting resources and services for their babies and/or children with Down syndrome, a support group for parents was established. I was not satisfied to be the driving force of the support group as a volunteer only, but also started

with intensive early-intervention therapy sessions for these children and their parents. My experience as an occupational therapist made this journey possible. The aims of occupational therapy, as stated by Rogers and Holm (2009:479), are to prevent and reduce inability, and then initiate lasting change within the person. This brief explanation of what an occupational therapist tries to achieve was exactly the goals strived for by me. The child had already been diagnosed with Down syndrome and that could not be prevented, but by assisting the parent to help the child to achieve a better quality of development, further developmental delay was prevented. To reduce constraints, namely motor, cognitive and speech development, the intervention had to be a holistic approach. This meant that not only did the baby require therapeutic intervention, but the parents also needed extensive support. The support that parents needed was to accept their baby with Down syndrome, as well as for the physical and mental day-to-day care. The other challenge was to motivate the parents to be more assertive in the community. The ability to answer questions about Down syndrome was a challenge for parents. The biggest challenge for me was to initiate a positive transformation in the child with Down syndrome as well as the parent. As an occupational therapist and community worker, I believed that the occupational therapist was the ideal holistic health professional to provide the “just right challenge” to promote and improve the developmental systems needed for the child with Down syndrome. Holistic in this context means the totality and incorporation of therapy and the functioning in respect of a person/baby (i.e. cognitive, motor, sensory, language and social function) in so far as intervention is concerned, with the involvement of the parent or a caregiver (Rogers & Holm 2009:479) (**cf.** Definitions and concept clarification :vi).

As a young occupational therapist at the time, I remained securely grounded within the parameters of the occupational therapy academic curriculum, even though I had no practical experience in this specific field. I did not expect that, with only theoretical knowledge and no practical experience, my work would lead to the current full-quality support to people with Down syndrome and their families.

No journey takes place without challenges and the very first challenge was to change the very negative perception of Down syndrome, the referral timeframe and associated ideas on referring in the healthcare system in the Tertiary Health arena in the Free State.

The historical approach was to accentuate to the physical, sensory, learning, cognitive, language, social and environmental constraints of a child with Down syndrome, once the diagnosis had been made (Medical Model). This view did not directly involve the child with Down syndrome, nor the person who would have to take care of the child. The reality was that the caregivers were the people receiving the least amount of attention and support. This is why occupational therapists, using a holistic approach, immediately involved the parents/caregivers during these therapeutic processes.

Furthermore, until 2004, even in the Free State, the recommended age to enter early intervention was six or even nine months of age for babies with Down syndrome, and other early intervention studies indicated 11,9 months (Bailey, Hebbeler, Scarborough, Spiker & Mallik 2004:889). I was determined to change the concept of this late referral to that of referring directly after birth. After a few years of working with babies, an audit at the BCIC indicated significant benefits when babies with Down syndrome were referred before three months of age (Russell & Joubert 2009:4). The decision was then made to start with early referrals of babies with Down syndrome. To re-iterate the point of early referrals, papers were presented at the following international and national conferences: the Down Syndrome Congress (2006), Genetics Congress (2007), the 31st OTASA (Occupational Therapy Association South Africa) Congress (2007), the Paediatric and Child Health Congress (2008) and at the 32st OTASA Congress (2009) to soundboard the researcher's ideas and beliefs with peers.

My dedication and support experienced by the parents indicated that working with babies with Down syndrome was not the destination, but the start of a journey. My therapeutic involvement did not stay in the therapy arena only. Parents would phone me on Sundays just to say they had missed me over a weekend. This kind of dedication only comes with time and leads to an enthusiastic journey for me that took off to help parents to help their children to reach their full potential in their community.

It soon became clear that my years of experience working with parents and their children with Down syndrome had to lead to outputs that are more specific. As a professional health worker, I used a programme developed at the BCIC, as there was no programme specifically developed for children with Down syndrome in the South African context (Russell & Van Wyk 2003). Down Syndrome South Africa, of which I am part as a volunteer, could not provide information on a specific programme developed in South

Africa for the child with Down syndrome. The answer to this void was to develop an early-intervention programme that would be ideal for both parents and other occupational therapists. The Developmental Resource Stimulation Programme was developed and implemented by me as the author. This lead to the question that if the programme appeared to improve the total development during the therapeutic sessions, could it be proven clinically or statistically, or was it a personal assumption? This was the main impetus for undertaking this study.

For the record, my interest in Down syndrome did not stem from the fact that I marketed myself as an expert. Far from it! “Down syndrome” picked me!

CHAPTER 1 INTRODUCTION AND ORIENTATION TO THE STUDY

1.1 INTRODUCTION

This first chapter of the study sets the scene by exploring the historical management of early intervention of the child with Down syndrome (DS), including the role of the parent/caregiver. The researcher's understanding of the intervention process in the DS population made the approach to the research more valuable. As an occupational therapist, the goal of a holistic approach is to assist the child with DS in his/her development, to evaluate, improve and maintain the typical development, assist in functional performance, and lastly to gain self-belief (Health Professions Council of South Africa 2009:1). The child with DS should not be seen as isolated parts, but as a whole person, comprising cognitive, language, motor, sensory and social-function systems. This holistic approach also involves the parents/caregivers. The input of occupational therapy is to engage people in dignified participation, in meaningful occupations and to be integrated into society which includes all aspects of life and thus improves quality of life (Martin 1994:308). This implies that the occupational therapist could be an indispensable professional to manage children with DS according to the scope of occupational therapy practice (Health Professions Council of South Africa 2009:1).

The researcher's specific interest in Down syndrome started in 1990. Sixty-two babies with Down syndrome received occupational therapy treatment at the BCIC (acronym used not to compromise the anonymity of the participants) from then till 2010. The positive clinical outcomes, especially early walking (before 27 months) of these children stimulated this

interest further. According to studies done by Karimi, Nazi, Sajedi, Akbar-Fahimi and Karimloo (2010:42) and Nilholm (1996:53) a more holistic approach to the developmental problems of these children has the possibility to make a long-term difference in their functioning in its totality.

It is a documented fact that DS is a chromosomal disorder, which has been recognised to be the single most common cause of mental handicap, occurring in approximately one in 700–1000 births (Capone 2004:45; McIntosh, Helms, Smyth & Logan 2008:386). The most common obvious dysmorphic features in a new-born with DS are the epicanthic folds of the eyes; a small nose with a broad, flat bridge; a small mouth with a protruding tongue; small low-set ears and earlobes; a single crease on the palm of the hand and hypotonia (floppiness) (Bhatia, Kabra & Sapra 2005:679; Capio & Rotor 2010:17; Capone 2004:48; Castillo 2008:136; Committee on Genetics 2001:442–444; Gémus, Palisano, Russell, Rosenbaum, Walter, Galuppi & Lane 2001:70; Marder & Cholmáin 2006:497; Palisano, Walter, Russell, Rosenbaum, Gémus, Galuppi & Cunningham 2001:494; Van Cleve & Cohen 2006:48). Children with Down syndrome are also characterised by cognitive deficits, with speech as well as motor-developmental problems (Hernandez-Reif, Field, Largie, Mora, Bornstein & Walkman 2006:396). These delays may vary from mild to moderate and may imply that there are deficits of learning that have an impact on the modification or adaptation of learning (Bhatia *et al.* 2005:679; Moeschler, Shevell & Committee on Genetics 2006:2306).

There is a need for an effective early-intervention programme that takes these developmental problems into account and then influence the independence of the child with DS positively. According to the literature, early intervention is a systematic programme of therapies, exercises and activities designed to address developmental delays specifically experienced by children with DS (Colorado Springs Down Syndrome Association 2011:1/2; Down Syndrome South Africa 2010:1/4; Heyn 2012:1/15; Fergus 2009:1; Majnemer 1998:67; MEDSavailable 2012:1/2; New York State Department Of Health n.d.:106; *NHSChoices website* 2012:2/4). Fergus (2009:1) mentions only physiotherapy and speech therapy as possible early-intervention treatments. According to Down Syndrome Association websites and support groups, occupational therapy only plays a role in the process of transition into independence of children with DS. After the physiotherapist and speech therapist had produced the primary foundation for development, these children would only then be referred to occupational therapy. These

programmes were not specifically developed for babies and children with DS (Carrie with Children 2011:2/7; Colorado Springs Down Syndrome Association 2011:2/3; MEDSavailable 2012:1/2; *NHSChoices website* 2012:2/4). There appeared to be no programme specifically developed for the child with Down syndrome (Brown, Johnson, Paterson, Gilmore, Longhi & Karmiloff-Smith 2003:1040; Capone 2004:48; Castillo 2008:150; Fidler *et al.* 2006:40, 43; Harris 1980:420; Kubo & Ulrich 2006:513; Palisano *et al.* 2001:494; Piper *et al.* 1986:184; Uyanik *et al.* 2003:68; Villamonte 2009:5).

Furthermore, a few studies only could be found on children younger than six months with DS on early intervention (Carr 1988:409; Del Giudice *et al.* 2006:52; Hines & Bennett 1996:99; Wasant, Tritlanunt, Sathienkijakanchai & Malilum 2008:1031). The majority of documented studies are on older children. Studies done by Capone (2004:48); Connolly, Morgan, Russell and Richardson (1980:1406); Fidler, Hepburn and Rogers (2006:40, 43); Jobling (1998:285); Kubo and Ulrich (2006:513); Uyanik, Bumin and Kayihan (2003:69) and Villamonte (2009:5) included children from two years onwards, as well as adolescents and adults with Down syndrome. In other studies (Harris 1980:420; Palisano *et al.* 2001:494; Piper, Gosselin, Gendron & Mazer 1986:184), referred to by Castillo (2008:150), it is found that early intervention is beneficial to the child with DS, but the programmes mentioned consisted of treatment methods only, with no description of the programme itself. Lauteslager (2000:68) developed an early-intervention programme for motor development that can be applied by physiotherapists. As mentioned by Capone (2004:48), in one early-intervention programme for the children with DS, the focus was unfortunately particularly on motor and speech development, involving the physiotherapist and speech therapist and not on a holistic intervention programme.

At the 65th World Health Assembly of the World Health Organization it was recommended that effective strategies within health and social sectors should be introduced with interventions that target early childhood years and family life, including attention to parenting skills (WHO 2012:4).

At this stage in South Africa, according to the Down Syndrome Western Cape Association, the active programme for the child with DS is The Washington Developmental Sequence Performance Inventory (DSPI), currently in use in the Western Cape Province (Botha 2009:1). However, this programme is not developed specifically for children with DS, but also for cerebral palsy and other causes of developmental delays. Another programme,

START (Strive Towards Achieving Results Together), has been developed for the South African child with developmental delay and/or cerebral palsy (Solarsh, Katz & Goodman 1990). The START programme was developed at the Sunshine Centre in Gauteng and it is used in the intervention of children with DS, since there are no other programmes available for the DS population (Solarsh *et al*. 1990). On further investigation it became clear that there is no early-intervention programme for children with DS in South Africa. This is according to the published information made available by the Free State Health Public Sector (Occupational Therapy Resource File 2009).

The researcher has shown an interest in the field of DS since 1989, followed by the establishment of a support group for parents of children with DS. The work with children with DS younger than three years in Bloemfontein started actively in 1990 within occupational therapy during play stimulation in therapy sessions. Years of professional work experience and assisting parents who had children with DS led to the development of an early-intervention programme specific for these children.

The Developmental Resource Stimulation Programme (DRSP) to be used in this study evolved from previous programmes for children younger than three years, developed by the researcher since the early 1990s. The DRSP is a unique, child-parent-specific, one-on-one, integrated programme for children with DS from birth to 42 months (Russell 2010). The reason for the age recommendation is to allow children with DS to have a six-month transition period into non-specific DS developmental programmes before entering preschool at three years. Each activity of the DRSP is designed to promote the total development of the child with DS, and comprises activities designed for cognitive, language, motor, sensory and play, as well as social-emotional development. An important attribute of the programme is the holistic therapeutic approach.

In 2010, the researcher embarked on this current study to investigate the impact of this programme on the child with DS. The DRSP was developed in such a manner that both the parent and the child with DS are actively involved. This will be discussed in detail in Chapter 3. The DRSP activities manual, within the South African context is easy to understand and/or read and consists of detailed sketches, descriptions of occupational activities for participation and stipulating the outcomes of the programme (goals). The material used in the DRSP is household objects which are durable and also cost effective and does not exclude any socio-economic group.

This study therefore aimed to investigate the impact of a specific programme for children with DS younger than 42 months. The DRSP as an early-intervention programme for the child with DS and the principles should be investigated to establish its use and suitability in the South African context.

The implementation of the DRSP could offer developmental stimulation to children with DS. Evaluation of the effectiveness and efficiency of the DRSP, developed by the researcher as an occupational therapist could possibly address this need for early intervention of the child with DS.

1.2 PROBLEM STATEMENT

There appeared to be no holistic development programme specifically developed for the child younger than three years old with DS (Brown, Johnson, Paterson, Gilmore, Longhi & Karmiloff-Smith 2003:1040; Capone 2004:48; Castillo 2008:150; Fidler *et al.* 2006:40, 43; Harris 1980:420; Kubo & Ulrich 2006:513; Palisano *et al.* 2001:494; Piper *et al.* 1986:184; Uyanik *et al.* 2003:68; Villamonte 2009:5) (**cf.** 2.3.3.1; 2.6.1; 2.6.9). As there is a motor development early-intervention programme developed for specific use of physiotherapist, an occupational therapy early-intervention programme with a holistic approach was necessary in this age group of children with DS.

In South Africa there appeared to be a need for specific DS early-intervention programmes for the child younger than 42 months.

The following questions then arise: What is the impact of the DRSP on the early intervention of the child with DS? What is the measured duration of intervention required to achieve specific outcomes? What is the involvement and participation of the parent in this process? Lastly, are parents/caregivers satisfied with the DRSP? The aim of this study was compiled from these questions.

1.3 AIM OF THE STUDY

The aim of this study was to investigate the impact of the DRSP on DS children younger than 42 months in the South African context.

The objectives of the study were:

- To investigate the impact of the DRSP on developmental progress in children with DS younger than 42 months.

- To establish the duration of intervention required to achieve a positive outcome.

- To measure objectively to what extent the parents/caregivers are able to perform the required activities of the DRSP correctly and independently after instruction.

- To determine parental/caregiver satisfaction with the DRSP.

1.4 METHODOLOGY

- A quantitative approach with a quasi-experimental and descriptive study design was followed (Carpenter & Suto 2008:170; Leedy & Ormrod 2010:233; McMillan 2008:230). According to Macnee (2004:166) accuracy and consistency in measurement forms the core of a successful quantitative research. Burns and Grove (2007:530) further explain quantitative research as a formal, objective and methodical process.

- To investigate objective one a non-randomised control group pre-test-post-test design was followed including two groups. The intervention (experimental) group and the control group, consisting of 16 participants in the intervention group and 14 participants in the control group. The effect of the early intervention by means of the DRSP was measured using the Bayley Scales of Infant and Toddler Development (Bayley 2006a:1; Rademeyer 2010:125) and DRSP Checklists (**cf.** Chapter 4). All 30 parents/caregivers of the intervention group and the control

group completed *The Social-Emotional and Adaptive Behavior Questionnaire of the Bayley Scales of Infant and Toddler Development* (Bayley 2006a:1) during the pre-testing and the post-testing.

- To investigate objective two a descriptive design was undertaken. This objective determined the *number of sessions* per activity and the *session length* that enables a child with DS to master the DRSP activities.

- A descriptive design was undertaken to investigate objective three. This objective was assessed by scoring the parents' transference of intervention using the DRSP checklist for parents.

- For objective four a descriptive design was also used. A questionnaire was compiled to obtain information regarding the parent participants' satisfaction with and their opinions on the intervention process.

1.5 THE VALUE AND EXTENT OF THE STUDY

The value of this study lies therein that the lack of specific early intervention, for children with DS younger than 42 months, may be addressed. Ultimately, the outcomes of this study could assist the occupational therapist in using one programme, namely the DRSP, specifically developed to assist parents and children diagnosed with DS in the South African context.

This programme affords occupational therapists to be instrumental in the management of children with DS according to the scope of occupational therapy practice (Health Professions Council of South Africa 2009:1). Taking the challenges of children with DS and all the health professionals historically involved with intervention into consideration, the DRSP could alleviate the burden of both health professionals and families with children with DS. When a child with DS is born with a behavioural phenotype that include specific cognitive, language, physical, sensory, learning and social constraints, health professionals immediately become involved in the management of the baby, which consists of medical doctors and allied health professionals such as occupational

therapists, physiotherapists and speech therapists. The occupational therapist, who is equipped with a holistic approach to intervention and has a comprehensive knowledge of the therapeutic process, could be the principle person to assist in the management of these children. The profession of occupational therapy assists people of all ages to achieve health and life satisfaction through improving their ability to carry out activities that they need or choose to do in their daily lives with the immediate, active involvement of all the members including parents/caregivers, which affects them (Creek 2009:105). Contrary to websites and literature reviewed, where the occupational therapist only intervenes at a later stage, this study could show the benefits of early intervention by an occupational therapist (Colorado Springs Down Syndrome Association 2011:1/2; Down Syndrome South Africa 2010:1/4; Heyn 2012:1/15; Majnemer 1998:67; MEDSavailable 2012:1/2; *NHSChoices website* 2012:2/4).

The early enrolment of children with DS into this programme will enable parents to help their child to develop to their full potential at an earlier age.

In the South African context with its vast population, the utilisation of resources is difficult. In a South African Health Services document, it is stated that there is a shortage of healthcare staff in almost all countries in the world. The document further states that there is a massive human resource crisis and a document on this crisis do not offer any creative solutions (Cullinan 2006:26; Molamu 2011:9). The utilisation of DRSP not only determines the implementation of a goal-specific stimulation programme, but also creates a better resource system for children with DS. The DRSP enables parents to become more involved in the developmental process of their child with DS than in the past. It should assist with the collaboration between the intervention of the occupational therapist and the parent/caregiver. Because this programme was developed to address the child with DS and the parents' specific needs, it could afford these children a rightful place in a mainstream school and society, when they develop the cognitive ability.

1.6 DELINEATION FOR THE STUDY

The delineation of the small study population of children with DS younger than 42 months resulted in the inclusion of a non-randomised control group. Regardless of the delineation

for this study, the DRSP could be a useful intervention programme for children with DS, as well as any other client with an intellectual disability and slow developers.

1.7 ETHICAL CONSIDERATIONS

- Ethical approval for this clinical study was obtained from the Ethics Committee (ECUFS no. 01/2011) of the Faculty of Health Sciences, University of the Free State. Written approval by the Head of the School of Medicine: Faculty of Health Sciences and the Head of the Department of Paediatric and Child Health were received (Appendix A). The researcher received written, informed consent from all the parents as well as for their children with DS, who took part in the study, (Strydom 2005a:59). Parents were informed that the data could be used in future publications (Appendix B).

- Part of the ethical procedure was an application to the National Health Research Ethics Council. The Clinical Proof Registration Application ID no. is 2404.

- The ethical aspects applied for this study is described in detail in Chapter 4, Research Approach and Methodology (**cf.** 4.8).

1.8 CHAPTER EXPLANATION AND OUTLINE

Chapter 1: *The introduction and orientation of the study*: This chapter describes the background and need for this study. The problem statement and objectives, summary of the methodology as well as the value and the ethical considerations construct this chapter. It will direct the reader to the introduction of the child with DS and the restraints in their development, as well as the possible solutions to these restraints.

Chapter 2: *Literature review on Down syndrome, occupational therapy, early intervention*: A literature review on DS and aspects of development and early intervention are covered in this chapter. The background to the syndrome is presented. The development of the child with DS is stipulated, with the different constraints these children experience. This is

followed by a description of the intervention and the specific involvement of all the role players, such as the health professionals and parents/caregivers.

Chapter 3: *Developmental Resource Stimulation Programme*: An overview of the process of developing DRSP is given in this chapter. The components of the programme are addressed in this chapter, namely:

- treatment approaches and techniques used during intervention;
- strategies of treatment namely handling of participants, presentation of activities and positioning of participants;
- occupations involved in the programme used by the participants; and
- a description and the outcomes of each activity.

Chapter 4: *Research Approach and Methodology*: This chapter focuses on fundamental research principles and a methodological approach crucial to the study's value. The objectives are discussed separately with the focus on theoretical aspects, study population, sampling, pilot study, data collection, data analysis and error of measurement. A quantitative approach, with a quasi-experimental and descriptive study design is followed. The data is collected through testing participants prior to the intervention and after the completion of the intervention.

Chapter 5: *Results*: This chapter presents the results of this study. Results are displayed and discussed in graphs and tables after the data analysis. The pre- and post-test data of the participants was described in objective one with clinical improvement in certain developmental domains. No statistical improvement was evident. In objective two the duration of intervention the research showed that developmental activities of children with DS could be mastered within a six-week period. Objective three was to determine if the parent understood the information on specific developmental matters of their child with DS during intervention. This study showed that parents strive to be empowered so that they could assist their child with DS to master activities correctly and independently. In objective four, a self-administered questionnaire was used to obtain the parents of the intervention group's opinion on the intervention. The results showed that the parents were satisfied with the DRSP intervention, including the activities and process. This chapter forms the basis on which recommendations are made.

Chapter 6: *Discussion of results*: This chapter discusses the impact of the DRSP on the outcomes of the child's development with DS. This chapter further provides a critical analysis of the mastering of abilities of development through the age bands of the children with DS and the duration of early intervention to achieve a positive outcome. In addition, this chapter interprets the findings of the parents' participation, measuring objectively independent performance of the DRSP and how they perceived the intervention. The chapter concludes, to determine parental/caregiver satisfaction with the early-intervention process. The objectives are argued accordingly.

Chapter 7: *Conclusions and Recommendations*: This chapter summarises the results of Chapter 6 of the study and discusses the relationship between the DRSP and early intervention for the birth to 42-month-old child with DS in the Free State. The conclusions, recommendations and limitations are indicated.

1.9 SUMMARY

This introductory chapter gave a brief overview of the management of early intervention for the child with DS with a new approach by using the DRSP. The problem statement, aim of the study, a short description of the methodology and the value of this study were presented. An introduction to the ethical considerations was given, with an outline of the chapters as part of this thesis.

In the following chapters the literature review of DS and occupational therapy as a treatment approach and the results of the study are presented.

CHAPTER 2
DOWN SYNDROME, OCCUPATIONALTHERAPY AND EARLY INTERVENTION

Dr John Langdon Down (1828–1896) said the following: "You take your aim; be sure you aim high enough. That's the thing – aim high enough." (Down Syndrome Western Australia Association 2011:1).

2.1 INTRODUCTION

In the previous chapter an introduction and orientation of this study was given, which included the problem statement, aim of the study, methodology, the value of the study, ethical considerations and the outline of the chapters. The researcher will attempt to give an overview of the history, aetiology and characteristics associated with Down syndrome (DS), as well as a classification system, namely the International Classification of Function, Disability and Health for Children and Youth (ICF-CY), the role of the Occupational Therapist, and the importance of early intervention regarding the child with DS. The following Figure 2.1, is a summarised outline of the chapter.

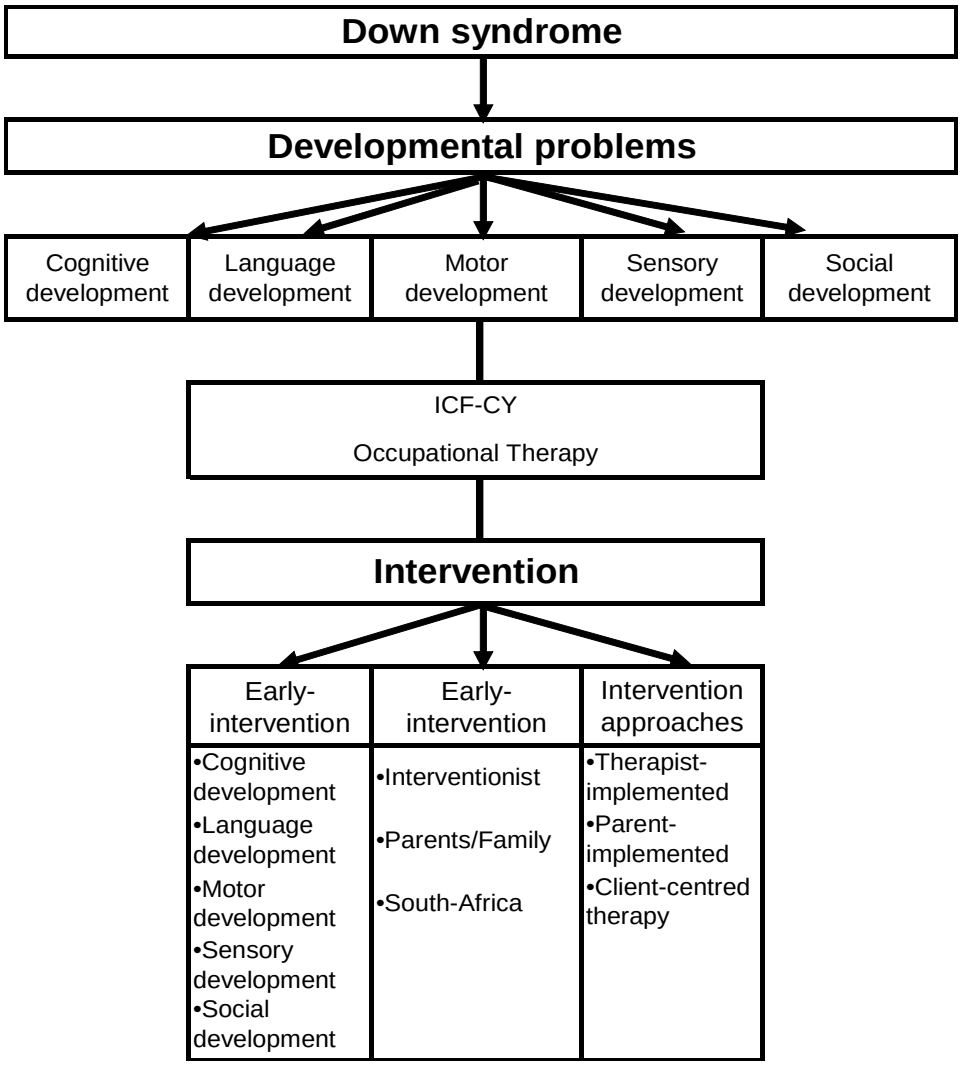


Figure 2.1: Outline of chapter 2

2.2 BACKGROUND TO DOWNSYNDROME

Down Syndrome (DS) is a multisystem neuro-genetic (chromosomal) disorder, which has been recognised to be the leading genetic cause of intellectual disability occurring in approximately one in 650–700 births. Trisomy 21 is the most common of this malformation syndrome (Alexander 2011:112; Capone 2004:45; Daunhauer & Fidler 2011:8; Hennekam, Kratz & Allanson 2010:49; McIntosh *et al*. 2008:386; Roizen 2013:308). In South Africa the incidence of DS is one in 770 births, or one to three per 1000 (Christianson 1996:89; Molteno, Smart, Viljoen, Sayed & Roux 1997:428; Naidoo, Aldous, Ramdhani, Winship, Henriques & Kormuth 2011:27; Urban, Stewart, Ruppelt & Geerts 2011:45).

There are three genetic variants in DS.

- Extra chromosome 21: In 92% of incidents of DS is caused by an error in cell division, which results in an extra chromosome 21 in all cells.
- Mosaic trisomy 21: In 2–4% of cases, the extra chromosome 21 is only present in some cells and then called mosaic trisomy 21.
- Translocation trisomy 21: In 3–4% of cases, material from one chromosome 21 is translocated onto another chromosome. This means cells have two normal chromosomes 21, with additional chromosome 21 material on the translocated chromosome, usually chromosome 14 or 15 (Committee on Genetics 2001:442; Hennekam *et al*. 2010:49; Jones 2006:9; McIntosh *et al.* 2008:388; Nadel 2003:156; Scully, Landon & Evans 2009:434; Van Cleve & Cohen 2006:47). Trisomy 21 translocation affects almost every organ system and results in a wide spectrum of constraints, which are based on intellectual disability predisposed to distinct developmental outcomes (Daunhauer & Fidler 2011:8; Hennekam *et al*. 2010:50; Spiker & Hopmann 1997:1/36). Chromosome analysis is necessary to confirm all cases.
- This information on the variants of DS should be taken in account when sampling is done for studies. Especially the Cardiovascular anomalies which occur in 40% of children with DS. In 20% of the recorded trisomy 21 syndrome cases, frequent death occurs due to these abnormalities (Hennekam *et al.* 2010:53; Roizen 2013:309). This current study was planned to take place over a six-month period and cardiovascular abnormalities (or anomalies) would have complicated the sampling. This variable influences development negatively (Daunhauer & Fidler 2011:12; Fidler 2005:92).

This entity of Down syndrome was originally described by John Landon Down, an English physician, in 1862. He was the first to publish an accurate description of a person with Down syndrome, but used the unfortunate term, “mongolian idiocy” (Castillo 2008:135; Fishler, Koch & Donnell 1976:744; Hennekam *et al.* 2010:49; Mégarbané, Ravel, Mircher, Sturtz, Grattau, Rethoré, Delabar & Mobley 2009:611; Ward 1999:22). In 1866 the first detailed description of signs and symptoms that affect these individuals were given. However, it was only discovered by Lejeune, Gautier and Turpinin 1959 that trisomy of chromosome 21 was the underlying abnormality in DS (Neri & Opitz 2009:2650). Today,

the term *Down syndrome* is widely accepted and was adopted by the World Health Organisation in 1965 (Ward 1999:19). Very little new information has been added to the clinical description of the condition, apart from the description of the single transverse crease in the palm noted by John Langdon Down's son Reginald in 1908, and the characteristic grey spots on the iris of the eye, noted by Brushfield in 1924 (Committee on Genetics 2001:442).

In 1862 Langdon Down examined the palates and tongues of the residents of the mental hospital where he worked. The first indication that he had identified a specific group of patients was when he discovered the unique physical characteristics and speech pathology when they were compared to the other patients in the mental hospital (Ward 1999:21). He even noted that this group of patients responded very well to training, managing better than would be expected (Ward 1999:23).

In the work done by Langdon Down, ten (10) cardinal features of trisomy 21 syndrome are described in the new-born, namely hypotonia, poor Moro reflex, hyper-extensibility of joints, excess skin on back of neck, flat facial profile, slanted palpebral fissures, anomalous auricles, dysplasia of pelvis, brachymesophalangy of the fifth finger and a single palmar crease. Other common dysmorphic features are a small nose with a broad, flat bridge and a small mouth with protruding tongue (Bhatia *et al.* 2005:679; Capio & Rotor 2010:17; Capone 2004:48; Castillo 2008:136; Committee on Genetics 2001:442–444; Gémus *et al.* 2001:70; Hennekam *et al.* 2010:50; Marder & Cholmáin 2006:497; Palisano *et al.* 2001:494; Van Cleve & Cohen 2006:48). Several neuromuscular and musculoskeletal characteristics in DS may result in developmental delay (Capone 2004:45; Karimi *et al.* 2010:39). Cardiovascular anomalies occur in 40% of children with DS, which is a frequent cause of death in about 20% of the recorded trisomy 21 syndrome cases (Hennekam *et al.* 2010:53; Roizen 2013:309).

Most individuals with DS have a mild (IQ 50–70) to moderate (IQ 35–50) range of intellectual disability, with individuals having Mosaic DS typically IQ scoring 10 to 30 points higher (Alexander 2011:112; Daunhauer & Fidler 2011:10; Durand 2001:634; Sourtiji, Hosseini, Soleimani & Hosseini 2010:2; Uyanik & Kayihan 2009:2). The child with DS's behavioural phenotype should be discussed in more detail and will follow in the next section.

2.3 DEVELOPMENTAL PROBLEMS

It is well documented that children with DS are characterised by cognitive deficits and speech problems, as well as motor-developmental problems (Hernandez-Reif *et al.* 2006:396). The delays vary from mild to moderate delay (Bhatia *et al.* 2005:679). Learning deficits and the adaptation to learning are an indication of the developmental problems that occur with the DS population (Moeschler *et al.* 2006:2306).

One of the unique characteristics of DS is the general hypotonia and laxity of the joints due to this hypotonia, which are a result of the neuropathology of DS. This neuropathology is a smaller cerebellum and brain stem and decreased myelination of the brain hemispheres, basal ganglia, cerebellum and brain stem after at least six months of age. It has been reported that three-month-old babies with DS were entirely normal at performing developmental tasks. Delays only start to occur after six months (Capone 2004:45; Karimi *et al*. 2010:39; Nadel 2003:161). These delays should be a motivation to start early with intervention to try and counteract the total effect of these delays.

As the researcher observed the limitations of development of children with DS in her clinical practice and current available programmes, it confirmed the need for the development of a specific early-intervention programme for children with DS. The most common approach to the general developmental processes of a child with DS is using the areas of development, namely cognitive, language, motor, sensory, and social development, in the following section (Kramer & Hinojosa 2010:27).

2.3.1 Cognitive development

It is essential to rethink the ultimate potential that these children with DS may have and therefore, cognitive development should receive more attention during this discussion.

- According to the literature, the foetal brain growth of the child with DS is clearly delayed (Johnson & Blasco 1997:231), with the result that children with DS are micro-cephalic at birth.

- Effectively all individuals with DS have cognitive impairment, which may range from moderate to profound.

- Regarding intervention in cognitive development, it is important to remember that the cognitive processing skills are the foundation for intelligence and depend on learning (Johnson & Blasco 1997:231). It comprises three components: attention, information processing, and memory (Johnson & Blasco 1997:231).

- This population not only shows delays and shortcomings, but shows relative strengths in visual short-term memory tasks which should be utilised in intervention programmes (Fidler, Hodapp & Dykens 2002:81; Hennekam *et al.* 2010 51; McDermott, Durkin, Schupf & Stein 2007:12).

- Lydic (1982:68), further states that children with DS should not be underestimated, although, in a later study Hines and Bennett (1996:96) state that the decline in their cognitive abilities takes place from early in the first year up to the age of five.

- Unfortunately, medical factors such as severe congenital heart disease or hypotonia have been noted to further effect cognitive abilities negatively (Capone 2004:48; Daunhauer & Fidler 2011:12).

Children with DS have delayed brain growth (Johnson & Blasco 1997:231). This may be an indication that these children with DS started with obstacles and constraints even at an early age in cognitive development. All components of cognitive development should be incorporated in the development of an intervention programme by using activities (Castillo 2008:150). Therefore, it is imperative to develop well-balanced, specific early-intervention programmes that may change or intercept this impairment and produce a more independent future for the child with DS.

2.3.2 Language development

Language includes receptive and expressive skills, while speech is the vocal expression of language (Johnson & Blasco 1997:236). Delays in language development in DS are more

common than delays in other developmental domains (Fidler *et al.* 2006:37). According to published studies, the one obvious and typical delay in a child with DS is their verbal processing (Abbeduto, Pavetto, Kesin, Weissman, Karadottir, O'Brien & Cawthon 2001:11; Vicari 2006:356), therefore the receptive language stronger than the expressive language. Capone (2004:48) found that delays occur in both early language-based and performance-based cognitive milestones. Melyn and White (1973:544) also described that the speech development of the child with DS is affected, especially expressive language. For more clarity, a combined summary of speech development information from different studies is given in Table 2.1 (Connolly *et al.* 1980:1408; Melyn & White 1973:544; Parham & Mailloux 2005:363; Solarsch, Katz & Goodman 1990: Profile No. 2.4):

Table 2.1: Speech development (adapted by the researcher)

Speech development	**Chronological Ages of DS**	**Typical Development**
Smile	2.9 months (Connolly *et al*. 1980:1408)	2 months (Connolly *et al.* 1980:1408)
First word	21.82 months (Melyn & White 1973:544)	10 months (Connolly *et al.* 1980:1408)
Two words	23 months (Melyn & White 1973:544)	12 months (Parham & Mailloux 2005:363)
5–7 words	31 months (Connolly *et al.* 1980:1408)	18 months (Solarsch, Katz & Goodman 1990: Profile No 2.4)

Table 2.1 demonstrates that the speech development of the child with DS shows a significant delay of expressive language. An important factor, described by Capone (2004:49), is the significant correlation between language and cognition of the child with DS. This implies that when there are language constraints, the child with DS's cognitive development will be affected. This fact should motivate holistic early-intervention programmes including all the developmental domains, taking the International Down Syndrome Association's drive of implementing mainstream schooling into consideration. Language development should be stimulated and improved to assist children with DS to develop to their highest possible potential. To facilitate language acquisition there should be a more contingent responsiveness and the use of modelling, expansions and repetitions (Spiker & Hopmann 1997:18/36). The parent as primary caregiver could be

taught how to promote language acquisition, which would enable them to play a significant role in their child's language development.

2.3.3 Motor development

The first measurable delay in the child with DS is noted in motor development, as one of the development systems, and therefore, typical development should firstly be discussed. When planning intervention the understanding and knowledge of typical motor development is important.

In the early 1920s, it was believed that motor development progresses from gross movements to fine movements and from proximal control to distal control (Case-Smith, Fisher & Bauer 1989:657). According to this widely accepted proximal-distal principle the development of proximal postural control is related to the development of fine motor skills of the distal extremities (Case-Smith, Holland & Bishop 2011:670; Wang, Howe, Hinojosa & Weinberg 2011:608).

The upper extremity is used for transitions in postural control such as moving the body from one position to another. To execute the transition, strength of trunk and upper extremity are required. The development and maintenance of postural stability (gross-motor development) are complex processes that necessitate the involvement of multiple systems such as the sensory system, central nervous system processing and co-ordination of motor output and the vestibular system. Sensory information from somatosensory, visual, and vestibular sources help with the orientation of the head and body position in space and postural control by coordinated motor outputs. The visual and somatosensory system gathers information from the environment (e.g. position in relative to other objects) and the vestibular system, gathers information from the vestibular apparatus of the ear (Rajendran & Roy 2011:3/5).

Initially all movements are reflexive and develop from the spine and brainstem areas. It is important to know that in a new-born there are no purposeful movements. In the newborn there are two kinds of reflexes, namely primitive and postural reflexes. Primitive reflexes are spontaneous, stereotypical responses to specific stimuli, whereas postural reflexes and reactions are observed throughout life and aim at keeping the head and body in an

upright position. A baby will typically follow a specific motor pattern which develops in stages and sequences (Johnson & Blasco 1997:224). The “higher” centres control the “lower” centres, is a typical description of motor development (Kaplan 2010:392; Venter 2011:70). Typical motor development is essential for the baby’s motor-control achievement and learning. As the baby develops, more control over movement against gravity is achieved and the primitive reflexes decrease and integrate as postural reactions appear (Uyanik & Kayihan 2009:2/22).

According to the International Classification of Functioning, Disability and Health Framework (Jette 2006:731), three general systems are involved, namely the person, the task and the environment. The person system consists of emotional, cognitive, perceptual, sensory and motor abilities of the person. The physical systems consist of cardiovascular, musculoskeletal and neurological systems of the person (Kaplan 2010:392). The environmental aspects, according to Adolfsson (2011:17) are a holistic view of a child’s everyday life situations.

As these two development domains are different in their neurological status and as well as the biomechanics (Kuhtz-Buschbeck & Ulmer 2008:25), fine-motor and gross-motor development should be seen as two developmental units and therefore will be discussed separately.

2.3.3.1 Gross-motor development

Gross-motor developmental delays are well-described in DS. Interestingly, each child with DS has his/her own specific developmental pattern and tempo (Fidler 2005:92; Lauteslager, Vermeer & Helders 1998:5; Mazzone, Mugno & Mazzone 2004:120; Wang & Ju 2002:443). This factor (client-centredness) should be taken into consideration in the choice of activities to stimulate motor development and will be discussed in the section dealing with intervention programmes (**cf.** 2.6.9). Atypical gross-motor development characteristics can be observed and measured in children with DS (Abdel Rahman & Shaheen 2010:37; Bhatia *et al.* 2005:679; Capio & Rotor 2010:17; Capone 2004:48; Castillo 2008:136; Committee on Genetics 2001:442–444; Gémus *et al.* 2001:70; Hennekam *et al.* 2010:50; Marder & Cholmáin 2006:497; Palisano *et al.* 2001:494; Van Cleve & Cohen 2006:48). Components that can be included are:

- muscle hypotonia (low or decreased muscle tone);
- joint hyper-extensibility and mobility;
- delayed or poor acquisition of postural control with trunk control;
- avoidance of weight-bearing and weight shifts;
- difficulty with protective response (rapid displacement of the body); and
- poor equilibrium and balance.

As already mentioned the specific neuropathology associated with DS are, the reduction in the number of cerebellum and brainstem neurons and a decrease in brain weight of the cerebellum and brainstem (Karimi *et al.* 2010:39; Torres & Buceta 1998:94; Woollacott & Shumway-Cook 1986:45). This may contribute to poor postural control and balance in sitting and walking. It need not be a direct result of hypotonia only (Capone 2004:45; Connolly, Morgan, Russell & Fulliton 1993:171; Hennekam *et al.* 2010:51; Karimi *et al*. 2010:40).

Four patterns of muscle tone and motor functioning in infants with DS have been observed by Daunhauer and Fidler (2011:12) and Fidler (2005:92):

- Type 1 (15–25%) babies have typical muscle tone and achieve milestones like head control, bearing weight on feet with support, and lifting the torso on extended arms by four months in prone.
- Types 2 and 3 (50–60%) babies show a discrepancy between upper and lower-body motor functioning. Type 2 infants have a strong upper back, neck, shoulders and arms, but are unable to bear weight on their legs.
- Type 3 infants have strong legs and lower torso, but a weaker upper torso, neck, head, shoulders, and arms.
- Type 4 (15–25%) babies are weak all over, with flaccid arms and legs and often have accompanying cardiovascular challenges.

The four patterns of muscle tone may be beneficial in the application of motor activities and the expectations of the child's abilities and therefore, ultimately the involvement of the parent during intervention. These different types of muscle tone may predict the length of intervention required, especially a Type 4 muscle tone. Low muscle tone is evident in

children with DS and therefore, facilitating of automatic reactions from an early age to enhance the muscle tone should be reflected in intervention (**cf.** 2.6.7.1).

Melyn and White (1973:544) as cited in Castillo (2008:142) did important research on the specific age delay in the motor development of the child with DS and this is helpful in comparative studies of typical development. As information on typical development is available, children with DS could be compared to typical development to establish their definite motor constraints (Christianson 1996:90). When a parent of a child with DS requests information on typical motor development, Table 2.2 may be useful. Castillo (2008:142) and Melyn and White (1973:544) have compiled tables on motor and speech development for children with DS. Melyn and White's table is still quoted by many as a seminal source (Harris 1981b:14; Lydic 1982:70; Palisano *et al.* 2001:494; Vicari 2006:356) and it serves as a guide for professionals treating or working with children with DS. The researcher found this information useful and effective in occupational therapy planning of treatment. Even though there are predicted ages for gross-motor development for children with DS and their atypical characteristics of, generalisations should not be made. There is a variation of possible development ages and that each child with DS develops at his/her own specific tempo. Table 2.2 for motor development was adapted and combined as follows for comparison:

Table 2.2: Motor development (adapted by the researcher)

Motor development	**Chronological Ages of DS** (Connolly *et al*. 1980:1408; Melyn & White 1973:544)	**Typical Development** (Nichols 2005:284)
Holds head erect	3.5 months–3.95 months	3 months
Roll over from prone	5.7 months–6.38 months	7 months
Crawling on hands and knees	12.5–12.9 months	8–10 months
Creeps	17.3 months	10 months
Stands momentarily alone	21.5 months	12 months
Walking	22.72 months–26.09 months	12–18 months
Hand to mouth (finger feeding)	24.3 months	9 months

According to Table 2.2, children with DS may start walking at 22.72 months where as typical developed children should walk at 18 months. It is therefore, important to render early intervention to try and decrease this delay, as it is not that considerable. The difference is only between four to eight months. Early intervention should be a priority for these children with DS to afford them the opportunity to decelerate the observed decline in motor development (Connolly *et al*. 1980:1405).

The information on gross-motor development describes the constraints predicted in the child with DS and predicts developmental delays. Latash, Wood and Ulrich (2008:6) state that the acquisition of stable motor skills may be important for the cognitive development of the child with DS. Johnson and Blasco (1997:224) further state that immobility prevents exploration of the environment and, in turn, inhibits cognitive development occurring through the manipulation of objects. This information on improved gross-motor development that could assist in cognitive development should therefore motivate health professionals to influence the gross-motor development of children with DS from an early age. Development is an overlapping process and has a sequential order, for example, if one sequence develops, the next development of sequence has already begun to develop

(Colangelo & Shea 2010:491). Taking this information in consideration it is important to discuss the child with DS's motor patterns. In the following section these motor patterns will be discussed.

2.3.3.1.1 Description of motor patterns/motor problems during the development of basic movements:

Infants with DS have obvious motor difficulties that are confined to rhythmic milestones such as rolling, reaching for objects in midline, standing and stepping. Non-rhythmic milestones are sitting and creeping/crawling (Cobo-Lewis, Oller, Lynch & Levine 1996:457). The child with Down syndrome's sequential development is similar to typical developing children despite the rhythmic and non-rhythmic difficulties (Mazzone *et al.* 2004:120) and should validate the possibilities for children with DS even with constraints. Therefore, children with DS should have opportunities and not be underestimates (Lydic 1982:68). Further knowledge of motor patterns is essential when working with children with DS and with the development of an early-intervention programme. Motor patterns include milestone development and form the basis for intervention (Nilholm 1996:51; Wu, Ulrich, Looper, Tiernan & Angulo-Barroso 2008:268). Lauteslager (2000) developed an early-intervention programme for motor development that can be applied by a physiotherapist. In this programme (2000:68–74) the motor patterns of the child with DS are described in detail.

a. Motor ability when in prone position

Correct positioning is important to postural reactions and control and important to attain motor milestones (Colangelo & Shea 2010:490; Lauteslager *et al.* 1998:7; Olsen 2010:190). Further more prone positioning may be a key component in gross-motor development, as will be discussed in Chapter 3 (**cf.** 3.3.3.2.2b).

As early as 1970, the child with DS's prone position was described as being extremely flat (Lauteslager *et al.* 1998:7). The following description is based on the work done by Lauteslager (2000:68). With the Landau reaction it was noted that there is a lack of trunk extension and self-righting reactions of head and limbs. It was found that there is a connection between the degree of muscular hypotonia and lack of trunk extension and self-righting reactions. These children have a problem maintaining the position of the head

relative to the trunk. Some children compensate for this by resting the head on the neck to support the head position. Other children raise their head by supporting and transferring weight to extended arms that will ultimately extended through the trunk and hips. This lack of shoulder girdle and trunk stability may be the result of inadequate co-contractions because of the hypotonia (Colangelo & Shea 2010:524; Lauteslager *et al.* 1998:7).

The prone position encourages the development of extensor control of the head and neck, and in fact the motor development of infants. It appears that lack of experience of the prone position may result in decreased opportunities to learn motor skills requiring antigravity extension, such as crawling or pulling into the standing position (Colangelo & Shea 2010:524; Russell, Kriel, Joubert & Goosen 2009:11).

b. Motor ability in supine position

A “frog-like” position of the legs frequently occurs among children with DS while lying in supine (Lauteslager 2000:69). This is symptomatic of hypotonia. The hypotonia thought to be the cause of the position, because co-contraction has not been stabilised between the shoulder and hip joints (Colangelo & Shea 2010:500, 523; Lauteslager *et al.* 1998:7). As children with DS prefer a “frog-like” position it influences rolling over negatively.

c. Rolling over

Lauteslager *et al.* (1998:7) and Lauteslager (2000:25) describe the absence of trunk rotation in rolling over. The rolling over from back to front or the other way around occurs without dissociation between the shoulder and pelvic girdles of the child with DS (Lauteslager 2000:70). According to Lauteslager *et al*. (1998:7), as a result of hypotonia in the legs of children with DS, the legs play a relatively minor role in rolling and therefore, rolling is severely delayed (Cobo-Lewis *et al.* 1996:464). Colangelo and Shea (2010:527) recommend the side lying position to achieve dissociation of the body. This dissociation is necessary for rolling.

d. Moving forward on the ground

Moving forward on the ground happens when children with DS push themselves forward. They symmetrically support themselves on their arms and hands with no reciprocal

movements of the lower and upper extremities (Lauteslager 2000:70). For the child with DS crawling is a major challenge. However, a pattern of alternating “creeping” is displayed among some children with DS (Lauteslager *et al.* 1998:8).

e. Sitting posture

The sitting posture of the child with DS is described as follows: widely abducted hips and extended knees, with no trunk rotation. These children do not change their sitting posture very much and side-sitting rarely occurs (Lauteslager 2000:71). A static sitting posture is stabilised by extending the base and supporting weight with extended arms on the upper legs or the ground (tripod sitting). Any transfer of weight in this position is supported by arms and extended legs. Trunk extension and rotation are hardly ever observed. The head frequently rests on the neck for support (Lauteslager *et al*. 1998:8). This static sitting posture leads to a lack of balance and stability, together with hypotonia (Colangelo & Shea 2010:500, 529; Lauteslager *et al*. 1998:8).

f. Mobility in the sitting position

Children with DS demonstrate atypical movement patterns in coming to a sitting position. This influences transitions of movement patterns and the mobility independence of the child with DS. Children with DS use extreme symmetrical hip abduction to push themselves up from a prone to a sitting position (Lauteslager 2000:72). There is no crossing of the midline and this should be addressed in intervention programmes. The lack of trunk rotation results in compensatory movement patterns which reduce postural reactions (Abdel Rahman & Shaheen 2010:37). Hypotonia, especially Type 4, and the relatively short length of the arms are causes for this lack of trunk rotation when coming up into a sitting position (Lauteslager *et al.* 1998:8). Lauteslager (2000:29) observed that side-sitting or trunk rotation with crossing of the midline is not part of the movement patterns of these children. This observation was made by Lauteslager (2000:72) regarding side-sitting as an important principle for inclusion in an early-intervention programme, although it was not specifically included in his gross-motor intervention programme.

g. Standing

Children with DS have a tendency to stand, while supported, with over extended knees without attempting to step or jump, suggesting a deficiency in postural regulation (Lauteslager 2000:73). Balance problems also occur in standing. These children have a tendency to start with bear walking in reverse, where after standing occurs (Colangelo & Shea 2010:527; Lauteslager *et al*. 1998:8).

h. Standing up from sitting

The standing posture demonstrates exaggerated flexion of the trunk to compensate for the instability. The walking pattern is executed with a wide-based walk and a Duchenne-like gait with excessive hip ex-rotation and an abnormal arm position (Lauteslager 2000:74). During walking, there is a lack of trunk rotation (Lauteslager *et al.* 1998:9). With the correct specific intervention, the children with DS should have improved postural control in standing. The preparation for walking starts at the beginning of the intervention by influencing muscle tone.

The importance of positioning and transition of positions were emphasised by Colangelo and Shea (2010:523-529), Lauteslager *et al.* (1998:7, 8) and Lauteslager (2000:25, 29).

2.3.3.1.2 General movements

The importance of this section in this study is that general or Fidgety movements are a predictor of gross-motor development outcomes. General or Fidgety movements are commonly referred to as Writhing Movements that change to a Fidgety pattern, defined as an on-going stream of small, circular and elegant movements of the neck, trunk and limbs. Prechtl and Einspieler (1997:1365) describe Fidgety Movements (FMs) as circular movements of small amplitude and moderate speed; they are continual in the infant while awake, except during focused attention. General movements are transient in healthy infants and are a valid predictor of later neurological outcomes and motor performance (Prechtl & Einspieler 1997:1374). Abnormal Fidgety or Absent Fidgety movements are indicative of a poor outcome in motor performances (Mazzone *et al.* 2004:120). Mazzone

et al. (2004:123) found that children with DS have normal general movements and supports the findings found in normal children.

Prechtl describes the use of general movements as an observational tool (Brown 2009) and positive prediction for motor development. General movements are present among children with DS and are generally characterised by low speed, large amplitude, absence of fluency and smoothness, with decreased variability of limb movements, absence of small-ranged limbs movements and other gross movements (Mazzone *et al.* 2004:123).

2.3.3.2 Fine-motor development

In order to incorporate fine-motor development in an early-intervention programme the explanation of the typical neurophysiology is important. Fine-motor and gross-motor development should be seen as two developmental units, as these two development domains are different in their neurological status and biomechanics.

Biomechanics involve smooth co-contraction and grading of muscle activation around joints, length of muscles and soft tissue structures. Aspects of the central nervous system combine the motor, sensory, cognitive, perceptual, and affective neuronal groups simultaneously. This creates the experience of moving the arm and hand as it contacts an object (Barthel 2007:1/3). According to Exner (2005:304), effective use of the hands depends on hand skills, postural mechanisms, cognition and visual perception.

To understand the fine-motor and gross-motor development, information on the **neurological status** should be discussed. The control of the spinal motoneurons by the cerebral cortex via the lateral corticospinal tract provides the hand with its significant motor repertoire (Kuhtz-Buschbeck & Ulmer 2008:25). The corticospinal tracts have predominantly motor functions, especially the lateral corticospinal (pyramidal) tract, for skilled and willed movements (Kiernan 2009:19). The vestibulospinal tract stimulates the flexors of the upper limb and extensors of the trunk and lower limb (Kiernan 2009:17).

Descending motor pathways together with their associated cortical areas and sub cortical nuclei, motor neurons, the basal ganglia and cerebellum comprise the systems for controlling skeletal muscles that guide movements of the limbs and trunk. Descending fibres of motor neurons in the cerebral cortex are divided into two complementary, but

overlapping systems, both the corticospinal (pyramidal) and extra-corticospinal system. They initiate voluntarily planned and fine skilled movements (corticospinal). It sets a background of an appropriate body posture for efficient, accurate, voluntary movements (extra-corticospinal). The corticospinal tracts are the main tracts for nearly all voluntary muscle activity in the contralateral trunk and limbs. The distal limb musculature is responsible for the finer discreet movements. This is preferentially controlled by the lateral corticospinal tract. The proximal limb musculature and axial muscles of the neck, shoulder and trunk are controlled by the anterior corticospinal tract (Afifi & Bergman 2005:59–61).

The term extra-corticospinal (extra-pyramidal) motor system denotes all those portions of the brain and brain stem that contribute to motor control that are not part of the direct corticospinal-pyramidal system. This includes pathways through the basal ganglia, the reticular formation of the brain stem, the vestibular nuclei and the red nuclei. The indirect system is mainly concerned with maintenance of body posture and gross movements and also provides continuous adjustments necessary for a suitable background for fine, precise movements. The impulses conducted in the vestibulospinal tracts facilitate extensor muscle tone in the anti-gravity maintenance of posture and play a role in the control of the position of the head. Somatosensory information from proprioceptive receptors maintains the position in space and postural control by coordinated motor outputs. Proprioceptive muscle receptors like the muscle spindle and Golgi tendon organ, are the primary receptors that convey position sense. The pathway for conscious proprioceptive impulses to the cerebrum is via the posterior column-or fasciculus gracilis and cuneatus system. The spinocerebellar tract conveys unconscious proprioceptive impulses relating to muscle contraction, which results in coordinate movements (Afifi & Bergman 2005:72). The neurophysiology of the motor development is both unique and complex; and therefore, gross-and fine-motor development should not be seen as a single entity (composite).

As play is the primary occupation of children, fine-motor skills develops through the manipulation of play material. Therefore, an absence of explorative play would create a considerable barrier to fine-motor development. The fine-motor skills involve eye-hand coordination, balance, laterality, visual motor activities and reaction time (Aparicio & Balaña 2009:631; Connolly *et al.* 1993:175). As children with DS find opportunities to enhance their postural control, independent hand function will help with play and activities of daily living (Adolfsson 2011:37).

According to published literature a child with DS's fine-motor skills are more severely impaired than gross-motor skills (Castillo 2008:142) with problems in accuracy and timing of specific tasks that require bilateral coordination. Dolva, Coster and Lilja (2004:627), found that poor fine-motor skills may be disabling for children with DS, especially for cognitive development. This is important, as these functional skills are necessary for writing and for the formation of letters (Amundson 2005:588). As the child with DS starts life with many constraints or domino-effect delays in relation to the typical developed population, the developmental outcome for the child with DS is at risk without specific intervention.

2.3.4 Sensory development

The processing of sensory information is fundamentally a component of life. Daily events and situations are drenched with sensation (Watling 2010:439). The infant's first sensory experiences are what they see and hear (Ayres 2005:13). The sense of touch is already functional during the period in utero and later it is also associated with emotional satisfaction (Ayres 2005:16). Sensory development is reflected in the way a child responds to the different sensations such as sight, sound, touch, smell, movement and taste (Bayley 2006b:9). According to Ayres (2005:16-18) touch, sight, hearing, smell and taste are developed during the first month after birth. An individual understands what is happening in the world through hearing and vision and to have the ability to experience and interpret information (Russel & Nagaishi 2010:744). As eye defects occur in 60% of DS cases and hearing defects may occur in 50% of cases (Bhatia *et al.* 2005:679; Capone 2004:48; Castillo 2008:136; Committee on Genetics 2001:442–444; Gémus *et al.* 2001:70; Marder & Cholmáin 2006:497; Palisano *et al.* 2001:494; Van Cleve & Cohen 2006:48) it is imperative that stimulation of sensory development should commence from as early as possible. The parent as the primary caregiver has the advantage to be able to assist the children with those aspects of their development that are dependent on sensory experiences. The involvement of parents in a stimulation programmes that includes activities supporting the sensory development of the child are important, as it will contribute to functional emotional capacities that are influenced by sensory development.

Sensory inputs enable the perception of the position of the body in space and result in better body posture and quality of movement (Uyanik & Kayihan 2009:4/22). From this perspective, sensory activities are crucial in an intervention programme.

Sensory development encompasses all the senses and not only hearing and vision. Tactile sense is necessary the body movement, but is especially important in the hands. When there is sensory loss in the hand, fine-motor coordination is impaired and the manipulative ability will decrease (Radomski & Trombly-Latham 2008:213; Uyanik & Kayihan 2009:3/22). This may then lead to delays in the cognitive development (**cf.** 2.3.3.1; 2.3.3.2). Envisage a child with DS without the positive touch of the parent for fear of handling a child with a disability. The child will not only be emotionally detached from the parent, but opportunity to development will also be lost for the child with DS. When a stimulation programme encourages a parent to touch and assist their child, the child will not only benefit emotionally, but motor development will benefit. This should be a motivation to the development of specific early-intervention programmes.

2.3.5 Social development

Although social milestones begin with bonding, it reflects the feeling of the parent/caregiver for the child (Johnson & Blasco 1997:240). The research did not include the personality of the child with DS and therefore, no attention was given to the personality characteristics. The involvement of parents of children with DS should not be underestimated. Parents should be empowered to engage with their children with DS and a specific early-intervention programme should address this (**cf.** 3.3.3.2.4). Fortunately, in children with DS the incidence of behavioural problems and psychopathology are typically low (Castillo 2008:143). Children with DS use their strengths in social skills to counterbalance other weaker developmental domains. They further show definite competence in forming relationships (Fidler *et al.* 2006:38). It is important to convey this positive information on social development of the child with DS to the parents, who may have been inundated with negative feedback.

This section discussed the general development of the child with DS. The next section explains the integration of intervention of the child with DS into the International Classification of Function, Disability and Health Framework for Children and Youth (ICF-

CY) (Adolfsson 2012:2; Adolfsson 2011:15; Simeonsson, Leonardi, Bjorck-Akesson, Hollenweger, Lollar, Marhinuzzi & TenNapel 2006:3).

2.4 THEORECTICAL BACKGROUND ON ICF-CY

In the previous section, the problems surrounding the development of children with DS were highlighted. The researcher used the principles of the International Classification of Functioning, disability and health Framework for Children and Youth (ICF-CY) to guide the development of the DRSP. The ICF-CY was not selected to measure outcomes *perse*, but a checklist was developed (**cf.** 4.4.4.1). It is, however, important to have a theoretical understanding of the ICF and ICF-CY in order to inform on matters of intervention and research.

The ICF has the potential as a clinical problem-solving tool for rehabilitative clinical care (Jette 2006:731). Described frameworks in the medical, social and bio-psychosocial models do not include the correct emphasis on intervention. The ICF is based on an integration of the medical and social models (Ross & Deverell 2004:15). The ICF also contributes to more effective treatment, as the family's needs and goals are addressed and importantly, therapists and family work towards the same activities and goals (Alers 2008:10).

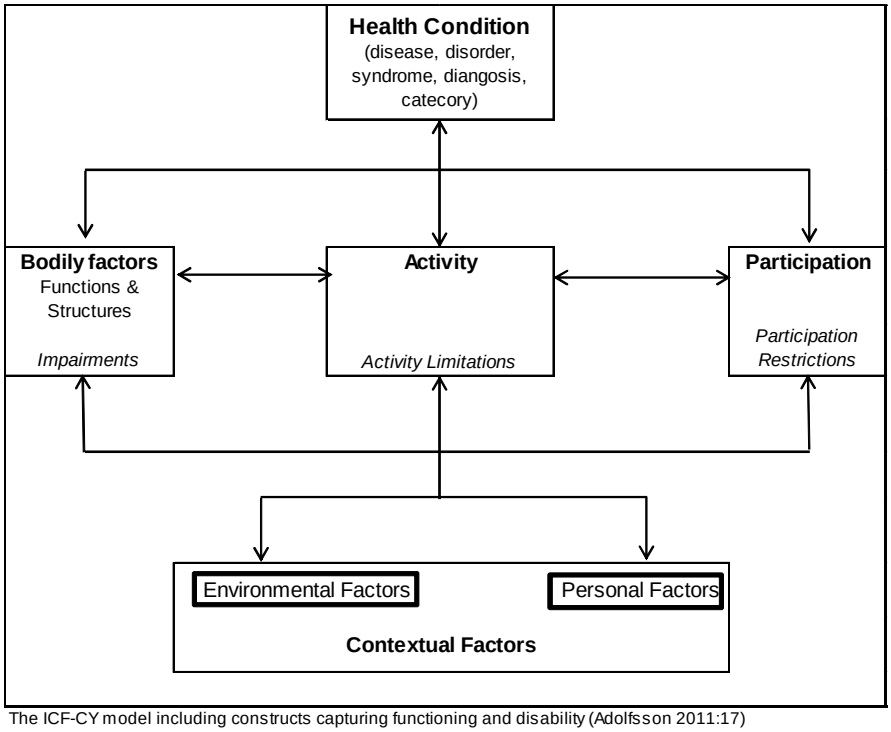
The ICF adult version was published in 2001 and the ICF-CY in 2007. Both are functional frameworks that classify health outcomes and can be used to describe functioning of all people, not only persons with disabilities (Adolfsson 2011:16). The ICF-CY includes all content in the adult version ICF with additional information to cover developmental functional characteristics of children from birth up to 18 years of age. Therefore, the ICF-CY is most applicable to this research.

The ICF was approved by the World Health Assembly in May 2001 (Jette 2006:730). This classification describes functional states associated with health conditions (Cieza, Brockow, Ewert, Amman, Kollerits, Chatterji, Üstün & Stucki 2002:205). The overall aim of the ICF or ICF-CY is to provide a unified and standard (common, global) language and useful contextual framework for the description of functioning, health and health-related states (Adolfsson 2012:2; Adolfsson 2011:15; Alers 2008:4; Carpenter & Suto 2008:10;

Engelbrecht, Casteleijn & Uys, 2008:8; Fearnhead & Knox 2005:5; Kramer & Hinojosa 2010:32; Ross & Deverell 2004:14; Simeonsson 2009:71; Weigl, Cieza, Andersen, Kollerits, Amann & Stucki 2004:13). The ICF-CY is an interactive health model with a complex relationship between six dimensions (Adolfsson 2012:3-4; Adolfsson 2011:17). The ICF-CY can contribute to practise and research in the following manner (Simeonsson 2009:71; Simeonsson *et al*. 2006:3):

- Provide a framework for inter-disciplinary practice
- Produce profiles of child functioning
- Clarify clinical diagnoses and co-morbidity
- Provide a functional basis for planning individualised treatments or interventions
- Offer codes for identifying intervention outcomes
- Provide the basis for documenting the gradient and hierarchy of change of functioning
- Standardise documentation of variables in research.

The following figure is a visual explanation of the ICF-CY.



The ICF-CY model including constructs capturing functioning and disability (Adolfsson 2011:17)

Figure 2.2: ICF-CY

The ICF-CY has six dimensions (Adolfsson 2011:17):

- Bodily factors are divided into functions and structures. The human function, such as the functioning at the level of body or body parts, the whole person and whole persons in their broad environment (Jette 2006:730; Ross & Deverell 2004:14).

- Activities such as the ability to perform actions (execution of a task or action). These activities cover the full range of life areas, from basic learning to social tasks (Adolfsson 2011:19).

- Participation, such as the experience of being part of society. These activities and participation have nine daily life-area domains, namely learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life (Cieza *et al.* 2002:205).

- Contextual factors, including environmental factors and personal factors (Luebben, Hinojosa & Kramer 2010:35). The environmental factors include physical, social and attitudinal factors. The personal factors provide a background of a child's life and living, such as age, gender, race and habits (Adolfsson 2011:19).

Descriptions of functional and environmental aspects according to Adolfsson (2011:17) are needed to attain a holistic view of a child's everyday life situations as simply naming a disorder or disease cannot describe everyday functioning of the child. According to Adolfsson (2012:9; 2011:34), sleep is not included in the ICF-CY component. Activities and Participation as a daily routine associated with self-care. However, it could be interpreted as 'rest' and linked as leisure activity (Adolfsson 2012:9).

The ICF-CY recommends the use of qualifiers with values from 0 (no problem) to 4 (complete problem). The researcher used qualifiers with values from 0 (unable to perform task/complete difficulty) to 4 (no problem/no difficulty/fully independent) in this study (**cf.** 4.3). Explaining improvement in development to parents indicate that a four is a higher number than zero and the reason for the values different from the ICF-CY.

The philosophy of occupational therapy to engage people in dignified participation and in meaningful occupations to be integrated into society, included in all aspects of life and thus improving quality of life is the same as described in the ICF-CY (Alers 2008:10). The occupational therapist has the knowledge to adopt a holistic approach for the early intervention of children. Occupational therapy will be reviewed using components of the Occupational Therapy Practice Framework in more detail in the next section of the literature study (Creek 2009:109).

2.5 OCCUPATIONAL THERAPY

According to the Health Professions Council of South Africa, the Occupational Therapy Scope (*Health Professions Council of South Africa Website* 2009:1/2) of the profession refers to the goal to evaluate, improve or maintain health, development, functional performance and self-belief of those in whom these are impaired or at risk. Occupational Therapy engages people in dignified participation and in meaningful occupations to be integrated into society, included in all aspects of life and thus improve quality of life, as described in the Occupational Therapy Practice Framework (Creek 2009:109; Rogers & Holm 2009:483). The Occupational Therapy Practice Framework: Domain and Process, 2nd Edition (OTPF) was recently introduced for use within the profession and is an official document of the American Occupational Therapy Association (AOTA 2008:625). The OTPF was developed to be consistent with the ICF (Case-Smith 2010c: 193) (**cf.** 2.4). It defines occupational performance as the result of the dynamic collaboration between the client, the context and the activity. The client factors are the development of performance skills to fulfil their social roles by engaging in the eight areas of occupation. The eight areas of occupation are activities of daily living, instrumental activities of daily living, education, work, play, leisure, sleep and social participation (AOTA 2008:631-633). The context includes seven inter-related conditions such as cultural, physical, social, person, spiritual, temporal and virtual (Rogers & Holm 2009:483).

Occupational therapy focuses on pleasure, productivity and restoration (Pierce 2001:252). The occupational therapist aims to prevent and reduce inability, and initiate residual change within the person. As seen in the ICF-CY, the occupational therapist needs to understand the client's environment, roles and developmental stage in order to measure the person's abilities and performance (AOTA 2008:642) (**cf.** 2.4). As play is the primary

occupation of children, it is important to understand play. The literature suggests that the way in which a child approaches play is more important than the play activity itself (Bross, Ramugondo, Taylor & Sinclair 2008:3).

The term *occupation* (units of activity) and related terms such as *activity*, *task*, *employment* and *work* are used in many ways within the profession (Adolfsson 2011:29; Jette 2006:730). It is everything people do to occupy themselves, which include self-care, leisure/play and productivity. Occupation comprises consistent patterns of action that emerge through transactions between the child and the environment, as seen in the OTPF (Dickie 2009:17–18). Blesedell-Crepeau, Cohn and Boyt-Schell (2009a:217) explain the concept as the day-to-day activities that people undertake which are important and meaningful to their health through engagement in valued occupations.

Regarding the correlation and relationship between the ICF-CY and OTPF will be discussed in the following section.

2.5.1 Correlation between ICF-CY and OTPF

There is a correlation and relationship of concepts between the ICF/ICF-CY and OTPF that will be described in more detail (Bendixen & Kreider 2011:352; Rogers & Holm 2009:484, 485). At the time of the research a table that illustrates the correlation and relationship between the ICF-CY and OTPF had not been compiled. There is however a table compiled by Leubben *et al.* (2010:34) that shows how the ICF an OTPF are interlinked. The limitations of this table are that sleep and rest were excluded, because it is described in the ICF-CY (Knox 2010:543; Luebben *et al.* 2010:36; Rogers & Holm 2009:484). It was decided to use this table as the OTPF was developed to be consistent with the ICF (Case-Smith 2010c:193). A description of the table follows.

Table 2.3: Comparison ICF & OTPF

	OTPF							ICF								
	Areas of Occupation							Activities and Participation (Daily Life Area Domains)								
Life Areas (Occupations)	Activites of daily living	Instrumental ADL	Education	Work	Play	Leisure	Social participation	Learning and applying knowledge	General tasks and demands	Communication	Mobility	Self-care	Domestic life	Interpersonal interactions and relationships	Major life areas	Community, social, civic life
Foundational (Body-Level) Components	Client factors		Performance skills		Performance patterns		Activity demands	Body Functions and Structures								
								Mental	Sensory	Voice and speech	Cardiovascular, hematological, immunologica, respiratory	Digestive, metabolic, endocrine	Genitourinary, reproductive	Neuromusculoskeletal, movement-related	Skin and related structures	
Contextual factors	Context							Contextual Factors								
								Environmental Factors								
	Cultural	Physical	Social	Personal	Spiritual	Temporal	Virtual	Products, technology	Natural environment, human-made changes to the environment			Support, relationships		Services, systems, policies	Personal factors	

Note: Luebben *et al.* 2010:34

ICF-CY: Activities and participation (daily life-areas domain) (Adolfsson 2011:28)

OTPF: Areas of Occupation (Leubben *et al.* 2010:34; Rogers & Holm 2009:485)

The occupational-therapy profession uses the term *occupation,* whereas the ICF-CY uses the term *activities* and *participation* (Adolfsson 2011:27; Luebben *et al.* 2010:35). The ICF-CY (**cf.** 2.4) describes an Activities and Participation subdivision that consists of nine daily

life-area domains. The occupation domain of the OTPF includes all the daily life-area domains of the ICF-CY, namely activities of daily-living, instrumental activities of daily living, education, work, play, leisure, sleep, rest and social participation (Knox 2010:543; Luebben *et al.* 2010:36; Rogers & Holm 2009:484).

- When an occupational therapist does evaluation and intervention, information from the *learning and applying knowledge* domain is applied. An example may be to analyse the specific functional activity needed to overcome the restrictions of motor-developmental delay such as inefficient head control, sitting, crawling, rolling, walking and hand function.

- Aspects of the *general tasks and demands* domain are used when working with clients on carrying out a daily routine (Kellegrew 2000: 258). In this study, the daily routineat home was incorporated in the execution of the programme by the parent/caregiver. Activities were therefore part of the daily routine of the parent/caregiver caring for their child with DS.

- In the *communication* domain, the occupational therapist uses aspects such as repeating actions with words and comprehensive body gestures.

- The *mobility* domain is a major domain when working with children with DS. This includes changing and maintaining body positions, transferring from one position to another, lifting and carrying objects/toys, walking and moving. Mobility is the accumulating factor of preparatory development to assist in other areas of development such as cognitive and speech abilities. The quality of mobility is important for the development of the other development areas.

- The *self-care* domain includes eating, drinking, washing oneself, toileting, dressing and caring for body parts. This may be done with the parent/caregiver, the child, or both. In literature, the term, *adaptive behaviour,* is used to describe and measure functional skills in this domain (Daunhauer & Fidler 2011:14) (**cf.** 4.3.7.2.2).

- The *domestic-life* domain includes activities such as putting away toys.

- The *interpersonal interactions and relationships* domain during participation of stimulation activities is within the occupational therapy scope of practice (**cf.** 2.5). This domain has a long-term effect in forming relationships. According to literature (Ross & Deverell 2004:79), there is a social stigma attached to families with children with DS and they may become isolated from the community. Assisting parents/caregivers to accept and support the child with DS may contribute positively to better integration into society.

- The domain *major life areas* include formal as well as informal education.

- Finally, the *community, social and civic life* domain includes play, recreation and leisure (Knox 2010:549; Luebben *et al.* 2010:37). Play, recreation and leisure activities are a natural part of a baby/child's life and these encourage skills development through involvement with objects and interaction with others (Case-Smith 2010b:65).

ICF-CY: Body Functions and Structures (Adolfsson 2011:19)

OTPF: Client factors, performance skills, performance patterns, activity demands (Luebben *et al.* 2010:34; Rogers & Holm 2009:485)

This subdivision has two sections, namely body functions and body structures. The body structures relate to the anatomical parts of the body and the body functions to the physiology. These structures include mental functions, sensory functions and voice and speech functions. Client factors of the OTPF correspond to ICF-CY bodily factors (**cf.** 2.4), namely functions and structures and performance-skills subparts, motor and process skills, have some similarities and performance patterns are mixed within the ICF. Activity demands correspond to ICF-CY general tasks and demands (Adolfsson 2011:29; Luebben *et al.* 2010:34; Rogers & Holm 2009:485).

The researcher will focus on three primary systems at the body-function and structural level, as described in the literature, namely sensory functions and pain, neuro-musculoskeletal and movement-related functions, and mental functions (Luebben *et al.* 2010:39–40) (**cf.** 2.4). The concepts in the sensory functions are the ability to take in sensory information and process the information. Identifying the specific underlying

impairments, which prevent those functional activities, may result in delays in sensory, cognitive, speech and social development.

ICF-CY: Contextual Factors (Adolfsson 2011:19, 36, 41)

OTPF: Context (Luebben *et al.* 2010:34; Rogers & Holm 2009:485)

The Contextual Factors of the ICF-CY have two subdivisions, namely environmental factors and personal factors (**cf.** 2.4). The categories within these environmental factors have an impact on the child's ability to engage in life-area domains. The OTPF context consists of cultural, physical, social, personal, spiritual, temporal and virtual factors (Luebben *et al.* 2010:34). The personal factors include gender, race, age, fitness, lifestyle and habits that are grouped together (Rogers & Holm 2009:484).

2.5.2 Principles to guide occupational therapy

Blesedell-Crepeau *et al*. (2009a:218) states that the occupational therapist should engage in research to promote the development of the knowledge base of the profession. According to these authors, there are three principles to guide contemporary occupational therapy:

- Client-centred practice
- Occupation-centred practice
- Evidence-based practice

In order to execute the intervention for the child with DS and the study, the researcher followed the principles of a client-centred and evidence-based practice in this study (**cf.** 2.6.7.3).

The following section gives a broad literature overview and perspective on what has been published on intervention for the child with DS over the years.

2.6 INTERVENTION

In occupational therapy, effective intervention is to provide “just right challenge” to promote and improve the developmental skills needed for the child with DS. As it is stipulated by Rogers and Holm (2009:479), clients are capable of meeting their own daily occupational needs. Therefore, the occupational therapist should assist and guide the parents with children with DS to engage in early intervention and not be excluded. The various associations who work with DS only mention Physiotherapy and Speech Therapy as possible early-intervention treatment according to electronic searches. Following the foundation set by these therapies, occupational therapy only then plays an important role in assisting children learning the necessary skills for making the transition to independence (Carrie with Children 2011:2/7; Colorado Springs Down Syndrome Association 2011:2/3; MEDSavailable 2012:1/2; *NHSChoices website* 2012:2/4).

Scientific published literature, Down Syndrome Association websites and support groups all have similar goals for early intervention (Colorado Springs Down Syndrome Association 2011:1/2; Down Syndrome South Africa 2010:1/4; Eastern PA Down Syndrome Center 2012:1/6; Heyn 2012:1/15; Majnemer 1998:67; MEDSavailable 2012:1/2; New York State Department Of Health n.d.:106*; NHS Choices website* 2012:2/4). According to Fergus (2009:1), early intervention is a systematic programme of therapies, exercises and activities designed to address developmental delays specifically experienced by children with DS (Colorado Springs Down Syndrome Association 2011:1/2; Down Syndrome South Africa 2010:1/4; Heyn 2012:1/15; Majnemer 1998:67; MEDSavailable 2012:1/2; New York State Department Of Health n.d.:106; *NHSChoices website* 2012:2/4). Berg and Korossy (2001:211) describe a case study, undertaken by Séguin in 1866, who found that despite their “disagreeable appearance and apparent stupidity”; children with DS are morally good. Even after major obstacles that they had to overcome, the child in the case study was still cast away as “repulsive and incurable”. Fortunately, the modern attitude has changed and early-intervention programmes are reported to have a positive influence on adaptive and cognitive skills (Capone 2004:49; Carr 1995:6; Connolly *et al.* 1980:1407; Fidler 2005:97).

According to Lloyd (2009:1), intervention means “coming between” any negative and disabling effect that a developmental delay or disability might have on the developmental

process in general. Intervention is the attempt to minimise or sometimes prevent the impact of the disability or delay on the child's development. Early intervention for the child with DS is important because of the initial typical development until six months followed by delays in certain domains of their development (**cf.** 2.3). Even though intervention in the different development areas of the DS is discussed separately, intervention should not be done in isolation, but a holistic approach should be followed.

2.6.1 Early Intervention

Early intervention for the occupational therapist describes services for children from birth to three years, who have developmental delay or at risk (Meyers, Stephens & Tauber 2010:861).

Early intervention is important for the child with DS as they were among the first to be "mainstreamed' in public schools. This came to be because of the efforts of parent advocacy groups. They have been the pioneers in the trend toward inclusion (Roizen 2013:316). The international drive for future expectations of children with DS is to **mainstream** them in regular schools (De Graaf 2012:22/27). However, the same inclusion does not occur in South Africa (Engelbrecth 2012:19/22). This may be as awareness in South Africa has been neglected or that the children with DS at a school going age are not equipped to function in a mainstream school. The largest longitudinal study of education outcomes of 11 000 students with different intellectual disabilities, the National Longitudinal Transition Study, showed that more time spent in general education classroom positively correlated with higher scores on standardised tests in reading and mathematics (McVay 2012:21/133). Therefore, more emphasise should be on early intervention to help more children with DS to be enrolled into "mainstreaming".

The goals of early-intervention programmes are achieved by providing developmental and therapeutic **services for children**. Support and instructions for their families are part of the programme (Lloyd 2009; Spiker & Hopmann 1997:5/36). Studies have shown that the progressive slowing of the intellectual development of children with DS can be minimised by the provision of early educational input via time-sensitive interventions (Connolly *et al.* 1993:177; Fidler 2005:99; Kwong & Wong 1996:156; Woods, Corney & Pryce 1984:287).

Prior to 1981, the early development of children with DS had been well documented. However, there are **limitations to the availability of literature** on the application of early intervention programmes and therapeutic interventions. According to the following studies, there were only two evaluation processes involved in early-intervention programmes (Denhoff 1981:32; Lauteslager 2000:44; Piper & Pless 1980:463; Wang & Ju 2002:443). In a review the intervention programmes themselves were not questioned, but the statistical evidence of the effectiveness was challenged. Control groups are difficult to justify ethically. According to the literature there are methodological issues in terms of documenting effectiveness and that there should be a differentiation between experimental evidence and clinical accountability (Simeonsson, Cooper & Scheiner 1982:639; Ulrich, Ulrich, Angula-Kinzler & Yun 2001:7).

Early intervention includes early-detection, child- and family-centred intervention, and psychological support for parents and interdisciplinary input (Pretis 2000:24). The team for the **interdisciplinary** input should consist of doctors, paediatricians, community doctors, health visitors, occupational therapists, physiotherapists, speech therapists and social workers (Harris 1980:421; Woods *et al.* 1984:291). The key to success in early intervention is the collaboration between the team members and caregivers within their home or the child-care setting (Cohn 2009:397; Stephens & Tauber 2005:781; Van Hooste & Maes 2003:304).

Occupational therapy includes services in early intervention to address the functional needs of a child to adaptive development towards adaptive play, sensory, motor and postural development (Meyers *et al*. 2010:682). Early-intervention programmes **consist of therapies, exercises and activities**, but there appears to be no specific programme developed for babies and children with DS (Uyanik & Kayihan 2009:7). Furthermore, there are a few studies on intervention that focus exclusively on children with DS younger than six months (Carr 1988:409; Del Giudice *et al*. 2006:52; Hines & Bennett 1996:99; Wasant *et al*. 2008:1031). The majority of documented studies are on older children with DS. Studies done by Capone (2004:48), Fidler *et al.* (2006:40,43), Kubo and Ulrich (2006:513), Uyanik *et al.* (2003:2) and Villamonte (2009:5) include children from two years onwards, or adolescents and adults only with DS, in their research. An occupational-therapy study done by Dolva *et al.* (2004:621) includes five-year-old children with DS. In other studies mentioned by Castillo (2008:150), Harris (1980:420), Palisano *et al.* (2001:494) and Piper *et al.* (1986:184), it is found that early intervention is beneficial to the child with DS, but the

programmes mentioned consist of treatment methods such as NDT and not a specific intervention programme. One early-intervention programme for children with DS, mentioned by Capone (2004:48), focuses on motor and speech development, involving a physiotherapist and speech therapist only. Cognitive development was not part of this programme, and there was no evidence of an attempt at a holistic approach.

2.6.2 Intervention and cognitive development

As stipulated in the section on cognitive development (**cf.** 2.3.1), it is important that definite measures are taken to develop programmes that will assist parents to intervene in the cognitive development of their child with DS. According to Brassard and Boehm (2007:5), high expectations for children with disabilities and their participation in regular curriculums are important in order for them to become independent adults. This also strengthens the ability of the parents/caregivers to participate meaningfully in their child's education at home.

If the message from International Down Syndrome Association is ignored, the drive for the placement of children with DS in mainstream schools will not materialise. The effects of early intervention on cognition, as measured by Intelligence Quotient, are relatively concise (Capone 2004:52). Early-intervention programmes focus on the acquirement of gross- and fine-motor skills, speech and language skills, reading and writing skills, and educational strategies. There is an increasing demand for these specialised services from parents and therapists who recognise that exposure of children with DS to these training programmes improves the academic prognosis of the child with DS (Saenz 1999:392). The literature emphasises the importance, but specific early-intervention programmes are not described. It is essential for early-intervention programmes to be developed which could render the required intervention for children with DS and their parents.

2.6.3 Intervention and language development

Piper *et al.* (1986:184) documents the development, in a variety of domains, of a group of infants with Down's syndrome enrolled in an early-intervention programme. The specific programme used is not mentioned and not readily available. They found that these children initially displayed a global developmental delay, as was measured by either mental age or developmental quotient. They also found that the largest degree of developmental delay was in the area of language acquisition.

2.6.4 Intervention and motor development

There is limited research regarding the effectiveness of gross-motor intervention programmes in children with DS (Castillo 2008:150; Mahoney *et al.* 2001:153). Harris (1980:420) describes the decline of motor development, but she feels the emphasis should still be on early-intervention strategies to minimise even further motor delay. A literature review on motor development demonstrated any improvement in only three out of the nine studies. In one study, as a seminal source, the specific-skills intervention are emphasised such as motor-activity in play (Nilholm 1996:51; Wu, Ulrich, Looper, Tiernan & Angulo-Barroso 2008:268). A motor development programme for children with DS, from a PhD Physiotherapy thesis is based on motor skill development with 18 participants and 16 physiotherapists who did the intervention (Lauteslager 2000:117) (**cf.** 2.6.7.1). This is a valuable intervention programme for the child with DS, even though it is a methodical problem-specific physiotherapy programme with the emphasis on motor development (Lauteslager 2000:159) (**cf.** 2.6.7.1). The content of the programme, session lengths of 30-45 minutes (Lauteslager 2000:158) once a week and the presentation of the sessions are well described, but it did not involve parents (Lauteslager 2000:163-269). Another limitation of this programme was that it showed acceleration in basic motor skills only and did not discuss postural control and the child with DS's other development constraints are not addressed (Lauteslager 2000:159). In the South African context where resources are limited such a compartmentalised programme would not be able to address the developmental needs of the greater DS population.

On average, children with DS begin to walk approximately one year later than infants who display typical development (Angulo-Barroso, Yun & Ulrich 2008:231; Ulrich *et al.*

2001:84) (**cf.** Table 2.1). When children with DS begin to walk, their opportunities to interact and play with their age-peers increase significantly. Ulrich *et al.* (2001:84) mention that motor-activity play provides exploration and opportunities for new forms of cognitive development to emerge. The children with DS increase their language, play and exploration dramatically. The underlying view of this study is that for the success of intervention, a specific skill must be targeted, such as walking through treadmill training. The infants in this study demonstrated the ability to walk independently 101 days earlier than infants in the control group. In a more recent study, it was determined that early intervention, i.e. starting intervention treatment at six months, improves fine-motor developmental skills (Aparicio & Balaña 2009:636). These findings support the effectiveness of early intervention, and a skills-specific approach with the involvement of the parent (Angulo-Barroso *et al*. 2008:237; Ulrich *et al*. 2001:85).

2.6.5 Intervention and sensory development

Sensory development encompasses all the senses and not only hearing and vision. Tactile sense is necessary throughout the body, but is especially important in the hands. When there is sensory loss in the hand, fine-motor coordination is impaired and the manipulative ability will decrease (Radomski & Trombly-Latham 2008:213; Uyanik & Kayihan 2009:3/22). This may then lead to delays in cognitive development (**cf.** 2.3.3.1; 2.3.3.2). The child with DS has definite delays in all the development domains and a balanced early-intervention programme should be able to prevent sensory developmental problems.

Envisage a child with DS without the positive touch of the parent for fear of handling a child with a disability. The child will not only be emotionally detached from the parent, but the opportunity to develop will also elude the child. When a stimulation programme encourages a parent to touch and manipulate his/her child, the child will not only benefit emotionally, but motor development will thrive. This alone should be a motivation for the development of specific early-intervention programmes.

2.6.6 Intervention and social development

According to studies children with DS have strengths in social skills and in forming relationships (Fidler *et al.* 2006:38) and behavioural problems are low (Castillo 2008:143) (**cf.** 2.3.5). These positive factors could be the reason why no specific early-intervention programmes could be found.

2.6.7 Intervention and interventionist

All the role-players should have a common goal towards early intervention of the child with DS. Intervention should emphasise the empowerment of the partnership of all role-players and cooperation in decision-making and programme planning (Katz 2000:486; Pretis 2000:27; Spiker & Hopmann 1997:27/36; Stern 2009:381). The role of the interventionist is not only to accelerate the pace of development, but also to empower the parent. This may bring the interventionist outside his/her primary domain of expertise. Therefore, additional specialised training should be undertaken by interventionists to fully understand the implication of early intervention on the child with DS (Capone 2004:51).

2.6.8 Intervention and parents/family

The process of early intervention includes all the family members, which is considered the best practice (family-centred approach), because parents play important roles in most early-intervention programmes (Berlin, Brooks-Gunn, McCarton & McCormick 1998:242; Bonnier 2008:856; Del Giudice *et al*. 2006:51; King, Teplicky, King & Rosenbaum 2004:78; Lawlor & Mattingly 2009:35; Van Hooste & Maes 2003:298).

A common reaction of despondency is shared by parents on learning that their child has DS. They experience a multitude of different emotions, such as fear, anger, rejection, guilt, disappointment, denial, lack of self-confidence and self-pity (Carr 1995:12; Lloyd 2009; Selikowitz 1997:4). Caring and looking after a child with DS is an enormous responsibility and may place an added burden on the whole family (Hodapp 2007:281; Iarocci, Virji-Babul & Reebye 2006:13; Urikin 2006:319–320). Therefore, the parent needs support and their role should not be underestimated in planning early intervention.

Characteristics of an effective intervention according to the literature for the parents (Case-Smith 2010a:2; Hauser-Cram, Warfield, Shonkoff, Krauss, Upshur & Sayer 1999:985; Jordan 2009:1019) are:

- the involvement and,
- education of parents/caregivers and,
- the promotion of positive caregiver-child interactions.

A study done by Torres and Buceta (1998:99) confirms that active parental **involvement** has a positive effect on the development of child with DS. Parents interpret early intervention as providing an opportunity to "do something" (Pretis 2000:26). Early intervention should not be seen as merely training the child in developmental skills, but intervention directs the way the child perceives, explores and interacts with its surroundings (Teeters-Meyers, Stephens & Tauber 2010:694).

To assist parents' involvement in the intervention process they should be empowered. Parents should have a sense of empowerment through promoting the acquisition of self-sustaining and adaptive behaviour to cope effectively with their children and their environment (Brassard & Boehm 2007:233). Empowerment refers to the process of "conscientization", which builds critical analytical skills for an individual to gain self-confidence and self-sustaining and adaptive behaviour in order to take control of her or his life. Empowerment is about facilitating or enabling people to take control of their lives. This may include empowering both sexes to acquire skills they need for survival and self-reliance, acquiring confidence to reach their full potential and generally defining and setting their own agendas in life, ultimately to cope effectively with their children and their environment. However, institutions, including international cooperation agencies, can support processes that can nurture self-empowerment of individuals or groups. Empowerment is further defined as a process that makes it possible for people who are disempowered to exercise power and have more control over their lives (Women, Children & People with Disabilities 2012:3). The role of the professional is to shape, encourage and facilitate whatever self-development is necessary by incorporating the parents (Brassard & Boehm 2007:233).

The acquired knowledge and skills when adequate **education** and training take place encourage a sense of self-worth and then empowerment could follow (Letts 2009:169).

The implementation of an early-intervention programme may help to empower the parents who seem powerless when it comes to the induction of their child with DS into mainstream school and society. The delegates of the World Conference on Special Needs Education which represented ninety-two governments and twenty-five international organisations, assembled in Salamanca, Spain from 7–10 June 1994. They reaffirmed their commitment to Education for All. Inclusion proclaims that every child has a fundamental right to education and must be given an opportunity to achieve and maintain an acceptable level of learning (Jordan, Carlile & Stack 2008:220). The guiding principle of inclusive education is that schools should accommodate all children, regardless of their physical, intellectual, social, emotional, linguistic or other conditions. They state that this includes disabled and gifted children (United Nations Educational, Scientific and Cultural Organization 1994:5-6). This is important when standing up for the human rights of their children with DS. It is further important to be equipped with the necessary skills to manage their child during the intervention process (Cohn & Henry 2009:587; Kunagaratnam & Loh 2010:496).

The family provides the arena for a child to acquire language development and interpersonal **relationships**, which develops cognitive, language, communication and social skills. Contextual factors as expressed by Brassard & Boehm (2007:5, 6), that impact negatively on the child are illness, poverty, homelessness, single-parent status and cultural diversity. Parents with a child with DS have to cope with even more contextual factors, which may indicate that intervention may be one of the last considerations when prioritising expectations. Parents visiting the BCIC receive dependency grants (**cf.** 5.2.1) and concentrate more with regards to providing food and keeping their child healthy. Expensive transport therefore, may also impact negatively on visiting the BCIC to enroll in an early-intervention programme. Early intervention seems not to be a priority and therefore no future planning, for example formal schooling.

The importance of the family and the home should be taken in consideration when intervention is planned for a child with DS. The family is the most critical influence on the development of the young child. For the well-being and development of the child’s physical and psychological development the provision of the family is crucial.

2.6.9 Intervention and South Africa

Spiker and Hopmann (1997:15/36) describe a study done by Neser, Molteno and Knight (1989:217) to measure the developmental progress of a group of 55 preschool children with DS in South Africa, but not specifically on the effects of early intervention programme used.

There are two programmes utilized at large centres in South Africa. These are general programmes for early intervention, but not specifically developed for children with DS.

One programme was developed at the Sunshine Centre Association, in collaboration with the Children's Memorial Institute for Child Health and Development (CMI) in South Africa, namely the **START** (Strive Towards Achieving Results Together) programme (Solarsch *et al.* 1990:19). The START was developed to assist parents of children with disabilities to prevent isolation. The acronym underwrites the importance of equipping parents to assist their own child and not always a health worker. The manuals render information regarding the content, profiles on typical development, activity books and background information on cerebral palsy and the health disciplines involved in intervention. The START uses development domains. The limitations of the START are firstly that it was not developed specifically for children with DS. Also, the manuals may be complicated to a lay person and requires assistance from a health worker (Solarsh, Katz & Goodman 1990a:21). The START advocates constant check listing of development to establish what further stimulation activities should be used. Parents may therefore consider failing their child if there is not constant improvement. In a third-world context, the checklists could not be used by parents, as knowledge is needed. A variety of play material is needed also (Solarsh, Katz & Goodman 1990b:162, 163). The programme may not be used independently by parents. The attendance of the START course was compulsory and expensive for an interventionist.

Stimulation programmes should take the specific developmental patterns and tempo of a child into account. There should be opportunity for overlapping activities and not just check listing what a child should be able to do at a certain age. As an instructor, as well as primary trainer for the START programme from 1994 until 2006, the researcher was not convinced that the programme was adequate for the exclusive implementation for the child with DS and the parents. Numerous play materials are also needed to implement the

programme. Expensive play material should be replaced by less expensive more easilyavailable toys such as household utensils. Parent involvement could be more informal but constructive.

In the Western Cape, “The Washington **DSPI** Programme” (Developmental Sequence Performance Inventory), was adopted. This programme was developed by Model Programs, Experimental Education Unit, College of Education and Child Developmental and Mental Retardation Center, University of Washington, but not specifically for DS (Botha 2009:1). The strength of the programme is the developmental sequence performance inventory, which consists of age bands with developmental activities based on typical development. This is a promising programme, but numerous play materials are needed to implement the programme. There is no technical guide only an inventory of development, which implies that a professional has to assist a parent constantly. Attending the stimulation sessions is compulsory, which is positive for the intervention process.

It is therefore mandatory that further research should be undertaken to establish early-intervention protocols for the child with DS. The previous section focused on research that had been done on early intervention. Even though the researchers present and conclude their results, no named specific programme for use in interventional research was described. This does not assist in further research on the positive outcomes of early intervention in children with DS. However, the intervention models and/or approaches were mentioned in the literature.

2.7 INTERVENTION APPROACHES

Treatment approaches are well described, but the implementation in early-intervention programmes are not disclosed. In the following section, an attempt will be made to describe the different treatment approaches available for the child with DS.

2.7.1.1 Therapist-implemented treatment

The therapist-implemented treatment approach in this setting is different from the client-centred therapy approach described in occupational therapy intervention (AOTA

2009:649). This is the contemporary intervention implemented in consultation sessions according to the scope of practice of each discipline (Del Giudice *et al.* 2006:56). For example Lautenslager (2000:159) describes a problem-specific physiotherapy gross-motor programme (**cf.** 2.6.4).

The literature explains different neuro-maturation models of intervention approaches such as the theoretical models, which include two motor-intervention models, namely Neuro-Developmental Treatment (NDT) and Developmental Skills models and Sensory Motor Integration (Ottenbacher, Biocca, DeCremer, Gevelinger, Jedlovec & Johnson 1986:1095). These models are educational and service models in occupational-therapy treatment of the child. It is important to state that these service models use individual treatment or small groups, frequent treatment delivery (once or twice a week or month) and require strict discipline of the parent and the interventionist (early-intervention teachers, physical or occupational therapists, or adaptive physical educators).

- Neuro-developmental treatment model

Neuro-developmental treatment was developed in England by Berta and Karel Bobath as a “living concept”, specifically for the treatment of children with Cerebral Palsy (Harris 1980:422; Mahoney *et al.* 2001:154; Radomski & Trombly-Latham 2008:644; South African Neuro-developmental Therapy Association-Bobath 2009). This client-centred therapy approach involves treating the child with the objective of inhibiting abnormal tone and facilitating automatic reactions, such as righting and equilibrium, as a means to promote normal movement patterns to enhance function (Mahoney *et al.* 2001:154; Ottenbacher *et al.* 1986:1095; Radomski & Trombly-Latham 2008:644; Viljoen 2009:13).

- Developmental skills

The Developmental Skills sessions focus on children’s play and general motor activity (Mahoney *et al.* 2001:154). “Developmental Skills programs focus on the learning and mastery of a set of normally sequenced motor milestones; with intervention the target is identified from skills at the next higher level.” (Mahoney *et al.* 2001:154). This type of approach assumes that children will advance to a higher level of motor development and therefore independent functioning will take place through practice and reinforcement

(Mahoney *et al*. 2001:161). Sections of the South African intervention programmes correspond to this model (**cf.** 2.6.9).

- Sensory stimulation

Sensory stimulation with respect to integration is an innate neurobiological process that refers to the interpretation of sensory information about the environment received through the senses, to adapt motor response (Bundy, Lane & Murray 2002:5; Roley & Jacobs 2009:792). Ayres, an occupational therapist and educational psychologist offered a definition of Sensory Integration, namely "the organization of sensory input for use" (Kratz 2009:354; Uyanik, Kyihan, Bumin & Sener 2009:334) (**cf.** 2.3.4). A child's growth and development are dependent on the development of the tactile, proprioceptive and vestibular systems, ocular motor coordination and oral structures, so that the child may be sensory modulated in order to participate successfully in activity (Dunn 2001:613; Kratz 2009:356–357; Uyanik *et al.* 2009:335). Studies done with children with DS aged three to 10 years suggest that 49% experience definite differences to sensory experiences (Bruni, Cameron, Dua & Noy 2010:288). It was found that children with DS have less efficient reach strategies and may show specific praxis deficits in early development, especially to sensory components of daily activities related to motor performance (Fiddler, Hepburn, Mankin & Rogers 2005:135, 136; Shaaf, Schoen, Roley, Lane, Kroomar & May-Benson 2010:102). Early-intervention programmes should involve activities that allow the experience of sensory information, which is beneficial for function and development.

2.7.1.2 Parent-implemented developmental training

Parent-implemented developmental training implies that parents need to be involved in the assessment process, not only to provide information about their child's development and needs, but they should gain awareness of their child's early development (Brassard & Boehm 2007:3). In a study by Del Giudice *et al.* (2006:51), a parent-implemented developmental training programme is compared to the therapist-implemented treatment. This intervention is based on activities that can readily be incorporated in the daily care routines of the infants. The parent-implemented developmental training is found to be more effective (Del Giudice *et al*. 2006:56).

2.7.1.3 Client-centred therapy approach

A client-centred therapy approach involves the intervention models known to health professionals, specifically occupational therapists (AOTA 2009:649). The researcher is of the opinion that the occupational therapist is particularly well positioned to act as interventionist and to help in the intervention process of the child with DS. As client-centred therapy approach is a key to the occupational therapist's practice, with the client being at the centre of intervention (Richardson 2010:217).

Caretto, Topolski, McKinney Linkous, Lowman and Murphy (2000:61), show that occupational therapists are the largest group of professionals working within the field of DS in the United States, but in the South African, Free State, context according to service delivery; lack of occupational therapists working in the field of DS is disconcerning (Occupational Therapy, Free State Department of Health 2011).

In this literature review, it has been noted that South African data on occupational-therapy intervention are limited. Research information of other countries is available, but it involves older children from two years onwards, adolescents and adults with DS (Fidler *et al.* 2006:40, 43; Kubo & Ulrich 2006:513; Uyanik *et al.* 2003:69, Villamonte 2009:5).

Studies emphasise the limitations in the field of intervention in children with DS (**cf.** 2.6.1). It is unfortunate that occupational therapists have not taken this opportunity to do research in this field. Published research varies from gross-motor intervention to the impact of intervention on the parents and family (**cf.** 2.6.6). The researcher was disconcerted to be unable to find research on the effect of intervention on the total development of the child with DS. Research needs to be done on early intervention of children with DS by occupational therapists.

The use of intervention approaches conducted by an experienced occupational therapist has proven to be effective for improvements in occupational performances. This evidently leads to **evidence-based practices** (Daunhauer & Fidler 2011:8; Uyanik & Kayihan 2009:341). According to Delport and De Vos (2011:58) evidence-based practice is a type of intervention in which the professional uses research as a practice and problem-solving tool. A systematic procedure for documenting the effectiveness of an early-intervention programme should be done (Maitra & Erway 2006:299; Tickle-Degnen 2009:292).The

researcher used scientific reasoning to develop an appropriate intervention programme for the child with DS.

According to Rosa (2009:287), the following concepts are common to all occupational therapy models of client-centred practice:

- To respect the clients and their families and the choices they make;
- To recognise that clients and families have the definitive responsibility for choices about daily occupation and the occupational therapy services;
- To provide information including physical comfort and emotional support with the emphasis on individual-centred communication;
- To facilitate client participation in all the aspects of the occupational therapy service, including decision-making and for this study (**cf.** 3.3.1.3);
- To present a flexible, individualised occupational therapy service;
- To facilitate the client's capacity to solve their occupational performance issues as in this study more independence for the child with DS;
- To recognise and focus on the relationship between the person-environment-occupation relationship.

The researcher strived to accomplish and incorporated these concepts as principles in the DRSP (**cf.** 3.3.1.3).

2.8 CHAPTER SUMMARY

Taking the literature review and the descriptions of the availability of early-intervention programmes for the child with DS into account, this present study was necessary. The role of the occupational therapist, coupled with an understanding of the different frameworks such as the ICF-CY and OTPF, positions this profession to assist in early intervention with the child with DS. The researcher used the principles and theoretical background of the ICF-CY and OTPF to guide the development of the DRSP.The development of the early-intervention programme for children with DS (DRSP) used in this study will be discussed in Chapter 3.

CHAPTER 3
THE DEVELOPMENTAL RESOURCE STIMULATION PROGRAMME

I am only one. But I am still one. I cannot do everything, but still can do something. I will not refuse to do the something I can do. Edward Everett Hall (1822–1909) (Davidson 2009:303)

3.1 INTRODUCTION

The previous chapter focused on the literature of early intervention in DS with the different development areas and frameworks. As reported, the availability of specifically tailored early-intervention programmes for the young child with DS is limited. Early intervention, which is grounded early in life, is imperative to a child with DS's development (Aparicio & Balaña 2009:636; Carr 1995:6; Capone 2004:49; Castillo 2008:150; Connolly *et al.* 1980:1407; Harris 1980:420; Palisano *et al.* 2001:494; Piper *et al.* 1986:184). Early-intervention programmes result in positive outcomes for children, but it depends on the nature of the programme and principles and nature of the child and family (Del Giudice *et al*. 2006:56; New & Cochran 2007:294). The prerequisites for early intervention programmes for children with DS have already been identified in Chapter 2. This chapter focuses on the development and detailed description of the DRSP specifically designed for the child with DS.

3.2 BACKGROUND TO THE DEVELOPMENT OF THE DRSP

The researcher started with a general early-intervention programmes at the BCIC in 1989 and specific early intervention for children with DS in 1990. The development of the DRSP was initiated in this resource centre (BCIC) where the researcher, an occupational therapist, is the only professional health worker. The centre's aims are to provide information and deliver a service with regards to a variety of aspects surrounding child development, health and education for all children with or without existing developmental problems. Previous research done at the BCIC, established that parents and professionals have specific requirements regarding the development of children younger than three years with special needs (Nienkemper 1991:165), but there was inadequate information for managing children with DS and their parents.

The DRSP evolved from the "Play-Fun Stimulation Programme" (Russell & Van Wyk 2003) and the "Speel-Pret Stimulasie Program" (Russell 2006; Russell 2009). These original programmes were developed for informal settlements at the BCIC. The need for a therapeutic tool for the children with DS, who attend the BCIC for intervention sessions, was soon identified. This therapeutic tool had to be acceptable to and applicable for all socio-economic population and/or religious groups. The DRSP was therefore developed as an occupational performance programme for early intervention, specifically for the child with DS (Russell 2010).

The DRSP is a unique, child-parent-specific, one-on-one, integrated programme for children with DS from birth to 42 months. The reason for the age cut off is to allow children with DS to have a six-month transition period into non-specific DS developmental programmes before entering preschool at three years.

In developing the DRSP the researcher used a combination of scientific and pragmatic reasoning (Boyt-Schell 2009:320–321). The evidence from published literature and the researcher's personal experience working with children with DS and their parents reinforced the scientific reasoning (Case-Smith *et al.* 2005:3–4). Through pragmatic reasoning a new intervention programme was developed by adapting an existing stimulation programme to fulfil the development needs of children with DS (Russell 2006).

As discussed in Chapter 2, occupational therapy is defined not only as the study of occupations in relation to health, satisfaction and well-being, but also as the management of skilled performance required to perform these occupations (**cf.** 2.5). Each activity of the DRSP is designed to enable occupational performance through the development of performance skills. The activity 'Cover-the-Face' for example, in the age band 0–3 months (Russell 2010:11) promotes play and social participation. It defines occupational performance as the result of the dynamic collaboration between the client, the context (environment) and the activity. The client factors are the precedents for development of performance skills to fulfil their social roles by engaging in the eight areas of occupation. The eight areas of occupation are activities of daily life, instrumental activities of daily life, education, work, play, leisure and social participation. The context includes eight interrelated factors such as cultural, physical, social, person, spiritual, temporal and virtual conditions (Rogers & Holm 2009:483). The following section will describe the DRSP in more depth according to the components and activities manual and technical manual to be used during early intervention for the child with DS and their parents (**cf.** 3.3.1.2; 3.3.3).

3.3 **DEVELOPMENTAL RESOURCE STIMULATION PROGRAMME (DRSP)** (APPENDIX C)

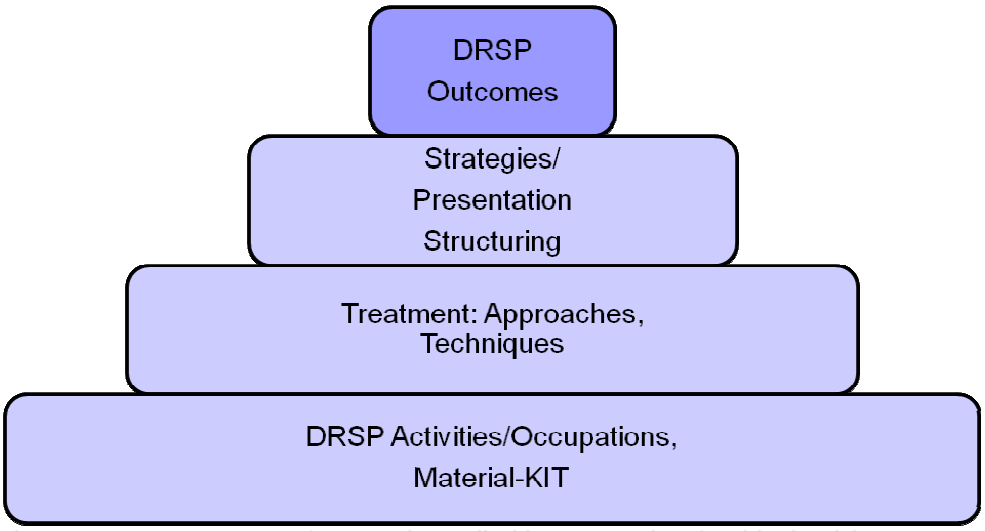


Figure 3.1: Components of DRSP (compiled by researcher for this thesis)

3.3.1 The components of DRSP

The components of the DRSP comprise of two parts; the DRSP activities manual (**cf.** 3.3.2) and the DRSP technical manual (**cf.** 3.3.3):

3.3.1.1 DRSP activities manual consists of:

- 85 activities, including the KIT with the description and outcomes of each activity to be used by parents during activity participation at home. The activities covered the following aspects, namely cognitive- language- fine-motor and gross-motor development (Appendix C);
- Treatment goals and techniques to be used during intervention (TIP) demonstrated by the occupational therapist and used by the parent;
- Instructions for positioning of the child by the parent;
- Recommended activities using occupations, such as play and social participation are used by the child and
- Expected outcomes of each activity in the DRSP activities manual.

3.3.1.2 DRSP technical manual includes:

- Treatment approaches, such as neuro-developmental techniques, developmental skills and sensory development stimulation to address the developmental areas, namely cognitive- language- fine-motor and gross-motor development (**cf.** 2.6.1; 3.3.1.3; 3.3.3.1);
- Strategies of treatment, namely handling of child (**cf.** 3.3.2.1);
- Positioning of child (**cf.** 3.3.3.2.2);
- Presentation of sessions (**cf.** 3.3.3.4) and;
- Implementation and structuring of treatment area (**cf.** 3.4).

3.3.1.3 Principles for an effective early-intervention stimulation programme:

In Chapter 2 it has been discussed that children with DS have cognitive deficits and speech problems, as well as motor-developmental problems (Hernandez-Reif *et al.* 2006:396) (**cf.** 2.3; 2.3.1; 2.3.3). Therefore, developmental delay is evident. Early intervention for the occupational therapist describes services for children from birth to three years (Meyers, Stephens & Tauber 2010:861) (**cf.** 2.6). As early intervention is a systematic programme of therapy approaches, exercises and activities designed (Fergus 2009:1) the DRSP may be an example of such a systematic programme. According to the literature the availability of early intervention programmes are limited, focused more on gross-motor development and not specifically for children with DS (Russell 2006) (**cf.** 2.6; 2.6.1; 2.6.9). It was therefore essential that research should be undertaken to establish early-intervention practice for the child with DS (**cf.** 2.6.9). The DRSP not only stimulate cognitive development, but incorporates language, fine-motor and gross-motor development of children with DS. The involvement and education of the parent/caregiver, as well as the interaction with children with DS of the parent/caregiver (**cf.** 2.6.8) were elements in the protocol of the DRSP as an early-intervention programme. The following was taken in consideration when the DRSP was developed.

- Timing: According to Ramey and Ramey (2004:11) the onset or beginning of the intervention should be early in childhood. Timing, not only the early referrals of children with DS, but the planning of the duration of an intervention programme is essential (**cf.** 6.4). This timing may also include the duration of the execution of activities in the DRSP.
- Intensity and recurrence(per day/week/month/year): Parents were encouraged to incorporate the DRSP as part of a daily routine during activities such as feeding, bathing, when picking the child up and dressing and undressing (Russell 2010:8, 11, 17, 31).
- Providing direct learning experiences for the children and caregivers (**cf.** 3.3.2.1; 3.4).
- Providing a broad range (breadth of services) of comprehensive services/support such as transportation to- and from intervention sessions, parent training and counseling (McCollum 2002:6).

- Attending to individual differences: Not all programmes benefit all children. Programmes need to be tailor-made for both child and family needs and abilities.
- Environmental support: To maintain the effects of early intervention, involving the whole family in decisions which affect the child is important (Brassard & Boehm 2007:11; Creek 2010:178; Guralnick 2005:316; Keilty 2010:4; Knox 2010:551; Ramey & Ramey 2004:11; Ramey, Ramey & Lanzi 2007:452; Ritzema, Saracino & Sladeczek 2010:4/32) (**cf.** 2.6.6).
- Active involvement and engagement of the parents/caregivers are crucial to effective outcomes of the intervention (Capone 2004:51; Del Giudice *et al.* 2006:56).
- Treatment strategies and principles, techniques, approaches and occupations involved during the implementation of the DRSP.
- The provision of applicable, age appropriate DRSP information material was made available with each session to use at home (Appendix C).
- A client-centred approach supports the factors for an effective stimulation programme and should be incorporated (**cf.** 2.7.1.3).

The DRSP was designed to strengthen the parent-child interactions without emotional constraints (Paige-Smith & Rix 2006:96) (**cf.** 2.6.1; 2.6.8). Traditional early-intervention models take a “bottom-up” approach in which the specialised professional focuses on treating specific motor-based components that appeared not to be effective in improving long-term motor outcomes (**cf.** 2.6.1) and not improving the occupation of children (O’Brien & Williams 2010:247). The researcher demonstrated and illustrated these techniques to the adult participants with committed perseverance and patience to enable independent performance at home (**cf.** 3.3.3.1.1; 3.3.3.1.2; 3.3.3.1.3; 3.3.3.2.2; 3.3.3.2.3; 3.3.3.2.4). The goal should be broader, with both social and physical contexts, where the role of a parent/caregiver is more relevant in the holistic approach for intervention of the child with DS (Virji-Babul, Kerns, Zhou, Kapur & Shiffrar 2006:81). This holistic approach was the key to the implementation of the DRSP, which included the involvement of the parent and the design of the activities for the developmental domains.

The following section will describe these components of the DRSP in more detail.

3.3.2 DRSP activities manual

3.3.2.1 Description of the manual

The DRSP consists of 85 activities which are based on the typical development of children, using three mugs, four teaspoons and a square facecloth (the KIT) (Appendix C). This KIT is readily available in any household and may regularly be used by children with DS. Usually toys and play material are stacked away and are only available on request, because parents do not always have the skills to implement it correctly (Nienkemper 1991:152). The household objects used in this study are durable and also cost effective. The KIT offers different textures, such as “coarse”, “smooth”, “hard” and “soft”, as well as different colours. These few materials could be utilized for a variety of activities and used for a period of 42 months to assist with the development of the child with DS (“light-weight toys in a handbag”). Another positive feature of the KIT, is that either genders may play equally well with the play material. Harris (1983:20) established that there are no significant differences between play activities for boys or girls with DS. Play does not have to be differentiated between genders, but activities should involve development components.

The DRSP activities manual has specific activities for specific age groups, starting from birth up to 42 months. Each activity has a detailed description, with a specific, appropriate name (Russell 2010:1–4). The participation and interaction between the parent/caregiver and child is essential, as the child is a socially occupied being who wants to do something with someone else that matters (Lawlor 2003:424). The materials used are stipulated and kept simple. To address possible literacy problems and forgetfulness, each named activity is accompanied by a sketch to reinforce the description of the positioning, handling and presentation. People forget up to 80% of what they are told during a consultation between a therapist and patient (Berger 2009:420). The detailed description, an easily comprehensible text, is given for the execution of the activity to orientate a participant or consumer who is using the programme (**cf.** Figure 3.2). The present format of the DRSP activities manual is currently available in English only.

Activity	Position	Description	Outcomes	Materials
17 "Moe-ket-si"	Sitting/Standing 	Mother hits the spoon against the mug, while she is *counting* to five. Child imitates while mother is counting. Do it rhythmically. Child takes a spoon in his hand and hits the mug. Continue rhythmically saying his name, e.g. John-ny or Moe-ket-si. These are two or three counts. As an illustration say the name or words, while hitting the mug: "Mommy loves you."	Motor stimulation: eye-hand co-ordination, hand function Sensory stimulation: Visual & Auditory Speech stimulation Play stimulation Perceptual stimulation: Counting, Rhythm	Mug Spoon

Figure 3.2: DRSP 24–42 months (2010:52)

Table 3.1 illustrates, show the 85 activities were allocated specific goals, categorised in developmental domains, and activity participation. In this table terminology from the OTPF was utilised (**cf.** 2.5.1). In the activity participation, the IADL was combined with the ADL as the children with DS are dependent on help from their parents. Social participation overlaps with social-emotional aspects of the development domains (**cf.** 2.3; 4.3.5.1), and was therefore not included again in the activity participation.

Table 3.1: DRSP according to developmental domains

DRSP Activities Categorised in Development Domains										
Age Bands	**DRSP Number of Activities**		**Developmental Domains during intervention**							**Activity Participation**
7	**85**		**GM**	**FM**	**COG**	**L**	**SE**	**Sen**	**PL**	**ADL/ IADL**
0–3	13		9*	4	6	8	3	9	2	
3–6	16		12	11	12	12	5	16	5	
6–9	10		10	9	8	7	3	10	3	
9–12	9		4	8	8	8	4	9	4	3
12–18	9		3	8	7	8	1	8	3	
18–24	7		3	7	7	7	2	7	2	2
24–42	21		4	21	21	21	4	21	8	

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **Sen** = Sensory stimulation, **PL** = Play, **ADL** = Activities of Daily Living, **IADL** = Intrumental Activities of Daily Living

*Number DRSP activities in a domain

3.3.2.2 Occupations

Activities of daily living, play and social participation through the participation of activities develop children's and babies' occupations. Changes in the developing baby influence the family's cultural, social, and physical contexts (Case-Smith 2005:92) (**cf.** 2.5). Initially parents appear to rely on the therapist to "fix" their child's problems and their role is to watch and observe. The more children with DS start to develop in the different development domains and parents became involved with intervention, the more their social and physical contexts change. They were also less isolated due to the social support from other parents who have children with DS (Case-Smith 2005:92). The following are considered the occupations relevant to young children.

3.3.2.2.1 Activities of daily living (ADL/IADL)

Research has shown that children with disabilities are at risk for reduced participation in activities of daily living at home and ordinary activities in their community (King *et al.* 2003:63). Typically, the perception is that children with disabilities are dependent and early-intervention should change this, starting with daily-routine participation. According to Kellegrew (2000:253), all children benefit from daily routines and these activities of daily living promote development (Adolfsson 2011:34). Instrumental activities of daily living (IADLs, where a third party is involved in facilitating activities) are included in the DRSP, as it was easier to delegate the activities of daily-living (ADL) activities to the parent in the category child rearing (James 2009:539). The DRSP facilitates interventions in preparation for activities of daily-living. For example, in the DRSP 0–3 months age band, the activity "Mouth closure" is an example of such a preparation. For eating, the child needs good mouth closure, which is the performance component for this occupation (Appendix D).

3.3.2.2.2 Play

Play is considered a primary occupation of childhood (Case-Smith, Law, Missiun, Pollock & Stewart 2010:22). Play is a recreational, spontaneous activity of a child with the absences of serious or harmful intent (Kramer *et al.* 2010:53, 54; Parham 2008:3). To learn through play the child engages in a purposeful activity (Kramer *et al*. 2010:54). Only

through play can a child express himself and how he perceives the world around him. Play is the medium which enables the child to learn and then to develop the necessary development skills with a positive outcome (Parham 2008:3; Russell 2009:2). Making intervention pleasurable is the key to engage the child (Pierce 2001:253). The play occupation of the baby in the first 12 months is exploratory and of a social nature. Exploratory play is also called sensory-motor play (Case-Smith 2005:96). The DRSP facilitates sensory-motor play (Heathcock, Lobo & Galloway 2008:316), which involves play and active parent participation. According to Del Giudice *et al.* (2006:56) active involvement and engagement of the parents/caregivers are crucial to establish effective outcomes in early intervention.

The 12 to 24-month old child engages in functional or relational play. A better understanding of the function of an object is established (Case-Smith 2005:98). The KIT of the DRSP promotes functional play from the onset as these objects are already used by parents involving feeding and washing the child with DS.

The 24 to 36-month old child engages in symbolic play. Their play links multiple scheme combinations into meaningful sequences of symbolic play (Case-Smith 2005:104). Specific DRSP activities stimulate symbolic play in this age group (Russell 2010:52).

3.3.2.2.3 Social participation

The most important relationships formed during infancy are those with parents/caregivers (Case-Smith 2005:94). According to the literature, children with DS use their strengths in social skills to compensate for weaker developmental domains, such as motor development. Figure 3.3 illustrates the use of motor development during a social participatory activity. Social participation is important during intervention. As children with DS show definite competence in forming relationships (Fidler *et al.* 2006:38) (**cf.** 2.3.5). The activities of the DRSP provide opportunities to promote and experience social participation between parent/caregiver and child with DS.

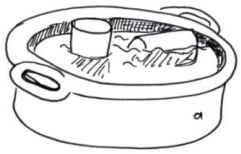
Activity	Position	Description	Outcomes	Materials
4 "Mugs in Water"	Kneeling in front of a bucket of water. Mother supports baby at his hips. 	Mother puts the mugs into the water. Baby tries to pick up the mugs from water. Baby may hit the water. Mother asks: "Where's the mug, now. It is in the bucket". Mother may sing a song with words such as "Ami tomake balo bashi baby". (*see Appendix*)	Motor stimulation: balance(kneeling), hand-eye co-ordination, hand function Sensory stimulation: touch, visual & auditory Play stimulation Perceptual stimulation: Position In Space Activities of Daily Living	Mugs Bucket

Figure 3.3: DRSP 9–12 months (2010:29)

3.3.2.3 Compilation of activities

Each activity in the DRSP was analysed using an activity analysis from two different perspectives, namely the occupational analysis and the activity analysis. The occupational analysis approach is first of all derived from the understanding of the specific situation and occupation of the client, namely the child and the parent/caregiver during intervention. This analysis places the client/person in the foreground. It attends to their actual bodily functions and structures, as explained in the ICF-CY and OTPF's client factors, performance skills, performance patterns and activity demands (Adolfsson 2011:17; Blesedell-Crepeau & Boyt-Schell 2009:360; Case-Smith 2010b:67) (**cf.** 2.4; 2.5). The second approach is commonly called the activity analysis in which the possible areas of concern should be anticipated, as well as generate purposeful activities (Blesedell-Crepeau & Boyt-Schell 2009:360, 367). Activity analysis is the method of clarifying and interpreting the usefulness of an activity. Occupational therapy practitioners should draw from their education, knowledge of activities and further professional experience when activities are analysed. These perspectives are important and a requirement for effective practice (Blesedell-Crepeau & Boyt-Shell 2009:363). The development of the DRSP followed the occupational-therapy process's six major components, namely theory, evaluation, problem definition, intervention planning, intervention-implementation and re-evaluation (Rogers & Holm 2009:479).

The participation of the parent/caregiver is essential when implementing the DRSP. The support, relationships and change in attitudes are essential to intervention (Ross & Deverell 2004:77).

The DRSP could be used as an intervention tool to render a relevant service in any cultural and social setting. The inter-relationship between the ICF-CY and OTPF (**cf.** 2.5.1) was illustrated and these international guiding frameworks were considered in the development of the DRSP. The researcher will use the terms *activity* and/or *participation* to explain the use of the DRSP. In the *Activities and Participation* subdivision of the ICF-CY the following was incorporated into the DRSP. The DRSP as a specific intervention programme could be applied in the daily life areas domain. An important feature of the DRSP is the emphasis placed on constant communication by the parent/caregiver while tending to their child with DS. It has preparatory activities included in the self-care domain, such as strengthening facial muscles for the protruding tongue, towards this self-care domain. The DRSP further has introductory activities, such as cognitive activities, that assist in informal education. There are preparatory activities for future development, such as positioning, an ability the child will need to put toys away at a later stage. Play activities within the DRSP correlate with this domain. The parent support and participation in the DRSP also apply the principles of this domain. In the subdivision body functions and structures according to the ICF-CY, the performance skills, performance patterns and activity demands have been specifically incorporated in the DRSP to accommodate these delays through the treatment approaches and techniques necessary towards therapeutic intervention (**cf.** 3.3.2.1.1). The contextual factors of the ICF-CY that play a role in the DRSP are support and relationships, attitudes and services, systems and policies (Luebben *et al*. 2010:44) (**cf.** 2.5.1). The tables in Appendix D support the fact that the DRSP encompasses important and relevant aspects associated with the ICF/ICF-CY and OTPF.

3.3.2.4 Expected outcomes in the DRSP activities manual

An outcome may be defined as post-intervention results or measurement, but it is the immediate, observed outcome of an intervention that implies the effectiveness of therapy (Price 2009:336; Unsworth 2000:148). Therefore, it is important that specific outcomes should be listed in a stimulation programme as illustrated in DRSP. The child and the

parent/caregiver focus on the outcome and goal rather than a specific motor component of a task. Outcomes are part of any intervention programme and the therapist and parent/caregiver may monitor the outcome of each activity. The specific outcomes of the DRSP include all the functions of occupational performance such as (**cf.** Figure 3.4):

- To enhance normal patterns of motor development by facilitation of normal muscle tone and introduce tone-inhibiting patterns;
- To facilitate righting, equilibrium and protective responses as a foundation for typical patterns of movement;
- To provide activities to facilitate sensory input (especially vestibular, tactile and pro-prioceptive sensations) (Davies & Gavin 2007:177; Van Jaarsveld 2009:24);
- To provide cognitive activities to stimulate and facilitate perceptual abilities;
- To provide appropriate oral treatment techniques to facilitate feeding and pre-speech activities;
- To promote the parent's role as primary teacher and caregiver in the programme; and
- To empower parents and to enhance their ability to cope with and assist during intervention.

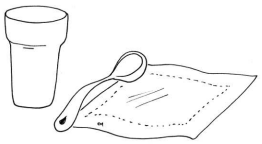
Activity	Position	Description	Outcomes	Materials
6 "Background-Foreground"	Sitting/standing 	Mother encourages baby to pick up two objects and name them e.g. "give me the mug, spoon, cloth". Mother may sing a song, after activity. "… (Baby's name) is so wonderful, wonderful, wonderful…" *(see Appendix)*	Motor stimulation: hand function, eye-hand co-ordination Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: Background-foreground	Mugs Teaspoons Cloth

Figure 3.4: DRSP 12–18 months (2010:37)

Theoretically all these functions should be achievable. The following section focuses on the DRSP technical manual.

3.3.3 DRSP technical manual

3.3.3.1 Treatment approaches and techniques towards therapeutic intervention

This section focuses on the different treatment approaches and techniques incorporated in the DRSP. In Chapter 2 a short description of the intervention models, accompanied by therapist-implement treatment approaches, such as NDT, was provided (**cf.** 2.6.7).

3.3.3.1.1 Neuro-developmental technique

As the child with DS has motor-developmental constraints, structured motor intervention is important (Castillo 2008:150; Mahoney *et al.* 2001:153) (**cf.** 2.3.3). Therefore, the principles of NDT were applied in the DRSP. Neuro-developmental treatment was developed for the treatment of children with Cerebral Palsy in England in the 1940s (Radomski & Trombly-Latham 2008:644) (**cf.** 2.6.7.1). This treatment approach involves handling the child with the objective of integrating abnormal tone and facilitating automatic reactions, such as righting and equilibrium (**cf.** Figure 3.5). This approach further promotes postural stability, which includes training in developmentally appropriate movement patterns and the promotion of muscle strengthening (Castillo 2008:150; Laws & Bishop 2004:437; Levitt 2010:39; Mahoney *et al.* 2001:161; Meadows & Williams 2009:4; NCSS 2007:25).

Activity	Position	Description	Outcomes	Materials
11 "Leg Roller"	Baby lies over mother's lower leg. 	Mother builds tower with mugs, while baby lies over her lower leg. Her leg poses as a roller. Mother holds baby by the shoulders and presses down for better arm support.	Motor stimulation: head control, arm support, balance, reach, co-ordination Visual stimulation Sensory stimulation - touch Auditory stimulation Speech stimulation	Two Mugs

Figure 3.5: DRSP 3–6 months (2010:20)

3.3.3.1.2 Developmental skills

The developmental skills sessions focus on children's play and general motor activity (Mahoney *et al.* 2001:154; Uyanik & Kayihan 2009:6) (**cf.** 2.6.7.2). "Developmental Skills programs focus on the learning and mastery of a set of normally sequenced motor milestones, with intervention the target is identifying from skills at the next higher level." (Mahoney *et al.* 2001:154). This type of approach assumes that children will gradually advance to a higher level of motor development and therefore independent functioning will take place through practice and reinforcement (Law *et al.* 2005:76; Mahoney *et al*. 2001:161). An occupational therapist can determine a child's motor deficits based on the sequence of development. Research has found that infants with DS have obvious rhythmic motor difficulties and non-rhythmic milestones may also be a problem (Cobo-Lewis *et al.* 1996:457) (**cf.** 2.3.3.1.1). It is important to know that the sequence of developmental achievement for the child with DS is similar to children with no known motor problems (Mazzone *et al.* 2004:120; NCSS 2007:25). This sequential development was important in the development of the DRSP which was closely linked to NDT principles.

The occupational therapist uses various tools of the profession to facilitate the traditionally accepted sequence of typical development (**cf.** Figure 3.6). The clinical reasoning of the therapist, manipulation of the environment, the use of teaching and learning theories and conscious use of "self" are involved in the Developmental skills intervention sessions (Kramer & Hinojosa 2010:29). The DRSP incorporates the developmental skills together with NDT principles and participation of the parents to enable a holistic service model.

Activity	Position	Description	Outcomes	Materials
2 "Side Sitting"		Encourage baby to play with mugs on the side opposite to his feet. His hands and arm must cross the midline in order to reach the mug. Do this activity to the other side. Repeat. Keep on talking to baby and verbalize the actions.	Postural control	Mugs

Figure 3.6: DRSP 3–6 months (2010:15)

3.3.3.1.3 Stimulation of sensory development

Activities allows for sensory experiences which contributes to the processing of sensory information that supports development and function (**cf.** 2.3.4; 2.6.7.1) (**cf.** Figure 3.7). Sensory stimulation consists of activities that promote visual perception, body awareness, tactile perception and visual-motor coordination (Castillo 2008:150; NCSS 2007:25) (**cf.** 2.6.7.3). The vestibular system is responsible for one's orientation in space, which means that this system keeps track of the body's movement in 3-dimensional space. (Dunn 2009:784). Any change in head position stimulates the vestibular receptors. As the vestibular senses are the most sensitive of the sense organs (Ayres 2006:62), even standing and walking make the head move in subtle ways. Vestibular stimulation consists of activities such as using and developing equilibrium reactions through push/pull movements (Castillo 2008:150). Vestibular input is a powerful input, especially when the proprioception and tactile systems do not help to organise the motor system (Kratz 2009:356). Studies have demonstrated that effective stimulation of sensory development, in addition to occupational therapy approaches, and accompanied by NDT, has a positive effect on motor skills in children with DS (Karimi *et al.* 2010:43; Uyanik *et al.* 2003:72) (**cf.** 2.6.7.3).

The DRSP consists of activities to engage the child with DS to stimulate development of the motor domain which facilitates sensory stimulation. These activities compliment all the developmental areas. The child with DS should be involved in movement activities to ensure that sensory stimulation resulted in the intervention process. DRSP activities were organised so as to carefully incorporate the cascade of the developmental processes. Activities rich in movement, such as side-sitting, engaged head turning and proprioception through the arms necessary for arm support. These are evidently preparatory activities for hand function and manipulation of play materials. The occupational therapist uses a sensory stimulation approach to manipulate the environment in such a way that the child may gain the mastery of skills, tapped by their own inner drive, towards more purposeful engagement and raises performance levels within meaningful tasks (Kratz 2009:354; Wuang & Su 2011:2405) (**cf.** Figure 3.7). Occupational therapists may use music as preparation for therapeutic activities, based on the principle that when presented in a specific manner (e.g. music that is calming together with slow rocking movements) sensory input through the auditory and vestibular systems can be calming and organising to (Hall & Case-Smith 2007:209). The researcher not only used songs together with the

sensory stimulation in the DRSP, but also included activities to stimulate proprioception and tactile systems (**cf.** Table 3.1). An example of activity using auditory stimulation is "Hello, Mommy loves you" (Appendix D).

Activity	Position	Description	Outcomes	Materials
5 "Hello, Mommy loves you"	Back/Supine 	Mother rolls up cloth and holds it in front of the baby. She lets the cloth touch the baby's face and moves it away from his face (24-30cm), until he focuses on the object. Talks to him, say for example: "Hello…, Mommy loves you!	Sensory stimulation – touch	Cloth

Figure 3.7: DRSP 0–3 months (2010:10)

3.3.3.2 Strategies of treatment

The principles of the DRSP should be consistently incorporated during strategies of treatment.

3.3.3.2.1 Handling of participants

A combination of different strategies of handling the participants was used by the researcher during intervention. The correct handling of the participant should facilitate active participation. The following principles were used during intervention for both the child with DS and parent according to Mahoney, Perales, Wiggers and Herman (2006:23–24):

- The child with DS was engaged throughout the intervention;
- The researcher was physically available and interactive;
- Turn-taking was important and the principle of 'wait for a response' was followed;
- Discipline was prompt, but with sensitivity; and
- The researcher was empathetic to the child's needs.

3.3.3.2.2 Positioning and structure

Positioning of the child with DS forms an important component of the DRSP. Positioning techniques play an integral part in the promotion of motor development, and have different goals and outcomes that influence the total development of the child with DS. The positioning of the child with DS is a challenge; therefore, the activities in the DRSP promote a variation of positions which should be implemented during intervention. All the positions involved in enhancing and promoting motor development form part of the DRSP (**cf.** 2.3.3.1.1).

a) The **Supine** (Colangelo & Shea 2010:523) position promotes:

- Flexor activity develops head control: midline control and chin tuck.
- Shoulder protraction and flexion against gravity.
- Hands to midline.
- Reduced demands on trunk and more effort can be given to head, oral, ocular and shoulder control.

b) The **Prone** position promotes (Colangelo & Shea 2010:524; Johnson & Blasco 1997:230; Nichols 2005:280):

- Head righting in a horizontal plane.
- Interaction of dorsal extensors and ventral flexors for propping on forearms to promote arm support.
- Shoulder stability during weight bearing (propping) and mobility on stability during weight shift (**cf.** Figure 3.8).
- Increased range of shoulder flexion is necessary when reaching from a horizontal position, which the child with DS needs for manipulation.
- Decreased effects of gravity on lateral asymmetries that occur with upright positioning.
- Hands are more likely to be in the visual field by nature of the shoulder position when propping.

Positioning of the child in prone during intervention sessions is of great importance, as gross-motor development proceeds from a sequence of prone milestones. A study done by Russell *et al*. (2009:14) showed significant differences between infants who spent 30 minutes or more in the prone position per day, compared to infants who spend less time in the prone position. These differences were seen in motor development, such as head control, turning of the head, weight displacement towards the thorax, active movement of the arms, especially pushing up on the arms, and positioning of the lower extremities in children that spent more time per day in the prone position. Prone positioning is a key component of the DRSP.

c) The **Side-lying** position promotes (Colangelo & Shea 2010:527):

- Lateral head righting (a component of neck stability in the upright position).
- Differentiation of two sides of body (lower side-weight bearing and upper side-mobile).
- Hands easily placed in visual field.
- Hyper-tonicity reduced, tonic labyrinth reflex inhibited.
- Effects of gravity on shoulder/extension reduced.

d) The **Side-sitting** position promotes (Nichols 2005:280; Russell 2010:14):

- Arm support.
- Crossing of midline.
- Trunk rotation.
- Weight bearing on extended arms.

The DRSP introduced side-sitting to counteract the lack of dissociation between the shoulder and pelvic girdles of the child with DS.

e) The **Sitting** position promotes (Colangelo & Shea 2010:529):

- Anterior/posterior and lateral stability of the neck and trunk.
- Weight shift on hips, hips in a slight anterior tilt.
- Arms liberated: shoulder position independent of trunk.
- Shoulder girdle provides stable base for arm movements.

Sitting as a transitional posture is important as studies show that children with DS have no side-sitting or trunk rotation (Lauteslager 2000:29).

f) The **Squatting** position (Brown 2009; MacNeill-Shea & Mezzomo 1985:1658)

Breaking up of movement patterns or specifying motor patterns were incorporated in the DRSP, for example, the weight-bearing activities to ensure ankle and shoulder-girdle strengthening.

It was found in a study that children with DS squat heels-down and that this may pose a problem with similar motor-developmental milestones such as stair climbing, jumping and later bicycle riding. A “squat-in-play” position with heals up is at a 21-month level of typical developing children.

g) The **Standing/supported standing** positions promote (Colangelo & Shea 2010:527):

- Erect spine: liberated arms.
- Neutral or slightly posterior pelvic tilt.
- Hips extended with neutral rotation.
- Knees stable but not locked in hyper extension.
- Ankles in 90 degrees flexion, neutral evertion.
- Improve circulation and bone growth from upright weight bearing.
- Increased alertness from upright position and extensor activity.
- Decreased effects of flexor hyper tonicity in the neck and trunk when weight bearing on extended hips and knees.

Activity	Position	Description	Outcomes	Materials
8 "Where's the Mug?"	Tummy/Prone 	Mother puts mugs in front and sides of baby. Baby reaches out to mugs. Mother puts a mug on left side of baby. Baby leans on left arm and reaches for mug with his right hand. Repeat above activity to right side. Mother talks to baby – e.g. "Where is the mug?" Mother repeats any sounds of the baby. Mother may sing to baby e.g. "My God is so great, so strong".	Motor stimulation: head control, reach, balance, hand-eye co-ordination, weight bearing and shifting, balance and equilibrium reactions Sensory stimulation touch, proprioception Auditory stimulation Visual stimulation Speech stimulation	Mugs

Figure 3.8: DRSP 3–6 months (2010:18)

3.3.3.2.3 Postural control

The successful outcome of any activity depends on well-integrated postural control. Refined motor control, such as postural control is important during reaching tasks (Barthel 2010:190; Giuffrida & Rice 2009:688; Heathcock *et al*. 2008:322; Levin & Sveistrup 2008:110; Shaaf *et al*. 2010:114). The importance of coordination between the pelvis and head, arms and trunk segments (HAT) is also taken into account throughout the programme with activities in postural control as an outcome (Kubo & Ulrich 2006:517) (**cf.** Figure 3.9). Studies have shown that children with DS improve their balance through physical activity and that the postural control activities make provision for this outcome (Villamonte 2009:17). This is also found in the long-term effect of treadmill interventions on gait development. It has been established that children with DS walk three steps independently on the ground about four months earlier than children without this intervention (Angulo-Barroso *et al.* 2008:231).

Automatic postural reactions are considered essential components of motor behaviour, such as righting, equilibrium and protective reactions. Righting reactions include responses that keep the head in normal alignment and provide for body axis rotation. Equilibrium reactions deliver postural shift mechanisms when the centre of gravity is altered or changed. Protective reactions assist in preventing a fall when the centre of gravity is rapidly displaced (**cf.** 2.3.3). According to the literature, the variation in movement patterns may be due to delayed righting reactions (Haley 1987:674). Low

truncal tone of most infants with DS is likely to be associated with the relatively later appearance of equilibrium reactions and the relatively earlier appearance of protective reactions or a combination of the two (Haley 1987:677).

Constant repetition of activities was central to the intervention sessions using the DRSP. There should be repetition of all activities, as children with DS are no different from typical developing children where the concept of repetition priming is relevant (Vicari 2006:360). These children's ability to imitate should be used during an intervention session (Vanvuchelen, Feys & De Weerdt 2011:155). A combination of repetition and imitation formed part of the intervention sessions.

Activity	Position	Description	Outcomes	Materials
Tip	From Back to Tummy/prone 	Slightly bend the baby's left leg forward under his chest while stretching his right arm forward above his head. Pull the leg over towards the floor. Rotate the baby forwards onto his tummy. The baby will bring his arm across and turn onto his tummy. Baby may roll to the side first before rolling over. Place a mug to the side you want him to roll to, to encourage his movement.	Postural control	None

Figure 3.9: DRSP 3–6 months (2010:14)

3.3.3.2.4 Presentation strategies

During a therapeutic intervention process presentation strategy is needed.In this section the therapeutic use of self, appreciative inquiry, effective teaching and responsive teaching as presentation strategies will be discussed.

The most important role-players in the life of the child with DS are the parents/caregivers. They should be equipped with the necessary skills to cope and manage their children during the intervention process (Cohn & Henry 2009:587–588; Kunagaratnam & Loh 2010:496) (**cf.** 2.6.6). The implementation of the DRSP provides the parent/caregiver with the necessary tools to be able to assist with the early intervention of their child with DS (**cf.** Figure 3.10).

Activity	Position	Description	Outcomes	Materials
Tip		Another method of holding a baby. Mother position her hands on baby's back and front of chest. Mother's hands are open, palms against baby's body. 	Motor stimulation: head control, sitting position	

Figure 3.10: DRSP 0–3 months (2010:13)

The occupational therapist encourages the individual to engage in meaningful activities and promotes the exchange of information (Schultz 2009:468) (**cf.** 2.5). Successful implementation of a programme depends on the manner and success of knowledge transference to a client. The following describes the methods and teaching principles the researcher used during implementation of DRSP.

a) Occupational therapist: therapeutic use of self

As stated in the literature, the intervention approach is performed by qualified professionals (Uyanik *et al.* 2009:336). The therapeutic relationship is different from the therapeutic use of self. The therapeutic relationship commonly addresses communication, developing rapport and a collaborative partnership between therapists and clients (Price 2009:337; Taylor, Lee, Kielhofner & Ketkar 2009:198). Occupational therapists view the therapeutic use of self as a means of encouraging clients to engage in occupation. The therapeutic use of self is an inevitable aspect of the therapeutic partnership (Gill 2012:5; Knight 2012:1; Taylor *et al*. 2009:198). Knight (2012:2–4) stipulates that there should be a genuineness about the therapist, also known as transparency. The therapist's transparency should model the behaviours that she is encouraging the adult participant to develop, such as how to motivate the child with DS to participate in an activity and how a therapist would control difficult situations. The researcher is transparent, which implies that her feelings and reactions (verbal and nonverbal) in connection with intervention are known to the parents. Being understood by another person gives the parent the encouragement to form a meaningful relationship. A further principle is the 'here-and-now' disclosure. This deals with the therapist's thoughts about and reactions to the parent and

the session. This may be a tool to promote empathy and generate a sense of trust (Knight 2012:7; Price 2009:331).

The value of therapeutic use of self in this study was to gain the trust of the parents and to engage them in their child's early intervention. Parents respond well to the transparency, as they need both a professional and an empathic therapist (Price 2009:337). The therapeutic use of self and a client-centred practice ensures a holistic approach.

b) Appreciative Inquiry

According to the literature, parents/caregivers and children with developmental disabilities may require training in the use of positive coping strategies (Ritzema *et al.* 2010:19/32). This is a post-modern approach to a consultation and can be referred to as a social-contractual approach. Certain aspects of a positive coping strategy, namely Appreciative Inquiry have been used. A definition of Appreciative Inquiry is "a vision-based approach of open dialogue that is designed to help organisations and partners to create a shared vision for the future and a mission to operate in the present" (Stavros, Cooperrider & Kelley 2003:16). This approach is a specific methodology used in predetermined sequence which involves identifying and building on existing strengths and opportunities. The four steps or elements of the SOAR model, namely strengths, opportunities, aspirations and results fit well with the Appreciative Inquiry approach (Stavros *et al.* 2003:12). The researcher incorporated these four steps or principles of the Appreciative Inquiry during DRSP sessions. Not only the strengths of the activities of DRSP were explained, but also the strengths of the child with DS as well as the parent involved. The DRSP created an opportunity to involve the parent to assist the child with DS. With this opportunity to contribute to the improvement of development of their child, the parent may be aspired. Successful completion of activities by parents was an encouragement for the researcher to continue with the DRSP. During and after a session results could be measured which made the follow-up visits more positive. The Appreciative Inquiry was a useful construct to use in this early intervention programme for children with DS.

c) Effective Teaching

A second strategy that was applied in the DRSP was Effective Teaching, which is not simply a matter of applying principles of teaching according to rules. Those principles need to be adapted to a person's own personal strengths (Biggs & Tang 2007:41; Radomski & Trombly-Latham 2008:777). The occupational therapist in her role as educator should adhere to guidelines of client-centred practice. The interventionist should have an in-depth knowledge and understanding of the children's problems, knowledge of appropriate interventions supported by effective communication and interaction skills (Case-Smith & Rogers 2005:812; Dunst & Trivette 2009:165; Wilkinson 2005:32–34). Teaching principles and methods are important in the management of the consultation and presentation of the DRSP. These principles were fundamental to the development of the technical manual.

As the parent/caregivers are an active part of the intervention process, the researcher as the interventionist, demonstrated the activities that were to be performed at home with their child, to them. Principles for effective learning are needed during this intervention process. Bulger, Mohr & Walls (2002:2), describe effective learning by using the "four aces" namely outcomes, clarity, engagement and enthusiasm for effective teaching (Walls 1994:6).

Effective strategies according to Brassard and Boehm (2007:39) include the enthusiastic manner of the therapist, humour during a session and playing with the child on the floor (**cf.** Figure 3.11). The researcher incorporated these effective learning strategies during intervention sessions.

Ace ♣: One: Outcomes

This implies that an outcomes-based orientation towards the intervention will be followed. The parent/caregiver knows in advance that clear goals will be set towards the intervention process. This will inform them where they are going and how to get there. The credibility of teaching is ensured by providing the parent/caregiver with tangible, compelling reasons to continue with the therapeutic activities at home. By being informed of these goals, the parents should be more relaxed and involved in the learning process from the onset. The DRSP endeavours to achieve an outcomes-based orientation.

Ace ♦: Two: Clarity

During intervention, the occupational therapist's expectations should be clear from the onset. Alternate instructions should be communicated, and demonstrated during intervention sessions to involve all the parents'/caregivers' senses. Prior knowledge of the parents/caregivers should be expanded. The reinforcement of the parents'/caregivers' pre-existing knowledge could promote to their positive attitudes towards therapy and intervention.

Ace ♠: Three: Engagement

Learn by doing. Correct and repetitive demonstrations are valuable during intervention. In studies of children with DS the findings indicate that visual instructions (demonstrations) to the parents facilitated greater skills performance (Meegan, Maraj, Weeks & Chua 2006:78). The occupational therapist should therefore involve parents to such a degree to ensure that the execution of activities is performed correctly before the end of a session. Credible reasons for activities in combination with active involvement of parents could ensure their commitment during the intervention process from the onset.

Ace ♥: Four: Enthusiasm

Enthusiasm is contagious. A positive learning environment enhances outcomes. The occupational therapist should continuously encourage parents to motivate and keep them enthusiastic about the intervention and the involvement with their child. By focusing on every positive improvement discovered during each session, continued enthusiasm is ensured. The key to motivation is experiencing success, even though it may be modest (Brassard & Boehm 2007:39).

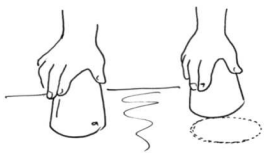
Activity	Position	Description	Outcomes	Materials
SHAPE 1 "Shapes Circle"	Sitting/Standing in front of box/Standing in front of table 	Child sits or stands in front of a table or box. Mother asks child to make a circle with the mug's round edge on wet sand. Mother points with her finger to the round shape and says: "It is round, it is called a *circle."* Repeats activity.	Motor stimulation: eye-hand co-ordination, hand function Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: Shape	Mugs Sand in small tray

Figure 3.11: DRSP 24–42 months (2010:44)

d) Responsive Teaching

Relationship-focused intervention is a general approach to developmental intervention that encourages parents to use responsive interactive strategies with their children, such as to take one turn and wait; or to follow the child's lead during any routine interaction with their children (Mahoney & Perales 2003:74). Responsive teaching is a comprehensive parent-mediated intervention curriculum for children from birth to six years of age which addresses three areas of development namely cognition, communication and social emotional functioning. Effective intervention is not only dependent on parent involvement, but rather that parents should be encouraged and supported to engage in highly responsive interactions with their children (Mahoney, Boyce, Fewell, Spiker & Wheeden 1998:15; *Responsive Teaching International Outreach Website* n.d.). The Responsive Teaching Strategies also apply to children with DS, as outlined in an article by Mahoney *et al.* (2006:23–24), and were adapted and incorporated during the presentation of the DRSP intervention sessions (**cf.** Table 3.2). Mahoney *et al.* (2006:18) describe the Responsive Teaching Strategies as a method of teaching and opportunity for parents/caregivers to notice developmental improvements (Karaaslan, Diken & Mahoney 2011:369). Teaching should not be 'trainer-oriented', with the parent initiating all the teaching exercises without any regard to the needs of the child (Pino 2000:343). Responsive Teaching overcomes this kind of teaching and affirms the holistic methods associated with the DRSP. This strategy describes five levels of teaching, namely Reciprocity, Contingency, Control, Affect and Match. In Table 3.2, the categories associated with these five levels are explained.

Table 3.2: Adaptive Responsive Teaching strategies (compiled by researcher for the thesis)

Reciprocity	**Contingency**	**Control**	**Affect**	**Match**
Engagement	**Awareness**	**Moderate Direction**	**Animation**	**Developmental Match**
Be physically available and interactive Play frequently together	Observe child's behaviour Be sensitive to child's needs	Communicate without asking questions Imitate child's actions and communications Give child opportunities to make choices	Wait with anticipation Respond to child in playful ways Accompany communication with pointing	Interpret child's development Know the skills child seems ready to learn Match child's developmental level
Balance	**Timing**	**Facilitation**	**Enjoyment**	**Interest Match**
Take one turn and wait Play with sounds back and forth Communicate less and child more	Responds quickly to child's signals Discipline promptly and comfort	Wait for a mature response Play for a purpose	Act as playful partner Interact for fun Repeat activities with enjoyment	Follow child's focus of attention Follow child's lead
Joint Action Routines	**Intent**		**Warmth**	**Acceptance**
Play face to face games Repetitive play Action sequences Play with toys Communicate during activity routines	Respond to unintentional vocalisations Accept incorrect word choice/ rephrase Translate child's actions and feelings into words		Be gentle Respond affectionately to child's cries Comfort child when fussy or irritable	Value what child is doing Accept child

A combination of the principles from Appreciative Inquiry, Effective Teaching and Learning and Responsive Teaching were utilised during the DRSP intervention process.

3.3.4 Implementation of the DRSP

The DRSP, with its elements of developmental qualities should be implemented as an intervention programme (**cf.** 2.6.1; 2.6.8; 2.6.9; 3.2). A further recommendation should be implementation of the DRSP over a six-month period, every second week.

The intervention session consists of:

- an introduction;
- demonstration of DRSP activities using therapeutic strategies;
- time allocation for practising DRSP activities by a parent/caregiver; and
- feedback from the parent about issues on the intervention.

The parent, with the child with DS, form an active and integral part of each session. The initial starting point of the early intervention is the developmental age of the child with DS, as obtained from an evaluation process.

3.3.4.1 Duration and content of the session

The policy document by NCSS (2007:31) on “Best Practice” suggested that an individualised intervention session should be a minimum of 30 to 45 minutes per session, depending on the client’s need. The frequency of intervention depends on the needs of the clients, as identified by the occupational therapist.

The length of the session should be adapted according to the tolerance of the children with DS. Further adaptations should be made when the children with DS became fussy, cries or walks away from the stimulation material (KIT).

- The first two to five minutes of the session should be set aside for feedback from the previous session. The evaluation of the parent’s performance of activities at home should be done by check listing.

- The next intervention activities, as listed in the programme, should be demonstrated for a period of eight to 30-minutes.

- The last two to five minutes of a session should be devoted to practising the activities that would be performed at home by the parent/caregiver.

3.3.4.2 Procedure of the session

During an intervention session, each activity should be explained in an appropriate manner to the parent.

A holistic approach should be used during the sessions.

- The sessions should be relaxed (comfortable) and non-threatening, so that the parent has the opportunity to ask questions regarding the programme, or any of the aspects of DS. The sessions should end by providing the parent with any other information necessary to enhance and support the intervention of her/his child with DS.

- The first intervention session always commences after a pre-test was done to establish the developmental age of the child with DS so that developmentally age-appropriate activities of the DRSP could be used.

- At the end of the intervention session, activities should have been established that could be performed by the child and could be integrated into the home programme.

- As no parent/caregiver should be discouraged or demotivated by the intervention at home, the preferred activity load is two to three activities only for the two-week period before the next intervention session is introduced. If a child could tolerate more activities, these should be given to the parent to be performed at home. The activities should be demonstrated on the child and then the parent gets the opportunity to perform the activities. Each activity should be practised until the parent would be able to manage these activities at home. The activities are developed in such a way that a parent could perform it as many times as possible every day. This principle of repetition encourages compliance with the home programme and therefore the sustainability of the child's activity performance. In addition, activity manual pages should be provided to further support the sustainability of the programme and execution at home (**cf.** 3.2.2.2.1; 3.2.2.2.2; 3.2.2.2.3). The parent's attitudes towards the service should be discussed (Luebben *et al*. 2010:44).

- Each activity for every session should be prepared. The results for each session had to be scored by using the DRSP checklist scoring, which included the process notes. This scoring should take place after the session.

3.3.4.3 Therapeutic area

A 5 x 4 metres office space may be used for the intervention sessions. According to the Brassard and Boehm (2007:39), the room should be attractive, but modest, with minimum distracters such as mirrors. Other materials should not be easily visible or should be removed. Furniture and other materials should be adapted to ensure minimum distraction. This implies that the treatment area should be as empty as possible without any distracters such as cluttered office equipment and open cabinets. An office with only a desk, chair and therapeutic mats may be appropriate. The walls should be bare so that no external stimuli could distract the child with DS (Bayley 2006a:9).

3.4 CHAPTER SUMMARY

Guralnick (2005:318) explains the concept of specific intervention the closest in those false expectations should minimise and new approaches should stimulate to improve outcomes to existing intervention programmes. This explanation underwrites what the researcher intended to accomplish with the implementation of the DRSP. The DRSP was developed specifically for the child with DS and the proposed specific outcomes. This evidence based practice endeavours to demonstrate that the DRSP is a holistic home-based programme that could have positive outcomes on the development of the child with DS. The role of the researcher was to utilise the DRSP during interventional occupational-therapy sessions with children with DS.

This chapter presented an overview of the DRSP and the development of this early-intervention programme for the child with DS. The following chapter focuses on the methodology in terms of the four objectives and on the research approach and methods. This includes the study design, study population, sampling, pilot study, data collection, data analysis and error of measurement.

CHAPTER 4
RESEARCH APPROACH AND METHODOLOGY

No Man is an Iland, entire of it selfe; every man is a peece of the Continent,

a part of the maine... (spelling according to original poem)

John Donne, English poet (1572–1631)

(Leedy & Ormrod 2010:xiii)

4.1 INTRODUCTION

The previous two chapters focused on the relevant published literature fundamental to this study. The content and principles in support of the DRSP (**cf.** 3.2) were also discussed to present a background to this chapter.

This chapter focuses on the methodology in terms of four objectives and on the research approach, design and methods. Table 4.1, gives a summarised outline of the aim, objectives and methods of the study.

Table 4.1: Summary of the aim, objectives and methods of the study

The aim of this study was to investigate the impact of the DRSP on DS children younger than 42 months in the South African context		
Objective One	To investigate the impact of the DRSP on developmental progress in children with DS younger than 42 months	Nonrandomised control group pre-test-post-test design
		Measurement instrument: Pre- and post-test using the Bayley Scales III & Socio-Emotional and Adaptive Behaviour questionnaire (Appendix E)
Objective Two	To establish the duration of intervention to achieve a positive outcome	Descriptive design
		Measurment instrument: DRSP Checklist (Appendix F)
Objective Three	To measure objectively to what extent the parents/caregivers are able to perform the required activities of the DRSP correctly and independently after instruction	Descriptive design
		Measurement instrument: DRSP Checklist (Appendix G)
Objective Four	To determine parental/caregiver satisfaction with the DRSP	Descriptive design
		Measurement instrument: Parent Questionnaire (Appendix H)

4.2 RESEARCH APPROACH

A quantitative research approach was followed. Solid fundamental research principles and a strong methodological approach are crucial to any study's value.

The researcher agrees with Polit and Beck's (2008:15) explanation of quantitative research as a methodology that is closely linked to the "positivist tradition" in research. The numeric description of comparisons between groups (Carpenter & Suto 2008:170; Fouché & Delport 2005:75; Joubert, Bam & Cronjé 2008:72) in the study was the researcher's predominant preference for this research approach. Quantitative data in this study include the measurable activities of the DRSP (Carpenter & Suto 2008:3; Joubert *et al.* 2008:2; Leedy & Ormrod 2010:97; Polit & Beck 2008:19) (**cf.** 3.3.2.4).

According to Macnee (2004:166), accurate and consistent measurement is the key to successful quantitative research. In addition, Burns and Grove (2007:530) describe quantitative research as a formal, objective and methodical process that describes variables such as the cognitive, speech and motor development of the child with DS, as well as the intervention and the relationship between them, in order to establish a "cause-leads-to-effect" relationship (Jackson 2011:22; Leedy & Ormrod 2010:231; Maree & Pietersen 2007c:149; McMillan 2008b:219; Quantitative Research Design n.d.:2/5; Sukamolson n.d.:5/7).

4.3 OBJECTIVE 1: To investigate the impact of the Developmental Resource Stimulation Programme (DRSP) on developmental progress in children with Down syndrome younger than 42 months

4.3.1 Introduction

To investigate the impact of the DRSP on children with DS younger than 42 months, a non-randomised control group pre-test-post-test quasi-experimental design was applied including an experimental and control group (Leedy & Ormrod 2010:234; Maree & Pietersen 2007c:150; Quantitative Research Design n.d.:2/5). The essence of a quasi-experimental design is to determine a cause-effect relationship (Ellis & Levy 2009:326) that exists between pre-testing and post-testing (one factor) and the intervention (a second factor). The advantage of this design is to quantify the difference between the pre-test and post-test measurements of the children with DS after a six-month intervention period (Cottrell & McKenzie 2011:9; Creswell 2003:20; Leedy & Ormrod 2010:234). For this study the term intervention group will be used as opposed to experimental group.

According to literature studies intervention periods are between seven weeks and one year (Connolly *et al*. 1980:1406; Del Giudice *et al.* 2006:54; Mahoney *et al.* 2001:154; Spiker & Hopmann 1997:15/36). The deciding factor for this study was the observation made by Mahoney *and other authors* (2001:161), that the first change in motor development occurred after children had received an average of six months of intervention

(Mahoney *et al*. 2001:161). Furthermore, a six-month period between two evaluations is stipulated as good practice in the Bayley Scales III manuals (Bayley 2006b:62).

Table 4.2, presents a schematic outline for objective one.

Table 4.2: Schematic diagram of objective one

Objective One	
Quasi-experimental design	
Nonrandomised control group Pre-test-Post-test	
Study population & Sampling	
•Children with DS (Birth - 42 months)	
Intervention Group	**Control Group**
Inclusion •Trisomy 21 •Available for two weekly sessions •Available transport •Children included should have a parent/caregiver available for entire duration of the study (to rate 2 aspects: parent questionnaire of Bayley and implement activities)	**Inclusion** •Trisomy 21 •Available for pre- and post testing •Available transport to evaluations •Children included should have a parent/caregiver available for entire duration of the study (to rate parent questionnaire of Bayley)
Exclusion •Adverse events •CP •Heart disease	**Exclusion** •Adverse events •CP •Heart disease
Sites	
Site 1	Site 1,2,3
Intervention	
DRSP	Intervention programmes at different sites
Measurement intrument (both groups)	
Bayley Scales III for pre-test and post-test by Occupational Therapist & Socio-Emotional and Adaptive Behaviour Questionnaire for pre-test and post-test rated by parents	
Evaluator (both groups)	
Same Occupational Therapist for pre-test and post-test	
Moderating (both groups)	
Two Occupational Therapists knowledgeable in early childhood development	

4.3.2 Study design

A quasi-experimental design, specifically a non-randomised control group pre-test-post-test design (Cohen, Manion & Morrison 2007a:275; Cottrell & McKenzie 2011:9; Fouché & De Vos 2005:140; Jackson 2008:124; Leedy & Ormrod 2010:231, 234; Maree & Pietersen 2007c:150; McBurney & White 2010:289; McMillan 2008a:230; Sheskin 2004:602) was followed to investigate this objective. According to the literature, the pre-experimental evaluation, the implementation of the intervention (DRSP) and the post-treatment evaluation made this study a quasi-experimental design (Fouché & De Vos 2005:133, 141; Fouché, Delport & De Vos 2011:149; Jackson 2008:124; Leedy & Ormrod 2010:108, 233; McBurney & White 2010:289; McMillan 2008a:232; Sheskin 2004:83), with the inclusion of a non-matched control group without intervention on the DRSP.

In this study, the intervention group was enrolled in the DRSP. The independent variable is the variable that is controlled and manipulated, in other words, the intervention itself (Leedy & Ormrod 2010:224). The dependent variable (Maree & Pietersen 2007c:150) is the response that is measured and is the presumed effect of the intervention process.

4.3.3 Study population

The study population consists of (Joubert & Katzenellenbogen 2007:94; Strydom 2005b:193), all children who presented with common characteristics of DS, specifically Trisomy 21. These children's diagnosis had been confirmed by the relevant clinicians.

All children with DS, 42 months and younger, referred to the BCIC were included in the study. Their referrals were important for the successful execution of the study. The children with DS, 42 months and younger were referred by the Department of Genetics, the Department of Paediatrics and Child Health and private paediatricians. All available children with DS visiting two Down Syndrome Association Centres in South Africa and children with DS that could not attend two weekly intervention sessions were included in a non-matched control group.

The inclusion criteria for the target population were as follows:

- Children with DS diagnosed with Trisomy 21.
- Between the chronological age of birth and 42 months.
- Participants in the intervention group had to have transport available for the entire intervention period and reside near the BCIC.
- The intervention group participants had to be available for two weekly sessions for a period of six months per participant. The decision was made that the intervention duration per participant would be six-months (**cf.** 4.3.1).
- Parent had to be available to execute activities for the duration of the six-month period.
- The control group had to be committed to be available for pre-testing and post-testing after a six-month period.

The exclusion criteria for target population were as follows:

- Adverse events such as illness that could negatively influence attending intervention sessions and the child's endurance.
- Voluntary withdrawal from study.
- Cerebral Palsy with DS, because the physical challenges influence the development of the child (**cf.** 2.2).
- Heart disease and or open-heart surgery at the time of the intervention, because congenital heart disease is noted to be negatively associated with cognitive abilities (**cf.** 2.3.1).

4.3.4 Sampling

According to Polit and Beck (2008:24), the decisive factor in determining the adequacy of a study is the representativeness of the population (sample reflection). However, the size of an adequate sample depends on how homogeneous the participants are (Coughlan, Cronin & Ryan 2007:660; Leedy & Ormrod 2010:214).

4.3.4.1 Intervention group

The deciding factor for the study population was the availability of participants. The potential size of the group was determined by statistics obtained from the Department of Genetics of the Faculty of Health Sciences, which correlated with the statistics of the BCIC for a period of five years prior to the study. Therefore, this study made use of consecutive sampling (Leedy & Ormrod 2010:212), because of the availability. In a sense the participants have been chosen to be part of the study.

A small study sample seems to be applicable when including such young children with DS. The sample size in the two studies, by Del Giudice *et al*. (2006:54) and Lauteslager (2000:117) regarding young children with DS and early intervention were 21 and 18 participants respectively in the intervention group, and 11 participants in one control group with no control group in the other study.

The predetermined sample consisted of 15 – 25 children with DS. A realistic sample for the intervention was predicted to be about 15 intervention participants and 15 control participants.

4.3.4.2 Control group

The control group selection was determined by available and compliant parents of children with DS. Participants from the BCIC that could not attend two weekly intervention sessions for a six-month period were included in the control group. The other participants in the control group resided in two major cities in two other provinces in South Africa, where no DS specific intervention programmes were available. The children with DS from these cities visited their centres at regular intervals. The control group continued with their intervention in the respective communities. These interventions included physiotherapy, occupational therapy and speech therapy and the DSPI programme (**cf.** 2.6.9). Even though the control group received intervention, they were still included in the study (**cf.** 4.8.2).

Initially matching of the intervention and control group was considered according to gender, chronological age, weight and definite age-appropriate milestones such as head

control, sitting, rolling, walking and two-word utterances. Due to the small population sample (Carpenter & Suto 2008:79; Leedy & Ormrod 2010:212; Maree & Pietersen 2007a:177) this matching process was not feasible and the quasi-experimental design was appropriately applied.

4.3.5 Measurement

> ”It is established that a standardised measure is a published assessment tool that provides detailed instructions on test administration and scoring and has published results of reliability and validity” (Radomski & Trombly-Latham 2008:67).

The measurement of this objective included the evaluation instrument, the evaluator, two moderators and parents.

Prior to the study, other assessment tools were studied, such as the Peabody Developmental Motor Scales and Activity Cards, Adaptive version of the TIME (Toddler Infant Motor Evaluation), Bruininks Oseretsky Test of Motor Proficiency (balance subtest) (Villamonte 2009:5; Wang & Ju 2002:445), Gross-Motor Function Growth (GMFM) (Gémus *et al.* 2001:70; Mazzone *et al.* 2004:120; Russell, Palisano, Rosenbaum, Gémus, Gowland & Galuppi 1998:695), Griffiths Mental Scale (Hindley 1960:99; Kwong & Wong 1996:153). Even though Jiar, Supriyanto, Satria, Kuan and Han (2010:233) indicated a lack of standardised measurement instruments, a variety of tests are available.

Numerous comparisons have been made between the Bayley Scales III and the BSID-II (Bayley Scales of Infant Development 2nd edition), WPPSI-III (Wechsler Preschool and Primary Scale of Intelligence 3rd edition), PLS-4 (Preschool Language Scale 4th edition), PDMS-2 (Peabody Development Motor Scales 2nd edition) and ABAS-II (Adaptive Behavior Assessment System 2nd edition) (Bayley 2006b:75). The PDMS-2, for example, has limited data on children with special needs. The apparatus of the PDMS-2 does not include all materials needed for administration and the small objects could be a choke hazard (Kenworthy & Anthony 2013:286). The Bayley Scales III is a validated test (Bayley 2006b:75, 103) which is widely compared and with the strengths of a holistic evaluation, which was a further motivation to use the Bayley Scales III for this study. These positive

comparisons provide empirical support for the five areas of the Bayley Scales III (**cf.** 4.3.5.1). The Bayley Scales III is described as sensitive to performance differences between children in the normative sample and samples of children with various conditions that place them at risk for developmental delay (Bayley 2006b:103; Kenworthy & Anthony 2013:282). The Bayley Scales III was equally reliable for assessing individuals with different levels of development and clinical diagnoses (Bayley 2006b:59). The specifications of the assessment tool made it suitable for children with DS in both groups and met the requirements of the research. The purpose of the measuring tool, the quality of information obtained after testing, the ease of communication of the results, and the standardised nature of the test are requirements for a suitable test (Richardson 2010:219; Unsworth 2000:151).

The Bayley Scales III is one of the assessment tools most commonly used in children with intellectual disabilities (Shapiro & Batshaw 2013:299) and has been used extensively in numerous studies as an evaluation tool for children with DS (Albers & Grieve 2007:180; Blauw-Hospers & Haddlers-Algra 2005:426; Carr 1995:19; Harris 1981a:478; Harris 1983:17; Hutchon 2010; Lydic 1982:55; Mahoney *et al.* 2001:156; Nilholm 1996:54; Piper *et al*. 1986:191; Reed 2001:59; Woods *et al.* 1984:288).

This individually administered instrument assesses the developmental functioning of infants and young children (Bayley 2006a:1). The test has comprehensive scales, which identify children who may have delays in their total development. It provides a baseline from where intervention planning starts, which facilitates the follow-up progress (Elfant-Asher 2007:244–245). This test also provides information in support of intervention planning and goal setting (Brassard & Boehm 2007:414) and was thus selected as the most appropriate test for this study.

The Bayley Scales III, even though designed and normed in the US, is considered the gold standard in infant assessment (Rademeyer 2010:8). Although the Bayley Scales III and other measurement tools had not been standardised on the South African population, it is based on typical development in all populations. In the South African context, the Bayley II was used successfully in studies done by Baillieu and Potterton (2008:118) on HIV-positive infants. According to Rademeyer (2010:125) the Bayley III is assumed to be a valid test to use on black urban African infants in Gauteng, South Africa and local norms do not need to be created. Bayley Scales III may have limitations even for the DS

population as a method of analysis, but the test offers a holistic evaluation of a child's development.

The separation of the motor domain into fine-motor and gross-motor was a deciding factor in using the Bayley Scales III as the evaluation tool for this study. The literature states that there is a definite delay in both the fine-motor and gross-motor domains of the child with DS (**cf.** 2.3.3.1; 2.3.3.2). The DRSP involves all these domains and it is important to establish a comprehensive description of the child with DS' development and to progress towards specific goals. Evaluating all the domains renders goal setting for the development of early-intervention programmes.

4.3.5.1 Description of Bayley Scales of Infant and Toddler Development 3rd edition

The Bayley Scales III comprises the following; the developmental domains and a Social-Emotional and Adaptive Behavior Questionnaire are also provided (Appendix E):

- The **Cognitive Scale** evaluates how the child thinks, reacts and learns about the world around him/her. The cognitive scale is made up of nonverbal activities involving memory, problem solving and manipulation (Acton, Biggs, Creighton, Penner, Switzer, Thomas, Joffe & Robertson 2011:e795; Bayley 2006b:4). There are 91 age-related items (Bayley 2006a:48–83). Cognitive function during the first year of life correlates with cognitive functioning later in life. The information-processing type of tasks of the Bayley Scales III includes novelty preference, habituation and paired comparisons, memory, reaction time, and anticipation of patterns. These items were found to correlate with later cognitive functioning and intelligence test scores (Bayley 2006b:3).

- The **Language Scale** is composed of the receptive communication subtest, measuring verbal understanding and verbal concept development and the expressive communication subtest, measuring ability to communicate through words and gestures. Bayley (2006b:5) assumes that receptive and expressive language develop independently.

- The Receptive Communication assesses how well the child recognises sounds and how much the child understands spoken words and directions. This subtest consists of items that assess auditory acuity. It is the ability to respond to the sound of a person's voice, to respond to and discriminate between sounds in the environment and to localize sound (Bayley 2006b:5). There are 49 items (Bayley 2006a:84–102).

- The Expressive Communication evaluates how well the child communicates using sounds, gestures or words (Acton *et al.* 2011:e795; Bayley 2006b:5). There are 48 items (Bayley 2006a:103–119).

- The **Motor Scale** includes items that measure quality of movement, sensory integration, and perceptual-motor integration, as well as basic milestones and locomotion. It consists of two parts:

  - The Fine-Motor development assesses how well the child can use his/her hands and fingers to make things happen. The fine-motor subtest measures visual-motor integration, visual-spatial, and motor-control skills of the hands (Acton *et al.* 2011:e795; Bayley 2006b:7). There are 66 items (Bayley 2006a:120–144).

  - The Gross-Motor development determines how well the child can move his/her body. The gross-motor subtest measures large body complex movements and mobility. This subtest is composed of items that assess milestones in motor development and ultimately quality of movement (Acton *et al.* 2011:e795; Bayley 2006b:7). There are 72 items (Bayley 2006a:145–171).

According to the Bayley Administration Manual (Bayley 2006a:15) the test administration time can be adapted. This adaptation was applied for this study: 25–40 minutes for the child younger than two years and to 30–60 minutes with a short break for the two older children in the sample.

The original scores in the manual include scaled, composite and growth scores, developmental age equivalents and percentile ranks. Composite scores produce

performance levels in each of the five areas, based on cut-off scores. The normative data included comparison with age-equivalent peers as well as children in special populations (such as DS), sharing similar conditions (Bayley 2006a:5). The scaled scores and age prevalence in months are used for the interpretation of the research. The standard scores have a mean of 10, a standard deviation of 3 and a range of scaled scores from 1–19 (Bayley 2006b:51, 108). The qualitative description of scaled scores for children younger than 42 months is as follows: Extremely Low (scaled score of 1–3), Borderline (scaled scores of 4–5), Low Average (scaled scores of 6–7), Average (scaled scores of 8–12) and High Average (scaled scores of 13–14) (Psychometric Conversion Table 2012:1–2). According to the Technical Manual of the Bayley Scales III, the DS group scored between 2.5 and 3 standard deviations lower than children in the matched control group when the test was standardised. The mean scaled scores for Cognitive abilities were 3.6, Receptive Language 5.1, Expressive Language 4.9, Fine-Motor 4.0, Gross-Motor 3.4, and Social-Emotional 6.4 (Bayley 2006b:86). According to the literature, if significant standard deviation (>2) occurs, there is a possibility of intellectual disability (Johnson & Blasco 1997:237).

- **Social-Emotional and Adaptive Behavior Questionnaire** of Bayley Scales III

This parent/caregiver questionnaire is a reflection, based on their child's performance at home and the community. It further provides insight of the child with DS to the parent/caregiver. This parent questionnaire is completed by the parent after the pre-test and post-test for both the intervention and control group. This questionnaire is an important part of the child's evaluations as it provides information about how the child interacts with the parent and about the child's skills that helps him/her to get along, for example, how established their relationship may be. Further useful information from this questionnaire is the parents' ability to cope with their child with DS both at home and away from home on a daily basis (Bayley 2006b:10). This information is provided by the parent/caregiver, the person who knows the child best.

The questionnaire consists of two parts, namely:

The Social-Emotional Scale presents questions about the child's social-emotional skills such as the ability to express emotions and to enjoy developmentally appropriate

interactions with parents, adults and other children and sensory issues (Kim & Mahoney 2005:119). According to Bayley (2006b:8) approaches to the assessment of emotional and social functioning have been limited. Published research suggests that socio-emotional development in children with DS may be compromised (Wishart 2007:1000), but comparatively little research has been carried out into emotional understanding in either children or adults with intellectual disability. The questionnaire is based on functional emotional milestones. The normative sample for the Social-Emotional domain is divided into nine age categories and a Sensory Processing score calculation (Albers & Grieve 2007:180).

The Social-Emotional Scale has six ratings for each item to describe how often a particular type of behaviour is observed (Bayley 2006a:173):

- 0 = Cannot tell
- 1 = None of the time
- 2 = Some of the time
- 3 = Half of the time
- 4 = Most of the time
- 5 = All of the time

The ten Adaptive Behaviour Scales consist of questions about the different kinds of skills the child has, such as communication, community use, functional pre-academics, home living, health and safety, leisure, self-care, self-direction, and social and motor development. These questions consider critical views of parents to the diagnosis of a child with an intellectual disability (Uyanik & Kayihan 2009:1).

The Adaptive Behaviour Scales have four ratings to select from, which enables each item to rate the extent to which the child performs the adaptive skills (Bayley 2006a:173):

- 0 = Is not able
- 1 = Never when needed
- 2 = Sometimes when needed
- 3 = Always when needed

The information gained from the questionnaires assist with the teaching methods (**cf.** 3.3.3.2.4c) and treatment recommendations for intervention sessions (Elfant-Asher 2007:244–245). A further positive use of the questionnaire was that it indicates how the parent perceived and understood his/her child with DS. The questionnaire functions as a self-evaluation tool for the parents of their child's development.

4.3.6 Data collection

All participants (children with DS), both the intervention and control group were evaluated on two occasions (pre-test and post-test) with a six-month interval between evaluations using the Bayley Scales III. The Bayley Scales III parent questionnaire was also completed by the parents at the pre- and post-testing of the children as part of the evaluation (Appendix E). Figure 4.1 outlines the process of objective one.

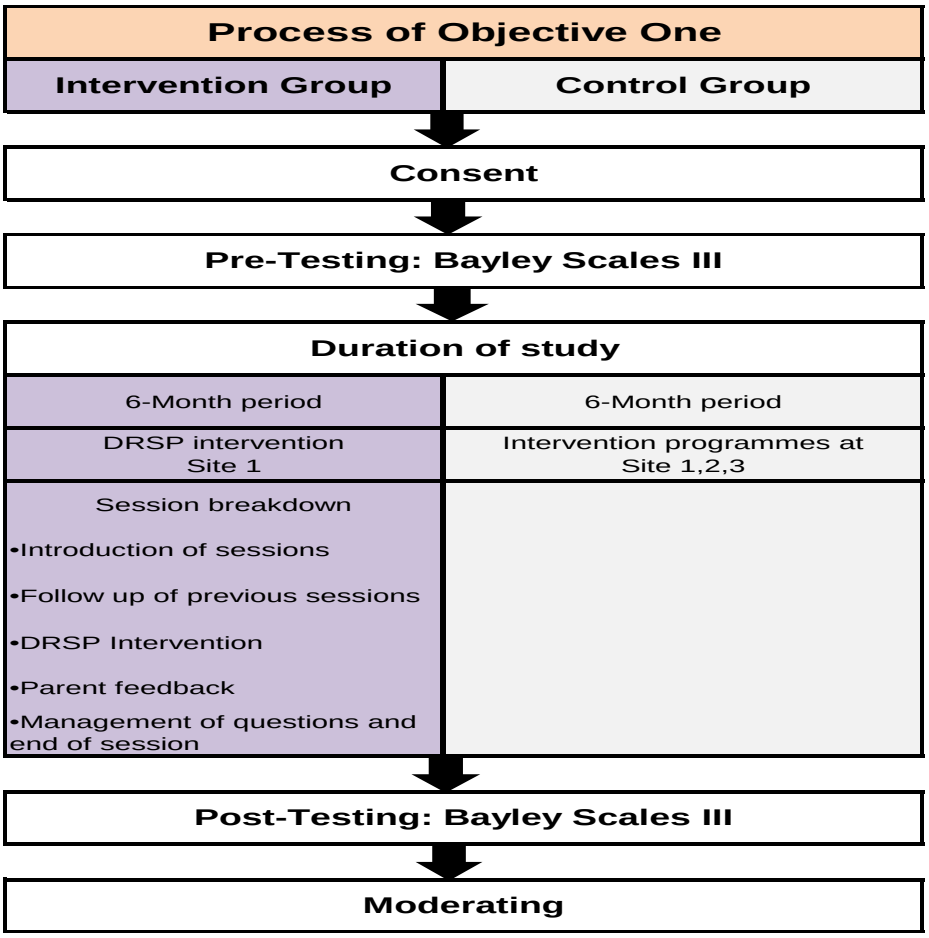


Figure 4.1: Schematic presentation of process of objective one

4.3.6.1.1 Data collection process

The study involved young children with DS for a six-month period, divided into an intervention or control group. All participants' parents gave written consent to participate in the study (**cf.** Figure 4.1). The pre-testing with the Bayley Scales III (Bayley 2006a:48–171) was done on all the participants in both groups (Appendix E). The therapist completed developmental domains during the evaluation process and the parents the questionnaire. The intervention group received the DRSP and the control group continued with their intervention programmes during this period. After a six-month period a post-test was performed on all the participants in both the intervention group and control group.

The study involved three sites. The treatment of the intervention group took place at site one from January until December 2011. The control group was situated and managed at sites one, two and three (**cf.** Table 5.2). The coordinator of the control sites did the sampling according to the predetermined specifications and inclusion criteria (**cf.** 4.3.3; 4.3.4.2). The control group continued with their individual intervention programmes during the six months. Demographic information such as contextual factors was gathered at the post-testing. The pre-testing of the control group started in May 2011 and the post-testing was concluded in February 2012. This timeframe for the control group could only be established once the intervention group was enrolled.

An independent occupational therapist from a tertiary hospital, trained in the Bayley Scales III, performed and scored the testing of all evaluations of the intervention and the control groups for the children with DS, but was not involved in the interpretation. The evaluations were video-recorded to obtain a true reflection of the evaluation sessions and were used in the moderating process.

4.3.6.2 Moderating

Moderating was an important tool that ensured quality standards for the evaluations in this study to be maintained (Brown 2009:17; UFS Policy Document 2006:4). Prior to the study, the moderators (with considerable experience and held in high esteem by their peers), namely two occupational therapists (**cf.** 4.8.5), were interviewed and the aim of the study was explained. This consultancy session formed part of the ethical procedures (Henry &

Kramer 2009:343). Although video recording has been criticised in the literature as intrusive, it provides a wealth of data (Carpenter & Suto 2008:102). All evaluations of all the participants were moderated using Appendix H to score the video recordings of the evaluations in order to enhance the validity of the measurements. The original scores of the evaluator and the researcher were compared to establish that the researcher was objective.

4.3.7 Data analysis

The data of the Bayley tests were summarised using descriptive statistics namely median and quartiles (Lombaard 2011:62; Leedy & Ormrod 2010:30, 271). Tests to measure the significance of the data were also performed.

The median was used, since it is a robust measure of centrality that is not influenced by extreme values in the data and was compared to the mean scores of the Bayley scales . The median is defined to be the middle value of the ordered observations and measures of central tendency (mean, mode, median) will be equal for symmetrical distributions, such as the Normal distribution (Joubert 2007b:131; Pietersen & Maree 2007c:187; Rice 2007:395). In the case of asymmetric (skewed) distributions, use of the mean as a measure of central tendency will be responsible for crude results (Leedy & Ormrod 2010:264).

The Inter-quartile range was used as a measure of dispersion and is reflected by the upper and lower quartiles (Jansen 2007a:19; Lombaard 2011:88; Rice 2007:402). The given Bayley standard scores follow a normal distribution, therefore, they can be compared with the median values obtained from the pre-test and post-test scores (Polgar 2009: 523).

The Bayley Scales III tests were compared using non-parametric Wilcoxon signed-rank test, Mann-Whitney test and 95% confidence intervals (Altman 1991:194; Cohen, Manion & Morrison 2007b:522; Joubert 2007a:144; Joubert *et al*. 2008:81; Leedy & Ormrod 2010:265). The Wilcoxon signed-rank test is a non-parametric test and similar to the paired *t*-test when two variables are compared in a single sample. This test is used for comparison within groups using pre-test and post-test (Pietersen & Maree 2007a:231).

This test is appropriate when the sample size is less than 30. The data set did not follow a normal distribution, therefore, the *t*-test was not applicable, and since it is a test used to evaluate the mean and would portray biased results. The Mann-Whitney test is also a non-parametric test used when two independent groups need to be compared based on a single variable between groups. It is useful to apply this test rather than the *t*-test when the samples are small (less than 30) and the assumption cannot be made that the variable is evenly distributed in the populations (Pietersen & Maree 2007a:233). In the case of this study, it was the preferred option, as the study sample was predicted to be small. A confidence interval can be explained as an interval containing random values calculated and obtained from the sample which has a specified probability of containing the parameter in question (Rice 2007:217). Therefore the inclusion of confidence intervals may be helpful to future researchers and occupational therapists, since the confidence intervals predict the range in which scores are expected to be achieved.

The above analysis of the Bayley tests were done by stratified analysis of the age groups (<9–months; >9–months).To acquire more specific data, correlated ages were grouped together to form a <9-month group and a >9-month group, particularly the fine-motor and gross-motor domains in the ages of children with DS (**cf.** 2.3.3.2).

Changes from pre- to post-test values are considered to be the dependent variables and the intervention as the independent variable (Maree & Pietersen 2007c:150).

The data analysis was performed by the Department of Biostatistics of the University of the Free State, using the software package SAS.

4.3.8 Pilot Study

The pilot study was done to establish the technical and procedural aspects involved during the testing of the participants and the procedures of the DRSP. Prior to implementing this research, approval was obtained from the Ethics Committee of the Faculty of Health Sciences of the University of the Free State and the approval of the head of School of Medicine, Faculty of Health Sciences and head of department of Paediatrics and Child Health (Appendix A).

The parents gave their written informed consent to participate in the pilot study prior to the start of the study (Appendix B). Two older children with DS, four and six years old respectively, were used for the pilot study, even though the Bayley Scales III tests up to 42 months only. Even in these older children the pilot study was effective to establish technical considerations. Younger children with DS were not used, because they were all included in the study. These two children with DS were evaluated, followed by an interventional DRSP session. One child with DS was an Afrikaans-speaking boy and the other a Sesotho-speaking girl.

The pilot study was done to pilot technical considerations such as the placing of the video camera and the positioning of the floor mats during the evaluation of the study. As the occupational therapist performing the test was qualified to use the Bayley Scales III, the pilot study was not done to investigate the performance of the therapist, but to examine the mechanics and the handling of the evaluation material. The mechanics of the test worked well and site one was well suited for the testing of the intervention group.

The second approach to pilot a study is the procedural approach. The procedural approach (Capio & Rotor 2010:19) was used to verify whether both the participants, the child with DS and the parent(s) would be able to understand the instructions and could respond to the demands of the testing protocol.

The two moderators who evaluated the video recordings were qualified occupational therapists who had attended a course on how to administer the Bayley Scales III. Therefore, it was considered not necessary to include these occupational therapists in the pilot study (Leedy & Ormrod 2010:93).

4.4 OBJECTIVE 2: To establish the duration of intervention required to achieve a positive outcome

4.4.1 Introduction

Descriptive studies indentify the characteristics of an observed phenomenon (Leedy & Ormrod 2010:182), and are useful to health-service providers in the development of

appropriate services (Morroni & Myer 2007:78). Descriptive statistics (Pietersen & Maree 2007c:183; Polit & Beck 2008:19) were used to organise and summarise data from the DRSP score sheets in a meaningful way.

This objective determined the *number of sessions* per activity and the *session length* that enables a child with DS to master the DRSP activities. To achieve this objective, all the participants of the intervention group were involved during 192 intervention sessions. The scoring was done by using the rating scale of the DRSP that was guided by the rating scale of level descriptors of the ICF-CY. The descriptors of each level were adapted to fit the content of the DRSP response categories (Appendix F).

4.4.2 Study design

To investigate the second objective a descriptive design was undertaken. The descriptive research design is applicable, because the DRSP checklist has an ordinal scale of measurement (Pietersen & Maree 2007c:183).

4.4.3 Study population and sampling

All the participants of the intervention group formed part of the study population (**cf.** 4.3.3; 4.3.4).

4.4.4 Measurement

This objective was assessed by scoring the intervention sessions of all the children with DS of the intervention group on the DRSP checklist (Appendix F). This information was utilised to establish the duration of intervention within which a specific goal (outcome) could be achieved. For example, how many sessions were needed to enable the child to perform an activity independently?

4.4.4.1 Description of the DRSP checklist

A comprehensive checklist to determine the level of independence in activity performance was designed according to the DRSP. There are 85 activities based on the typical development of children (Appendix F). The DRSP checklist, including the process notes was used during the intervention sessions of the intervention group. The timeframe i.e. number of sessions were determined for the achievement of independent activity performance to enable the children to reach a specific goal during the intervention. The participation of the child with DS was quantified using ordinal scale by applying the level descriptors from 0–4 based on the qualifiers for seven age bands, namely 0–3 months, 3–6 months, 6–9 months, 9–12 months, 12–18 months, 18–24 months and 24–42 months. Each activity in the age bands was analysed to goal specific abilities, namely; cognitive, gross-motor, fine-motor, language, socio-emotional, play and ADL (**cf.** Table 3.1).

The initial level of intervention (first intervention session) was determined by the pre-test age scores of the Bayley Scales III. When a child with DS scored an age score of four months, intervention started in the 3–6 months age band. As this intervention is eclectic and holistic (Humphry 2009:25), the DRSP checklists with the activities were applied accordingly during the 192 sessions (**cf.** 3.3.1.3; 3.3.2.2; 3.3.3.1). Even though development follows a sequence of cognitive, language and motor patterns, the intervention was interlinked between the age bands. The child with DS's abilities was scored, rather than the age in which a milestone is expected. For example, a child with DS may develop over two to three age bands in six months; developing through 0–3 months to 6–9 months. For the purpose of this part of the study, it was important to be able to establish the performance and practicability of an activity.

The DRSP checklist comprised of the following information:

- Subject identification in code
- Date of birth of client (child with DS)
- Specific activity in each age band
- Date of consultation/intervention
- Outcomes of intervention performed by child measured with an ordinal scale

- Field notes of researcher/analytical memos, such as dependency grants and literacy of parents / progress reviews
- Numeric recording of researcher with coding

The data was numerically encoded to facilitate statistical analyses in accordance with the adaptive level descriptors after each intervention session completion. The DRSP checklist information (Appendix F) was transferred to a data form for statistical analyses (Appendix F/1), applying the following level descriptors:

- 0= Unable to perform task (Complete facilitation or complete difficulty up to 95%)
- 1= Help required (Substantial facilitation or severe difficulty more than 50%)
- 2= Help required (Moderate facilitation or moderate difficulty less than 50%)
- 3= Mild facilitation (Mild difficulty 25% all of the time)
- 4= No problem (No difficulty or fully independent)

4.4.4.2 Moderating

All participants were recorded during all the sessions. It was decided to moderate 20% (38 sessions) of the video recordings by two independent practising occupational therapists in the paediatric field. The moderators were blinded for the study. These recordings confirmed the evidence of the performance of the participants in the intervention sessions and the researcher's DRSP checklists (Appendix F/1) were validated.

4.4.5 Data collection

The data for this objective was determined through the implementation of the DRSP during intervention sessions. The process of the implementation of the DRSP was described in Chapter 3 (**cf.** 3.3.4). The DRSP sessions included the introduction of each session to the parent/caregiver with a follow-up of the previous sessions after a two-week period. During this session the DRSP intervention was done with demonstrations and repetition (**cf.** 3.3.1.3). Feedback time and questions were managed at the end of the session and were not calculated with the intervention time. The specific time used only for

an intervention session was recorded for each intervention session and later confirmed through the video recordings.

4.4.6 Data analysis

A descriptive analysis was used. The data of the DRSP checklist for the child was scored according to the level descriptors, to evaluate the intervention progress of the intervention group and transferred to a data form (Appendix F/1).

Using the DRSP, the median number of sessions needed to master a certain activity for children who could not perform the activity independently at the start of the intervention was calculated in different age bands. These medians of individual activities were used to calculate medians for the five domains. Medians were used due to the discrete nature of the measurements, and skew distribution.

4.4.7 Pilot study

This pilot was necessary to plan the intervention sessions for the intervention group. This session was done after the pilot study evaluations and was video recorded. This session included the activities of the programme, age band 24–42 months. The demonstration and implementation of the DRSP for the two participants were easily understood and managed by the parents and children with DS.

4.5 OBJECTIVE 3: To measure objectively to what extent the parents/caregivers are able to perform the required activities of the DRSP correctly and independently after instruction

4.5.1 Introduction

Mahoney *and other authors* (2006:18) state that parents' knowledge of educational issues regarding genetic mental retardation syndromes, such as DS, has only been recorded and made available since 2002. This indicates the need to investigate the way in which the

parent/caregiver perceives and transfers information regarding intervention to the child with DS. The transference of intervention from the researcher to the parent to the child with DS played an essential role in this study. The parent/caregiver needed some knowledge and understanding of the transference of the intervention, in order to carry out the proper intervention at home so that the child with DS may reach optimal performance. According to the literature (Brassard & Boehm 2007:3), translating assessment into successful intervention in a clinical setting also involves ongoing consultation with parents/caregivers. Parents need to be involved in this assessment process (Brassard & Boehm 2007:3), not only to provide information about their child's development and needs, but also to gain an increased awareness of their own importance in their child's early development (client-centredness). The researcher assumed that, if parents were empowered to execute intervention correctly, this might improve their child with DS's development.

4.5.2 Study design

The descriptive design was applied to this part of the study, focusing on the measurable attributes of the DRSP. This was done in accordance with the parents'/caregivers' participation and their application of the transferred performance skills (Polit & Beck 2008:19).

4.5.3 Study population and sampling

All the parents of the participants of the intervention group were included in the study population (**cf.** 4.3.3; 4.3.4). The inclusion criterion was that the participants should be the primary caregiver of the children with DS and that they were responsible for the transference of the DRSP activities at home.

4.5.4 Measurements

This objective was assessed by the researcher by scoring the parents' transference of intervention using the DRSP checklist for parents (Appendix G).

4.5.4.1 DRSP checklist for parent/caregiver

The DRSP checklist for parent/caregiver comprised the following:

- The name of parent was encoded by using numbers only for moderating purposes
- Date of birth of the child with DS
- Specific activities in age bands
- Date of consultation
- Transference of intervention by parent in numeric recording with coding
- Field notes of researcher/analytical memos/progress reviews
- Numeric recording of researcher with coding

The data was numerically encoded to facilitate descriptive analysis. The information on the DRSP parent checklist (Appendix G) was transferred to a data form for statistical analysis (Appendix G/1). The following level descriptors were used:

- 0= Unable to perform task (Complete facilitation or complete difficulty up to 95%)
- 1= Help required (Substantial facilitation or severe difficulty more than 50%)
- 2= Help required (Moderate facilitation or moderate difficulty less than 50%)
- 3= Mild facilitation (Mild difficulty 25% all of the time)
- 4= No problem (No difficulty or fully independent)

4.5.4.2 Moderating

The same 20% video recordings of the DRSP intervention (**cf.** 4.4.4.2) were compared to the checklists by the moderators. The same two independent occupational therapists referred to in objective two moderated the intervention sessions.

4.5.5 Data collection

The data collection process (Polit & Beck 2008:15) refers to the systematic numeric values (systematic empirical investigation) of the parents' ability to perform and apply the task received during the intervention sessions (quantitative properties); resulting in the management of the intervention at home with their child (their relationships). This performance of the parents was scored in the DRSP checklist for the parents/caregivers (Appendix G). For this study there were 192 intervention sessions over a six-month period.

Time was allocated for feedback between researcher and parent with every DRSP intervention session. During these feedback sessions the progress of the child with DS was discussed and the progress was shown by using the level descriptors. Parent support was integral to performing tasks of the DRSP activities in collaborative partnership with the parent.

This DRSP parent/caregiver checklist determined if the parent understood the information and the specific developmental issues. The handling techniques, positioning and structuring were explained, discussed and demonstrated to the parent. The parent was given the opportunity to demonstrate the applicable activities of the DRSP, which their child had to perform at home (**cf.** 3.3.2.2; 3.3.2.3; 3.3.2.4; 3.3.3.1). It was important for the parents/caregivers to understand there would be a scoring process related to their performance during their participation in the child's DRSP intervention session, using the DRSP checklist for parents/caregivers (Appendix G). After an intervention session according to the performance of the child with DS, further DRSP activities were demonstrated and supplied to execute at home for the following two-week period.

4.5.6 Data analysis

Results were summarised by means of frequencies and percentages (Joubert *et al.* 2008:78). Using the DRSP checklist, the median number of sessions the parents needed to master independence in a certain activity (**cf.** Table 5.26) was tabled. These medians of individual activities were then used to calculate medians for the five domains. The data analyses were done by the researcher.

4.5.7 Pilot study

The aim of the pilot study for this objective was to experience the performance of the activities and implementation of the DRSP parent/caregiver checklist, by scoring their ability to perform the tasks.

The intervention session followed directly after evaluation, as explained in Objective 1 (**cf.** 4.3.8). Even though the parents of the two children knew the DRSP was developed for children with DS younger than 42 months, the activities were explained and demonstrated. The last three occupational performance activities of the 24–42 age band were selected (Appendix D). The parent then implemented the task/activity. The checklist was used in this session (Appendix G).

4.6 OBJECTIVE 4: To determine parent/caregiver satisfaction with the DRSP

4.6.1 Introduction

According to the literature (Kelly, Whyte, Treacy & Ghalaieny 2007:1/12), parent/caregiver satisfaction can be difficult to quantify, as the parents/caregivers have nothing to compare the service they are receiving to. There are international and standardised measures, such as the Programme d'intervention familiate (PRIFAM) (Pelchat, Lefebvre, Proulx & Reidy 2004:129); the Beach Centre Family Professional Partnership Scale and the Beach Centre Family Quality of Life Scale (Summers, Hoffman, Marquis, Turnbull & Poston 2005:50); the Client Satisfaction Questionnaire; the European Parent Satisfaction Scale About Early Intervention Services; and the Parent Satisfaction Scale (Khadye, Ziviani & Cuskelly 2011:251). These questionnaires did not meet the criteria of the study and were not specific to South Africa and for DS. To obtain an objective opinion from the participants in this study, a client-specific instrument had to be developed by the researcher, to evaluate the satisfaction of the parent/caregiver with regard to the intervention process and other factors, including the area of intervention.

4.6.2 Study design

A descriptive design was used (Fouché & De Vos 2005:143; Leedy & Ormrod 2010:97). The basic objective of a questionnaire (Delport 2005:166) is to obtain facts and opinions about a phenomenon from those who are informed on a specific issue.

4.6.3 Study population and sampling

All the parents of the participants of the intervention group were part of the study population (**cf.** 4.3.3; 4.3.4).

4.6.4 Measurements

A questionnaire was compiled by the researcher to obtain information regarding the participants' satisfaction with and their opinions on the intervention process. Twelve of the questions were related to the occupational therapist, three relevant to the service approach and two questions regarding the intervention area. The questions related to the occupational therapist included questions such as how the parents perceived the outcomes of the intervention (**cf.** 4.6.1). Other questions referred to the professionalism and conduct of the occupational therapist (**cf.** Table 5.27).

According to Leedy and Ormrod (2010:194–197), there are 12 guidelines for developing a questionnaire. The guidelines serve to encourage participants to be co-operative and to assist with participants' responses, which a researcher can use and interpret (Delport 2005:171; Maree & Pietersen 2007b:160). The following guidelines based on Leedy and Ormrod (2010:194–197) were considered in compiling a self-administered questionnaire (Appendix H):

- The questionnaire was brief and took a short time to complete. The questionnaire consisted of 19 questions grouped into two sections and it took 10-15 minutes to complete.

- Simple, clear, unambiguous language was used in the sentences. The questions were kept short. Correct but not highly grammatical words and sentences were used to prevent confusion.
- Unwarranted assumptions were kept to the minimum. There were no questions with underlying different meanings; and they were uncomplicated. Each question required a direct answer with a reduced amount of deliberation.
- The wording of the questions did not give clues as to preferred or more desirable responses.
- The questions were uniform in structure.
- The coding was determined in advance.
- The respondent's task was kept simple. The options were clear and easy to understand with negative, average and positive range.
- The instructions were clear.
- The questionnaire was of a professional nature, especially when a professional service was rendered.
- Not all questions had to be closed questions; there was an open-ended question.

Open-ended questions give the participants the opportunity to share their own specific opinions without bias and allow for any kind of result (Jansen 2007b:4). The 3-point Likert type scale (Maree & Pietersen 2007b:167) with three response categories provided an ordinal measure of a participant's satisfaction with the intervention. There were two sections with different level descriptors. The following level descriptors were used in section one:

- Poor (Below your expectations)
- Satisfactory (Your expectations were met)
- Good (Your expectations were more than met)

The following level descriptors were used in the second section:

- Always (Your expectations were always met)
- Sometimes (Your expectations were met)
- Never (Your expectations were never met)

4.6.5 Data collection

Parents completed a self-administered questionnaire (Katzenellenbogen & Joubert 2007:107) (Appendix H). It was completed at the end of the fourth intervention session at site one, because parents would have had sufficient exposure to intervention at that stage. The parental questionnaires were completed anonymously and privately to ensure confidentiality and to enable participants to be truthful. An interpreter was at hand to assist with any problems. The questionnaire was translated in Afrikaans, English and Sesotho.

4.6.6 Data analysis

The answers of the questionnaire were expressed in numerical values to investigate the parents' satisfaction during the intervention process.

The questionnaires were encoded and quantified. All variables were categorical and summarised by frequencies and percentages. This was done by the Department of Biostatistics of the University of the Free State using the SAS System. Open-ended questions were encoded and quantified by the researcher.

4.6.7 Pilot study

The questionnaire was used in a pilot study to determine whether the questions were understandable and measured satisfaction (Katzenellenbogen & Joubert 2007:116). The same parents of the two children with DS, who did not take part in the intervention study, participated in the pilot study and the data were not used in the research.

4.7 ERROR OF MEASUREMENT FOR THE FOUR OBJECTIVES

4.7.1 Introduction

Reliability and validity are the most important concepts in the context of measurement (Delport & Roestenburg 2011:172; Myer & Karim 2007:155). To obtain valid and reliable

data, the measurement procedures and instruments should be as close to the truth as possible. However, error or undesired variation may enter the process of selecting participants and measuring study variables. Validity is described as the ability of the instrument to measure what it is supposed to measure (Cohen, Manion & Morrison 2007c:133; Coughlan *et al.* 2007:662; Delport 2005:160; Leedy & Ormrod 2010:28). Reliability is the instrument's ability to measure the concept being studied consistently and accurately (Delport 2005:162; Delport & Roestenburg 2011:177; Leedy & Ormrod 2010:29; Polit & Beck 2008:768; Richardson 2010:229). Both validity and reliability reflect the degree of error in measurements.

4.7.2 Error of measurement

4.7.2.1 Measurement instrument (Bayley Scales III):

The validity of a test is the single most fundamental and important aspect of a test evaluation (Bayley 2006b:69). Therefore, the Bayley Scales III measures what it is supposed to. The purpose of this test was the design of comprehensive scales to identify children who may have delays in their total development. It then provided a baseline from which to start intervention planning, which made it easy to follow the progress (Elfant-Asher 2007:244–245). The test applied in this study demonstrated excellent concurrent validity, utilising several commonly used assessments for comparison, with moderate to strong correlations (**cf.** 4.3.5).

The test further exemplified outstanding standardisation practices and consistency over time. This established reliability (Brassard & Boehm 2007:414; Cohen *et al.* 2007c:146).

4.7.2.2 Measurement instrument (DRSP checklist):

It would appear that the DRSP checklist measured what it was supposed to measure. The checklist was designed to provide information of activities in the developmental domains. The level descriptors were well explained. As the checklist was not standardised, bias could have been an obstacle. The researcher's subjectivity could have compromised the scores. By viewing all the video tapes after each session, the researcher could verify

scores and reduce subjectivity which may occur during or after an intervention session. The researcher kept to the procedures of the DRSP as stipulated in the manuals (**cf.** Chapter 3). This may have reduced error of measurement.

4.7.2.3 Measurement instrument (Parent Questionnaire):

Both the Social-Emotional Scale (Bayley 2006a:96) and the Adaptive Behavior Scale's (Bayley 2006a:82) reliability scores reflect strong internal consistency (Bayley 2006a:12). Evidence of validity provided a confirmatory factor-analytic study with mean comparisons using match special groups and typically developing children (Bayley 2006a:12). Further validity was provided by correlation studies between Bayley Scale III and other programmes (**cf.** 4.3.5). The correlations are substantial and support the Bayley Scale III's parent questionnaires validity (Bayley 2006a:82).

The validity was not compromised as the measurement instrument; the questionnaire, measured what it intended to measure (Katzenellenbogen & Joubert 2007:117). It measured parental satisfaction, as it was based on their motivation and the perceived attitudes towards the DRSP. To minimise the error of measurement, the questionnaire was translated into the parents' language of preference, such as Sesotho, Afrikaans and English. After translations the researcher translated the English version back to Afrikaans to compare to see if there were differences.

4.7.2.4 Evaluator:

The evaluator is well trained in the use of the measurement instrument. She did a course in the mechanics of the Bayley Scales III prior to the study. This enhanced the reliability of the execution of the measurement instrument (Leedy & Ormrod 2010:93).

4.7.2.5 Moderating of evaluations and treatment sessions:

Two independent occupational therapists scored and moderated the evaluations from the video recordings. They completed forms for recommendations (Appendix E/2). According to Polit and Beck (2008:752), the error of measurement is the deviation between the true scores and the obtained scores of a measured characteristic. The evaluator and moderators gave identical judgments.

4.7.2.6 Sites:

The same venues at the different sites were used for all the pre-testing and post-testing as well as the intervention sessions. This ensured the reliability of the environment in which the children with DS were placed.

4.7.2.7 Testing time:

The testing time for the older children was longer than for younger children with DS. This may constitute a measurement error, as these children with DS could have been more tired after evaluation (**cf.** 4.3.5.1). It is however, acceptable according to the Bayley Scales III Manuals and it is justified by the child's age (**cf.** 4.3.5.1).

4.7.2.8 Intervention time:

The length of session relied on the tolerance and endurance of the child with DS during a session. This may have influenced scores for older children who might have been able to perform for longer periods than the very young children with DS and they may have had more time for repetitions.

4.7.2.9 Variables:

The education and socio-economic status of participants were written in process notes. The DRSP was developed to accommodate any level of education of the participants. As

the mothers completed the questionnaires it could influence the results of the questionnaires of the Bayley Scales III. They may have scored the questionnaires more positively as they could have desired that their children with DS had more potential, or on the other hand they could have been more critical of their child's abilities. The Hawthorn effect could have had an effect on the positive outcomes of the parent questionnaire.

4.8 ETHICAL CONSIDERATIONS

In order to fulfill ethical requirements the following will be discussed.

4.8.1 Ethical Approval

Ethical approval was obtained from the Ethics Committee of the Faculty of Health Sciences, University of the Free State. The allocated Ethics Committee approval number of the Faculty of Health Sciences is ECUFS no. 01/2011. Written approval from the Head of the School of Medicine: Faculty of Health Sciences and the Head of the Department of Paediatric and Child Health were obtained (Appendix A).

4.8.2 Informed consent

The researcher received written, informed consent (Appendix B) from all the parents who took part in the study (Strydom 2005a:59). The informed consent form was accompanied by an information letter about the study in English, Afrikaans or Sesotho according to their preference. The information letter (Appendix B) was based on the guidelines for informed consent as prescribed by the General guidelines of the Ethics Committee of the Faculty of Health Sciences. Informed consent (Carpenter *et al*. 2008:51; Joubert *et al*. 2008:61) implies that the parents will have sufficient information about the nature of the study and objectives so that they may decide whether to participate or not. Autonomy is further the basis for the practice of informed consent (McCormick 1998:2/4). The same ethical considerations were followed for the control groups at the three sites (**cf.** 4.3.6.1.1). The information letter informed parents of all participants that all the data would only be used

for research purposes and future publications. The parents would receive all video material after the study has been completed.

Parents were informed that their participation was voluntary and that they had the right to withdraw at any time without prejudice (De Vos *et al.* 2005:67). The parents of the control group were advised that no intervention from the researcher would be applied. These children with DS should continue their intervention programmes. Not receiving or discontinuing their intervention for purpose of this study would have been unethical, because intervention should be beneficial to participants (beneficence). Therefore they had the right to choose (autonomy) and to speak for themselves (through the parents) to continue with their intervention. The parents views, values and believes were respected (Bishop n.d. 1/1; McCormick 1998:2/4).

4.8.3 Pilot study

A pilot study was done after approval was obtained from the Ethics Committee of the Faculty of Health. The study commenced after this process (**cf.** 4.3.8; 4.4.7; 4.5.7; 4.6.7).

4.8.4 Right to privacy

All participants were assured that all the information would remain confidential. All respondent's information were kept confidential by means of decoding their names from DRSP checklists for the intervention group.

The completed questionnaires were encoded and data were transferred onto a data-sheet format for statistical analysis. These questionnaires as well as the record forms of the evaluations were kept in the office of the promoter after the completion of the clinical part of the study and analysed by the Department Biostatistics of the University of the Free State. The video recordings were kept in a safe place by the researcher.

4.8.5 Researcher, evaluator and moderators

To perform this research study, the researcher was ethically obliged to ensure that she was competent and adequately skilled (Strydom 2005a:63).

One occupational therapist performed all the pre-testing and post-testing of the participants in the study using the Bayley Scales of Infant and Toddler Development (Bayley 2006a:48–171). Two independent occupational therapists acted as moderators for the video-recorded evaluations of the participants in the intervention group, as well as the control group. Two other independent occupational therapists also moderated the intervention sessions of the researcher. All five occupational therapists were qualified in either NDT and/or SI. As they are registered at the Health Professional Counsel of South Africa they should exhibit core ethical and professional values and standards (HPCSA 2008:2).

4.8.6 Compensation

Parents of the intervention group were compensated for transport costs for the 12 visits of the research period, as well as the two evaluation appointments. The control group was not compensated, because their visits coincided with their scheduled sessions at their Down Syndrome Associations.

4.8.7 Language during intervention

The choice of language (English and Afrikaans) of the participants was used during intervention sessions. An interpreter proficient in the applicable African language was available for the intervention sessions.

4.8.8 Copyright

There is copyright on the use of the record forms of the Bayley Scales of Infant and Toddler Development. Original record form books were ordered from the US and used in the study. The researcher obtained an attendance certificate after the mechanics course

of the Bayley Scales of Infant and Toddler Development prior to the submission of the protocol in 2009.

The ISBN number (978-0-86886-807-3) was obtained for this 1st edition of the DRSP to ensure that the researcher used the original programme in its present format. The distribution to libraries will only happen after completion of the thesis.

4.9 CHAPTER SUMMARY

In order to establish the impact of the DRSP on the development of children with DS younger than 42 months, this chapter gave an overview of the methodology that was applied in this study. Methods for the four objectives were discussed to provide background to the study. The results will be presented in the following chapter.

CHAPTER 5
RESULTS

We shall not cease from exploration

And the end of all our exploring

Will be to arrive where we started

And know the place for the first time

T.S. Eliot (1943)

5.1 INTRODUCTION

The preceding chapters explained the reasons for undertaking the research, the research approach and methodology. This chapter will report on the results obtained and describe the statistical findings of the study, namely the results of the pre-test and post-test with the Bayley Scales III to establish the effect of the intervention with the DRSP, the duration of intervention to achieve a positive outcome in children with DS, parents' mastering of activities of the DRSP and parent satisfaction of the DRSP. The results are presented in the sequence of the objectives and by means of descriptions, graphs and tables.

5.2 DEMOGRAPHIC INFORMATION OF PARTICIPANTS

The intervention group consisted of 16 children with DS and 16 parents. Initially there were 18 children with DS in the group. The reason for the withdrawal was that two children with DS passed away. The control group consisted of 14 children with DS and 14 parents. The control group consisted initially of 18 children with DS. The reasons for the withdrawal were voluntary withdrawal from the study by one child's parents; two participants could not be located for follow-up testing and one child with DS passed away. The demographic

information of the 16 intervention group participants and the 14 control group participants in this study are shown in Table 5.1.

Table 5.1: Study participants

	Intervention/ DRSP group		Control group
Total participants	16		14
Gender:			
Boys	8		5
Girls	8		9
Language:			
English	2		9
Afrikaans	3		3
Sesotho	9		1
Xhosa	2		
Zulu			1
Age groups:			
0.1 - 3 months	5		2
3.1 - 6 months	2		2
6.1 - 9 months	2		2
9.1 - 12 months	2		3
12.1 -18 months	3		3
18.1 - 24 months	1		2
24.1 - 42 months	1		
Sites:			
Site 1: (12 urban & 4 rural)	16		
Site 1: (2 urban)			2
Site 2: (7 urban)			7
Site 3: (2 urban & 3 rural)			5
No intervention:			2 of 14
Interventions:			
Physiotherapy			9 of 14
Speech Therapy			4 of 14
DSPI			7 of 14
Occupational Therapy			2 of 14

5.2.1 Intervention group

The 16 participants in the intervention group were equally distributed with relation to **gender**, eight boys and eight girls. A diverse range of **languages** was represented, such as English, Afrikaans, Sesotho and Xhosa. The intervention group had participants in all the **age bands** (7) according to the DRSP, with the birth to three months age band having the largest number of children. The intervention group did not receive any form of intervention other than what is offered at **site one,** namely the implementation of the DRSP (**cf.** 3.3.4). The families came from different areas in the Free State within a radius

of 150 km. Prior to the study seven of the participants older than nine months received occupational therapy at the BCIC.

Contextual factors were not equally distributed, such as rural versus urban; day-care versus mother care and socio-economic status based on parents receiving care dependency grants from the South African Social Security Agency (SASSA). In the intervention group, 11 participants lived in urban surroundings and five in rural areas, with three children with DS in day-care and 13 in mothers' care. Thirteen of the 16 participants receive care dependency grants (81%). Only one parent of the intervention group was illiterate.

5.2.2 Control group

The 14 infant participants in the control group were not equally distributed in relation to **gender** (5 boys and 9 girls). The 14 participants in the control group also came from diverse **language groups**, including English, Afrikaans, Sesotho and Zulu, as is found in the three major cities. Twelve participants resided in urban areas and two in rural areas. The control group did not have participants in the age band 24–42 months. Two participants' parents from site one indicated that they had full-time jobs and would not be able to visit the BCIC every second week. They were allocated to the control group.

Four participants in the control group were in day care and five received care-dependency grants (35%). All the parents in the control group of the children with DS had skilled language proficiency.

In Table 5.2, the time schedule of the pre-testing and post-testing is illustrated.

Table 5.2: Time schedule of pre-testing and post-testing

	Site One	Site One	Site Two	Site One	Site Three
	Intervention 1st intake	Intervention 2nd intake	Control group	Control group	Control group
Pre-test	Month 1-5	Month 6	Month 5	Month 5 and 3 days	Month 8
Post-Test	Month 6	Month 12	Month 11	Month 11 and 3 days	Month 13

5.3 OBJECTIVE 1: To investigate the effect on developmental progress of the Developmental Resource Stimulation Programme (DRSP) in Down syndrome children younger than 42 months

5.3.1 Introduction

The effect of the DRSP intervention was assessed by using pre-test and post-test data to determine changes from baseline scores of the Bayley Scales III to six-month final scores. To orientate the reader the two groups will initially be illustrated and discussed separately and then the comparison will be given.

5.3.2 Intervention group

The pre-test and post-test median of standard scores of the 16 participants in the intervention group in comparison with the Bayley Scales III mean scores for children with DS, are illustrated in Figure 5.1 (**cf.** 4.3.7). The Bayley mean scores are seen as the expected performance.

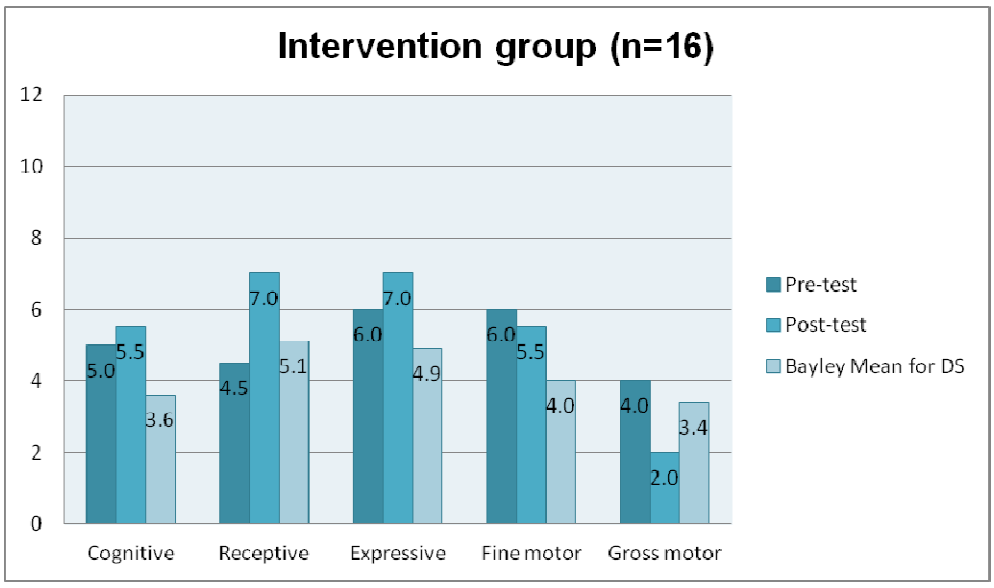


Figure 5.1: Intervention group pre-test and post-test median scores compared with Bayley Scales III mean scores

According to Figure 5.1, the pre-test median scores of the intervention group showed higher scores than the Bayley Scales III mean scores for the DS population (Bayley 2006b:86), in the cognitive, expressive-language, fine-motor and gross-motor domains. The receptive-language domain showed a marginally lower median score than the Bayley Scales III mean scores for the DS population.

The post-test median scores showed the same tendency presented in the pre-testing, with higher scores than the Bayley Scales III mean scores for the DS population. Even though the fine-motor domain median score declined, it was higher than the Bayley Scales III means scores for the DS population (Bayley 2006b:86). It is evident that there was a decline in the gross-motor domain median score.

Table 5.3: Descriptive table for the intervention group post-test

Median scores	**Intervention group (n=16)**		
	Extremely Low	Borderline	Low Average
Cognitive domain		5.5	
Receptive-language domain			7.0
Expressive-language domain			7.0
Fine-motor domain		5.5	
Gross-motor domain	2.0		

Note: Extremely Low (1–3), Borderline (4–5), Low Average (6–7), High Average (13–14)

According to general psychometric tables, a description of the post-test median scores of all the domains tested using the Bayley Scales III are presented in Table 5.3 (Psychometric conversion table 2012:1/2). The cognitive domain is described as “Borderline”, with a 5.5 median score. The receptive and expressive domains’ median scores of 7.0 (Low average) were higher than the comparative mean scores of the Bayley Scales III, respectively (5.1 and 4.9). The fine-motor domain median score was 5.5 (Borderline) in comparison with the Bayley Scales III mean score of 4.0. The gross-motor domain score (2.0–Profound) is lower than the Bayley Scales III (3.4). In Appendix I, the 16 participants’ individual scores are illustrated in graphs with short descriptions.

5.3.3 Control group

The pre-test and post-test median standard scores of the 14 participants in the control group, in comparison with the Bayley Scales III mean scores for children with DS, are illustrated in Figure 5.2.

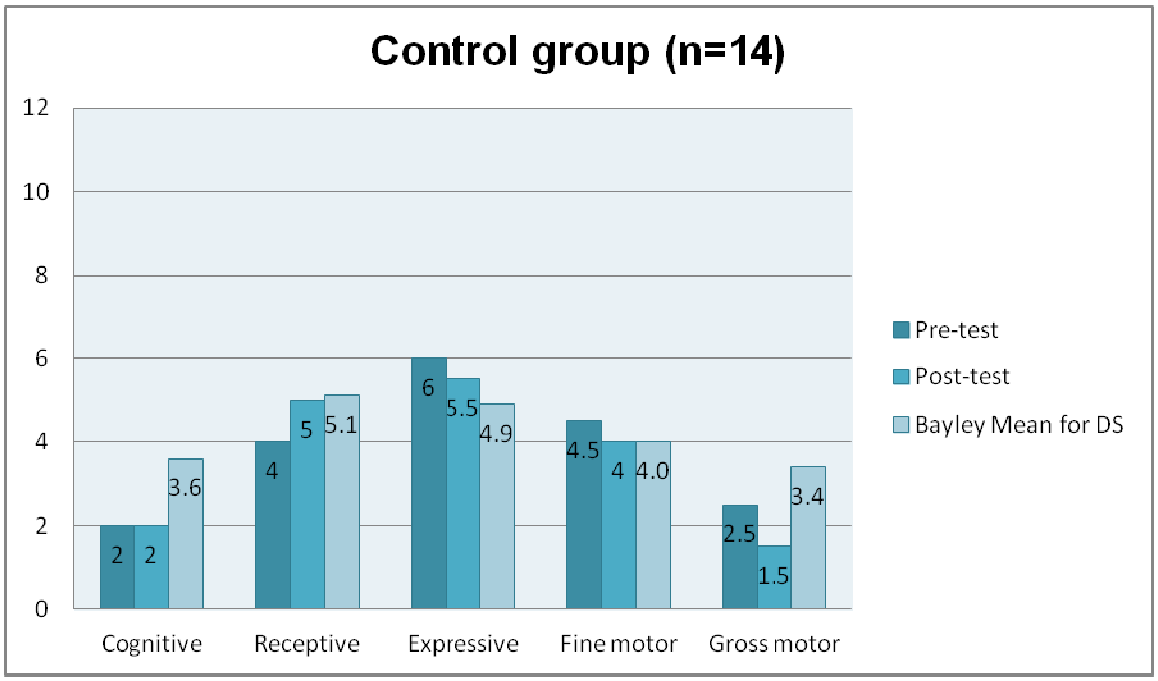


Figure 5.2: Control group pre-test and post-test scores compared with Bayley Scales III

In Figure 5.2 the control group showed a lower median score in the cognitive domain than the Bayley Scales III mean score for the DS population. The receptive-language median score of the control group was below the Bayley Scales III mean score. The expressive-language median score was higher than the Bayley Scales III, as well as the fine-motor domain. The gross-motor median score was lower in comparison with the Bayley Scales III mean scores.

The post-test median scores of the control group stayed the same as the pre-test median scores in the cognitive domain. There was an increase in the receptive-language domain of the control group. The expressive, fine-motor and gross-motor domains showed a decline in the median scores.

Table 5.4: Descriptive table for the control group post-test

Median scores	Control group (n=14)		
	Extremely Low	Borderline	Low Average
Cognitive domain	2.0		
Receptive-language domain		5.0	
Expressive-language domain		5.5	
Fine-motor domain		4.0	
Gross-motor domain	1.5		

Note: Extremely Low (1–3), Borderline (4–5), Low Average (6–7), High Average (13–14)

A description of post-test median scores of all the domains tested, using the Bayley Scales III, is illustrated in Table 5.4 (Psychometric conversion table 2012:1/2). The cognitive and gross-motor domains are described as 'Extremely low', with 2.0 and 1.5 median scores, respectively. The receptive (5.0), expressive (5.5) and fine-motor (4.0) domains' median scores were "Low average". Only the expressive-language domain median score was higher compared to the mean scores of the Bayley Scales III, for the DS population, even though there was a decline in the post-test median score for the control group. In Appendix J, the 14 participants' individual scores are illustrated in graphs with short descriptions.

According to Table 5.1, the control group received different intervention approaches namely nine (64%) of the participants received physiotherapy (Appendix J.1; J.2; J.3; J.4; J.6; J.7; J.10; J.11; J.13). Of these two participants' scores increased in the gross-motor domain, two participants' scores remained the same and five participants' scores showed a decline. The scores of seven (50%) participants enrolled in the DSPI (**cf.** 2.6.9) at site two declined or remained the same for all the developmental domains (Appendix J.1; J.2; J.3; J4; J.5; J.6; J7). Two of the four (29%) participants showed an increase in the scores of the language domain, when speech therapy was received in combination with occupational therapy (Appendix J.10; J.11). The two participants who received occupational therapy showed an increase in developmental domain scores in combination with physiotherapy and speech therapy (Appendix J.12; J.11).

5.3.4 Comparison within and between intervention and control group

Table 5.5: Median scores of pre-test and post-test and changes in scores within intervention and control group

TOTAL	Intervention group					Control group				
	Pre-Test (n = 16) Median	Post-Test (n = 16) Median	Changes (n = 16) Median	p-value	95% CI for change in Median	Pre-Test (n = 14) Median	Post-Test (n = 14) Median	Changes (n = 14) Median	p-value	95% CI for change in Median
Age in months	7.22	12.82				9.26	15.22			
IQR†	(2.5;15.3)	(8.4;21.3)				(4.5;13.9)	(10.4;19.8)			
Cognitive development	5.00	5.50	0#	0.5371	(-1;2)	2.00	2.00	-0.5#	0.3047	(-2;1)
IQR	(2.5;6)	(3;7)	(-1;1.5)			(1;5)	(1;4)	(-2;0)		
Cognitive age	4.66	8.50	4.23	<0.0001*	(3;5)	5.00	8.00	3.66	0.0005*	(1;4.1)
IQR	(0.53;9)	(5;13)	(3.4;4.8)			(2.3;7)	(5;10)	(2;4.1)		
Receptive language	4.50	7.00	1.00	0.1252	(-1;4)	4.00	5.00	1.00	0.7017	(-2;2)
IQR	(3.5;6)	(4.5;8)	(-0.5;3.5)			(3;5)	(1;6)	(-2;2)		
Receptive age	2.83	10.00	5.40	<0.0001*	(2.8;7.7)	4.33	10.00	4.66	0.0024*	(0.1;6.7)
IQR	(0.53;9)	(3.3;14.5)	(2.8;7.2)			(3.3;6)	(2.3;11)	(1;6.7)		
Expressive language	6.00	7.00	0.50	0.1333	(-1;3)	6.00	5.50	0.50	0.5352	(-1;1)
IQR	(5;7)	(5.5;8)	(-1;2.5)			(4;8)	(4;8)	(0;1)		
Expressive age	3.66	11.00	4.90	<0.0001*	(2.1;7)	4.83	9.50	5.00	0.0012*	(0;7)
IQR	(5.3;10)	(4.3;16)	(2.6;6.7)			(2.7;7)	(5;13)	(3;6.3)		
Fine-motor development	6.00	5.50	1.50	0.3210	(-2;3)	4.50	4.00	0.50	0.7451	(-5;5)
IQR	(4;6.5)	(4.5;7.5)	(-2;3)			(1;6)	(2;7)	(-1;2)		
Fine-motor age	5.00	10.00	5.00	<0.0001*	(4;6)	5.00	10.00	4.00	0.0006*	(1.7;6.7)
IQR	(0.53;9)	(5.7;15)	(4.2;6)			(3.3;6)	(7;10)	(3;5.7)		
Gross-motor development	4.00	2.00	-1.00	0.1443	(-3;1)	2.50	1.50	-0.50	0.0605	(-5;1)
IQR	(1.5;6)	(1;5)	(-3;1)			(1;6)	(1;3)	(-3;0)		
Gross-motor age	6.00	7.00	3.83	<0.0001*	(2;4.7)	6.00	7.50	2.33	0.0002*	(1;4)
IQR	(0.67;7)	(5;10.5)	(2.5;4.3)			(4;7)	(6;8)	(1.3;3)		

*Statistically significant at p<0.05

†IQR: Inter-quartile range

#Refer Appendix K for calculation of medians

Table 5.5 provides a summary of the pre-and the post-test scores per group, as well as of the changes in scores (post-test-pre-test) per group. The Wilcoxon signed-rank test was used to calculate the p-value. The confidence intervals predict the range in which scores are expected to be achieved (**cf.** 4.3.7). The following sections will describe these results

per developmental domain. Table 5.6 summarises the statistical analysis of pre-test scores and changes from pre- to post-test between the groups.

Table 5.6: Pre-test and changes from pre-test to post-test: Differences between intervention and control group and age

	(n=16/14) p-value	(n=16/14) 95% CI
Cognitive development: Pre-Test	0.1587	(-1;4)
Cognitive development Change	0.1576	(0;3)
Cognitive age: Pre-test	0.9492	(-4.1;4.0)
Cognitive age Change	0.0789	(0;2)
Receptive language: Pre-test	0.5680	(-1;2)
Receptive language Change	0.3795	(-1;4)
Receptive age: Pre-test	0.6266	(-3.7;3.7)
Receptive age Change	0.3175	(-1.3;3.9)
Expressive language: Pre-test	0.6886	(-1;2)
Expressive language Change	0.5400	(-1;2)
Expressive age: Pre-test	0.8829	(-2.1;5)
Expressive age Change	0.7866	(-2;2.3)
Fine-motor development: Pre-test	0.1970	(-1;3)
Fine motor development Change	0.6608	(-3;3)
Fine-motor age: Pre-test	0.7050	(-3.8;3)
Fine-motor age Change	0.1443	(-0.7;2.5)
Gross motor development: Pre-test	0.4198	(-1;3)
Gross-motor development Change	0.5999	(-2;3)
Gross-motor age: Pre-test	0.7365	(-4.1;1.3)
Gross-motor age Change	0.0724	(0;2.3)

*Statistically significant at $p<0.05$

Cognitive age and gross-motor age indicated nearly statistically significant differences in changes between the intervention and control groups (**cf.** Table 5.6). The Mann-Whitney

test was used to calculate the p-value. The confidence intervals predict the range in which scores are expected to be achieved (**cf.** 4.3.7).

5.3.5 Developmental domains

5.3.5.1 Cognitive domain

According to the comparative Table 5.5, in the intervention group the median change was zero in the cognitive domain (95% CI -1; 2), whereas the median decreased (-0.5) in the control group. There was a statistically significant change in the domain age of cognitive development ($p<0.0001$) in the intervention group and the control group ($p=0.0005$).There was a close to significant difference between the groups, regarding these changes (**cf.** Table 5.6).

5.3.5.2 Language development

According to Table 5.5, the median scores increased in the language domains in both groups, with a receptive median score change of 1.0 and an expressive median score change of 0.5. These changes within the groups were not statistically significant, nor were there significant differences between the groups.

The domain age for receptive language increased significantly for the intervention group ($p<0.0001$) and control group ($p=0.0024$). The change domain age for expressive language showed statistical significance for the intervention group ($p<0.0001$) and control group ($p=0.0012$).

5.3.5.3 Motor development

In the intervention group there was a median increase of 1.5 in the fine-motor domain and a median decline of -1.0 in the gross-motor domain. The control group showed a median increase of 0.5 in the fine-motor domain and a median decline of -0.5 in the gross-motor domain. The age changes, however, showed statistical significance in both domains for the intervention and control groups, but only the change in the gross motor domain was

close to statistically significant difference between the groups. Preferably more specific information was needed, specifically in connection with fine-motor development; therefore, no composite scores were analysed (**cf.** 2.3.3.2; 4.3.5).

5.3.6 Social-emotional scale

The Social-emotional scale, in the form of a questionnaire based on functional emotional milestones was completed by the parent.

Table 5.7: Comparison between intervention and control group: Social-emotional development

	Intervention group					Control group					Between intervention & control group (n=16/14)	
	Pre-Test (n = 16) Median	Post-Test (n = 16) Median	Changes (n = 16) Median	p-value	95% CI for change in Median	Pre-Test (n = 14) Median	Post-Test (n = 14) Median	Changes (n=14) Median	p-value	95% CI for change in Median	p-value	95% CI for change in Median
Age in months	7.21	12.82				9.26	15.22					
IQR†	(2.5;15.3)	(8.4;21.3)				(4.5;13.9)	(10.4;19.8)					
Social-Emotional	7.00	9.50	2.00	0.2327	(-2;4)	7.00	6.50	-0.50	0.8931	(-4;5)	0.2971	(-3;5)
IQR	(6.5;10.5)	(7;12)	(-1.5;4)			(4;10)	(4;11)	(-2;2)				

†IQR: Inter-quartile range

According to Table 5.7, the score increased for the intervention group by a median of 2 and the control group had a decrease of -0.5. None of these changes were statistically significant.

5.3.7 Adaptive behaviour scale

The Adaptive behaviour scale formed part of the questionnaire and the statistical data were the interpretation of a parent of their child with DS. The information was the subjective opinion of their child, because they knew their child the best.

> *The Adaptive Behaviour Scale is designed to evaluate the attainment of functional skills necessary for the increasing independence of the infant and young child* (Bayley 2006b:10).

Table 5.8: Comparison between intervention and control group: Adaptive behavioural scale

Adaptive Behavior	Intervention group					Control group					Between intervention & control group (n=16/14)	
	Pre-Test (n = 16) Median	Post-Test (n = 16) Median	Changes (n = 16) Median	p-value	95% CI for change in Median	Pre-Test (n = 14) Median	Post-Test (n = 14) Median	Changes (n=14) Median	p-value	95% CI for change in Median	p-value	95% CI for change in Median
Age in months	7.21	12.82				9.26	15.22					
IQR†	(2.5;15.3)	(8.4;21.3)				(4.5;13.9)	(10.4;19.8)					
Communication	9.00	9.50	1.00	0.9659	(-4;3)	7.50	7.50	-1.50	0.3796	(-3;2)	0.4272	(-3;4)
IQR	(7.5;12.5)	(7.5;12)	(-2.5;3)			(4;10)	(5;9)	(-2;1)				
Community Use	0.00	6.00	0.00	0.1914	(0;6)	0.00	7.00	1.00	0.0352*	(-1;8)	0.6237	(-5;2)
IQR	(0;8)	(0;9)	(0;5)			(0;6)	(0;8)	(0;7)				
Functional Pre-Academics	0.00	3.50	0.00	0.2031	(0;5)	0.00	6.00	0.00	0.0781	(-2;9)	0.7634	(-5;2)
IQR	(0;4.5)	(0;8.5)	(0;3.5)			(0;6)	(0;9)	(0;7)				
Home Living	0.00	3.50	0.00	0.2266	(0;5)	0.00	4.00	0.00	0.1602	(-1;7)	0.8281	(-5;2)
IQR	(0;4)	(0;7)	(0;4)			(0;4)	(0;6)	(-1;6)				
Health and Safety	9.50	8.00	-2.50	0.1928	(-5;3)	7.50	6.00	-2.50	0.0488*	(-5;0)	0.9001	(-3;3)
IQR	(5;13.5)	(5;10)	(-5;2)			(6;10)	(3;8)	(-4;0)				
Leisure	8.50	6.00	-1.50	0.1255	(-5;1)	7.50	7.00	0.00	0.7720	(-2;3)	0.1814	(-5;1)
IQR	(6.5;10)	(4;8.5)	(-4.5;0.5)			(4;11)	(6;10)	(-1;2)				
Self-Care	4.50	4.50	0.00	0.4675	(-3;1)	5.00	4.00	-2.00	0.1348	(-4;2)	0.4033	(-2;3)
IQR	(3;8.5)	(3;7)	(-2.5;1)			(4;9)	(2;7)	(-4;1)				
Self-Direction	8.50	6.00	-2.00	0.1472	(-4;1)	7.00	6.50	1.00	0.6113	(-2;2)	0.1392	(-4;0)
IQR	(5;11)	(4;9)	(-4;1)			(4;9)	(5;9)	(-1;2)				
Social	8.00	6.00	-2.00	0.0915	(-3;0)	7.00	5.00	-1.50	0.0706	(-3;0)	0.6732	(-3;1)
IQR	(5;10)	(4;9)	(-3;-0.5)			(4;8)	(3;7)	(-3;-1)				
Motor	5.50	4.00	-1.00	0.2174	(-3;1)	5.50	4.00	-2.00	0.0408*	(-3;1)	0.5023	(-1;2)
IQR	(4.5;7)	(3.5;5)	(-3;1)			(3;7)	(2;6)	(-3;0)				
SUM	58.50	56.00	-5.50	0.6786	(-17;17)	55.50	60.00	1.50	0.6821	(-17;23)	0.4667	(-8;26)
IQR	(46.5;78.5)	(44.5;72)	(-16;14)			(36;67)	(42;66)	(-13;19)				

*Statistically significant at p<0.05

The median scores are reflected in Table 5.8. The parents scored their children with DS high for communication and there was a decline in motor ability. There was a statistically significant decreased change in the motor-adaptive behaviour of the control group (p=0.0408) and increased change in the community-use adaptive behaviour (p=0.0352) and significant decrease in health and safety. The only positive change in the intervention group was communication. No significant changes occurred in the intervention group.

5.3.8 Comparison (matching) between six intervention and control group participants

Even though the study stipulated a quasi-experimental design, specifically a non-randomised control group pre-test-post-test (**cf.** 4.3.2), six matched comparisons (matched on gender and chronological age) could be established between the intervention and control group. Their findings are illustrated by graphs in Appendix L.

5.3.9 Two subgroups within the intervention and control group

The researcher divided the two groups by age to obtain a better understanding of their developmental tendencies; particularly with reference to the fine-motor and gross-motor domains (**cf.** 4.3.7). To acquire more specific data, ages were grouped together to form a <9-month group and a >9-months group. The rationale for these specific two subgroups originated from the literature; that three-month-old infants with DS, being entirely normal at birth, showed delays occurring only after six months (Fidler & Nadel 2007:264; Karimi *et al*. 2010:39; Nadel 2003:161). According to literature more delays are present later, after 16 months (Capone 2004:50; Hines & Bennett 1996:100; Piper *et al.* 1986:189). The development of the younger child with DS (<9 months) therefore, varies from the older child with DS (>9 months). The seven age bands and the participants in the age bands determined the division, as the age band 9–12 months was in the middle and could not be split. Data within the two divided age groups are summarised in Table 5.9 – 5.12, and statistical significance of differences between intervention and control groups is shown in Table 5.11.

Table 5.9: Changes within intervention and control group<9-months

	Intervention group < 9-months					Control group < 9-months				
	Pre-Test (n = 9) Median	Post-Test (n = 9) Median	Changes (n = 9) Median	p-value	95% CI for change in Median	Pre-Test (n = 6) Median	Post-Test (n = 6) Median	Changes (n = 6) Median	p-value	95% CI for change in Median
Age in months	2.63	8.73				4.27	10.25			
IQR†	(1.4;3.3)	(7.1;9.3)				(2.3;7.8)	(8.6;13.7)			
Cognitive development	4.00	5.00	0.00	0.5391	(-1;3)	2.50	3.50	-1.00	0.7500	(-4;6)
IQR	(2;6)	(3;7)	(-1;2)			(1;7)	(1;5)	(-2;1)		
Cognitive age	0.53	5.00	4.47	0.0039*	(3;5.5)	1.43	6.50	4.13	0.0313*	(3;5.7)
IQR	(0.53;0.53)	(5;6)	(3.8;4.7)			(0.53;4.67)	(4.7;8)	(3.33;4.46)		
Receptive language	4.00	5.00	1.00	0.4531	(-3;6)	5.00	3.00	-1.50	0.4375	(-6;2)
IQR	(2;6)	(3;7)	(-1;4)			(3;7)	(1;6)	(-4;2)		
Receptive age	0.53	3.33	2.80	0.0078*	(2.8;6.7)	2.00	4.17	2.17	0.0625	(0;5.7)
IQR	(0.53;0.53)	(3.33;7)	(2.8;6.46)			(0.53;3.33)	(0.67;7)	(0.13;3.67)		
Expressive language	6.00	7.00	0.00	0.4219	(-1;3)	7.50	7.00	1.00	0.7500	(-6;1)
IQR	(5;7)	(5;8)	(-1;3)			(6;8)	(4;9)	(0;1)		
Expressive age	0.53	5.00	4.33	0.0039*	(2.1;6.5)	1.67	7.00	5.40	0.0625	(-0.1;7.3)
IQR	(0.53;0.67)	(2.67;7)	(2.13;6.33)			(0.53;3.67)	(3.67;11)	(3.13;7)		
Fine-motor development	6.00	6.00	0.00	0.8203	(-4;4)	6.00	6.00	0.50	1.0000	(-7;6)
IQR	(5;7)	(4;8)	(-2;3)			(4;6)	(1;7)	(-5;5)		
Fine-motor age	0.53	6.00	4.80	0.0039*	(3.8;5.5)	3.33	8.00	4.73	0.0313*	(1.7;6.7)
IQR	(0.53;2)	(5;8)	(4;5)			(0.53;4.33)	(5;10)	(3.8;5.67)		
Gross-motor development	6.00	2.00	-3.00	0.0078*	(-5;-2)	6.50	1.50	-4.00	0.0313*	(-7;-2)
IQR	(4;8)	(1;3)	(-5;-2)			(6;7)	(1;3)	(-6;-3)		
Gross-motor age	0.67	5.33	3.67	0.0039*	(1;5.5)	2.83	6.17	2.83	0.0313*	(1;4.6)
IQR	(0.53;1)	(4.67;7)	(3.46;4.67)			(1;6)	(4.67;7)	(2;4.33)		

*Statistically significant at p<0.05
†IQR: Inter-quartile range

The intervention age group <9 months showed a median increase in receptive language. Median scores in cognitive, expressive language and fine-motor domains remained the same, with significant decrease in the gross-motor domain (**cf.** Table 5.9). The control group showed a median increase in the expressive language and fine-motor domain, with a decrease in the cognitive, receptive language and gross-motor domain.

Table 5.10: Changes within intervention and control group >9-months

	Intervention group > 9-months					Control group > 9-months				
	Pre-Test (n = 7) Median	Post-Test (n = 7) Median	Changes (n = 7) Median	p-value	95% CI for change in Median	Pre-Test (n = 8) Median	Post-Test (n = 8) Median	Changes (n = 8) Median	p-value	95% CI for change in Median
Age in months	17.77	23.77				13.78	19.22			
IQR†	(11.5;20)	(17.5;26)				(9.5;17.8)	(15.5;23)			
Cognitive development	5.00	6.00	0.00	1.0000	(-2;1)	2.00	1.50	-0.50	0.3125	(-3;2)
IQR	(3;6)	(3;7)	(0;1)			(1;4.5)	(1;3)	(-2;0)		
Cognitive age	9.00	13.00	4.00	0.0156*	(2;6)	6.00	9.50	2.00	0.0313*	(0;4)
IQR	(9;14)	(11;20)	(3;5)			(5;7.5)	(6;10.5)	(0.5;4)		
Receptive language	5.00	7.00	1.00	0.1875	(-1;6)	4.00	5.50	2.00	0.1563	(-2;3)
IQR	(4;8)	(6;8)	(0;3)			(3;4.5)	(4;6.5)	(0;2.5)		
Receptive age	11.00	15.00	6.00	0.0156*	(3;10.7)	5.17	11.00	6.33	0.0234*	(-2.8;9)
IQR	(5.33;15)	(13;20)	(4;9)			(4.33;7)	(10;13.5)	(3.3;7.3)		
Expressive language	6.00	8.00	1.00	0.4063	(-2;3)	4.50	4.50	0.00	0.8125	(-2;2)
IQR	(5;7)	(6;8)	(-1;2)			(3;6.5)	(3;7)	(-0.5;1.5)		
Expressive age	11.00	17.00	6.00	0.0156*	(2;8)	6.50	11.00	5.00	0.0313*	(-0.3;8)
IQR	(9;18)	(14;21)	(3;8)			(4.83;8)	(8;14.5)	(1.5;6.2)		
Fine-motor development	6.00	5.00	2.00	0.1094	(-2;3)	2.50	3.00	0.50	0.5938	(-6;6)
IQR	(2;6)	(5;7)	(1;3)			(1;5.5)	(2;6)	(-0.5;2)		
Fine-motor age	9.00	15.00	6.00	0.0156*	(2;8)	6.00	10.00	4.00	0.0234*	(-2;7)
IQR	(8;12)	(11;20)	(4.67;7)			(5;10)	(9;11.5)	(2;5.5)		
Gross-motor development	1.00	3.00	1.00	0.0625	(0;4)	1.00	1.50	0.00	0.5000	(-1;2)
IQR	(1;2)	(1;6)	(0;2)			(1;1.5)	(1;2.5)	(0;1)		
Gross-motor age	7.00	11.00	4.00	0.0313*	(0;5)	7.00	8.00	2.00	0.0156*	(0;4)
IQR	(7;8)	(10;12)	(2;4)			(5.67;7)	(7.5;10)	(1.2;2.8)		

*Statistically significant at p<0.05
†IQR: Inter-quartile range

The age groups >9 months showed the same tendency as the <9 months for the cognitive domain. The intervention group showed no changes in the cognitive domain (**cf.** Table 5.10). There were median change increases in the receptive language, expressive language, fine-motor and gross-motor domains. The control group showed a decrease in the median score for the cognitive domain. There were median increase changes in the receptive language and fine-motor domain, whereas the median scores for expressive language and gross-motor domain stayed the same.

Table 5.11: Pre-test and changes from pre-test to post-test: Differences between intervention and control group

	<9 months p-value (n= 9/6)	>9 months p-value (n=7/8)	<9 months 95% CI (n=9/6)	>9 months 95% CI (n=7/8)
Cognitive development: Pre-Test	0.7203	0.0782	(-3;4)	(-1;4)
Cognitive development Change	0.4763	0.1660	(-2;4)	(-1;3)
Cognitive age: Pre-test	0.2926	0.0143*	(-4.1;0)	(1;9)
Cognitive age Change	0.6334	0.0475*	(-1.2;1.3)	(0;4)
Receptive language: Pre-test	0.4375	0.0612	(-3;1)	(0;4)
Receptive language Change	0.2616	0.8130	(-2;7)	(-2;3)
Receptive age: Pre-test	0.0825	0.0529	(-2.8;0)	(0;10.7)
Receptive age Change	0.1368	0.6006	(-0.9;4.8)	(-2.7;5)
Expressive language: Pre-test	0.2279	0.1781	(-2;1)	(-1;5)
Expressive language Change	0.9037	0.5546	(-2;3)	(-2;2)
Expressive age: Pre-test	0.2222	0.0307*	(-3.1;0)	(0;12)
Expressive age Change	0.6364	0.4478	(-3.8;2.3)	(-3;4)
Fine-motor development: Pre-test	0.5892	0.2589	(-2;3)	(-2;5)
Fine motor development Change	0.9528	0.3476	(-5;5)	(-2;3)
Fine-motor age: Pre-test	0.2490	0.1623	(-3.8;0.7)	(-1;7)
Fine-motor age Change	0.9528	0.1283	(-1.7;2)	(-1;5)
Gross motor development: Pre-test	0.8110	0.4886	(-3;3)	(0;1)
Gross-motor development Change	0.3059	0.1153	(-2;4)	(0;2)
Gross-motor age: Pre-test	0.2547	0.1254	(-5.3;0.6)	(0;2.7)
Gross-motor age Change	0.3440	0.1129	(-1.0;2.7)	(-0.7;3)

*Statistically significant at p<0.05

Using the Mann-Whitney test the significance of pre-test values and changes between the intervention and control groups regarding test values is shown in Table 5.11. In the <9-months group only receptive-language age pre-test showed close to statistically significant difference between the intervention and control group.

In the >9-months group a number of statistically significant differences were found, namely cognitive age (pre-test), cognitive-age change and expressive age (pre-test) as shown in Table 5.11.

Table 5.12: Descriptive table post-test comparing the intervention and control group

	< 9-months		**> 9-months**	
	Intervention Median	Control Median	Intervention Median	Control Median
Cognitive domain	5.0	3.5	6.0	1.5
Receptive-language domain	5.0	3.0	7.0	5.5
Expressive-language domain	7.0	7.0	8.0	4.5
Fine-motor domain	6.0	6.0	5.0	1.5
Gross-motor domain	2.0	1.5	3.0	3.0

Note: Extremely Low (1–3), Borderline (4–5), Low Average (6–7), High Average (13–14)

The Bayley Scales III was fundamental to attaining standardised developmental domain scores to investigate the impact of the DRSP. The qualitative description of scaled scores for the Bayley Scales III is Extremely Low (scaled score of 1–3), Borderline (scaled scores of 4–5), Low Average (scaled scores of 6–7), Average (scaled scores of 8–12) and High Average (scaled scores of 13–14) (**cf.** 2.2).

Table 5.12 shows that in the subgroup <9-months for the intervention group median scores for cognitive domain and the receptive-language domain were “Borderline”. The expressive-language domain and fine-motor domain were “Low Average”, with only the gross-motor domain in the “Extremely Low” range. The control group’s cognitive, receptive-language and gross-motor domains were “Extremely Low” and expressive language and fine-motor “Borderline”. The subgroup >9-months for the intervention-group median scores for cognitive domain and receptive language was “Low Average”,

expressive language was “Average”, fine-motor was “Borderline” and gross-motor was “Extremely Low”. The control group >9-month subgroup median scores ranged between “Extremely Low” and “Borderline”.

The following four figures illustrate the two age subgroups in the fine-motor domain separately for the intervention and control group, to illustrate individual positive changes.

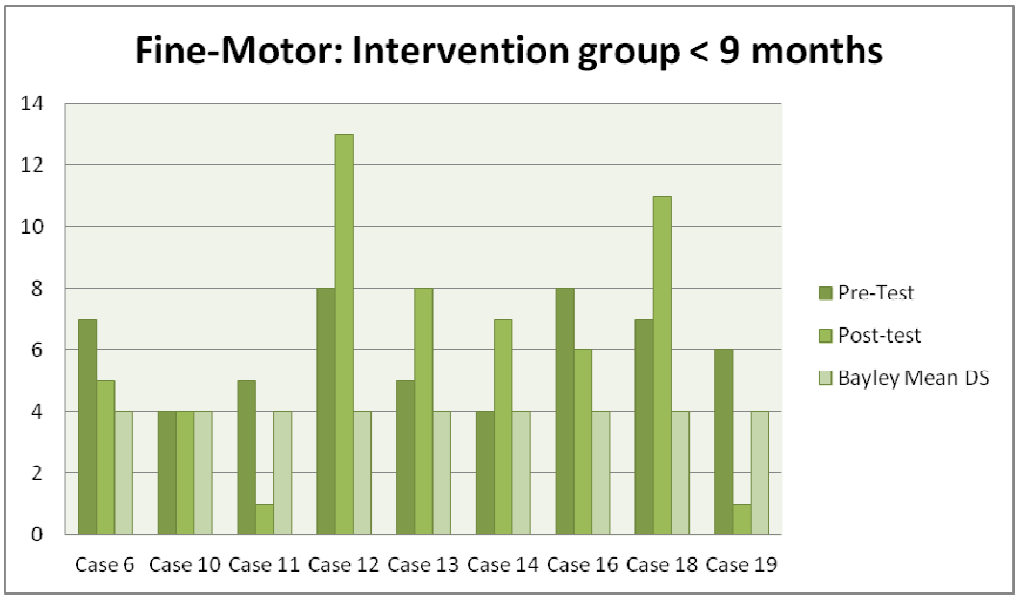


Figure 5.3: Individual differences in fine-motor development of 9 children <9 months: Intervention group

Figure 5.3 illustrates the scores of the intervention group for nine participants (participants I.6; I.10; I.11; I.12; I.13; I.14; I.16; I.18; I.19) for the pre-test and post-test <9-months subgroup. This graph illustrated that the post-test scores of six of the nine participants, scored higher than the Bayley Scales III mean scores for DS. The post-test scores of two participants indicated poorer scores than the Bayley Scales III means scores for DS and one participant scored the same (Appendix I).

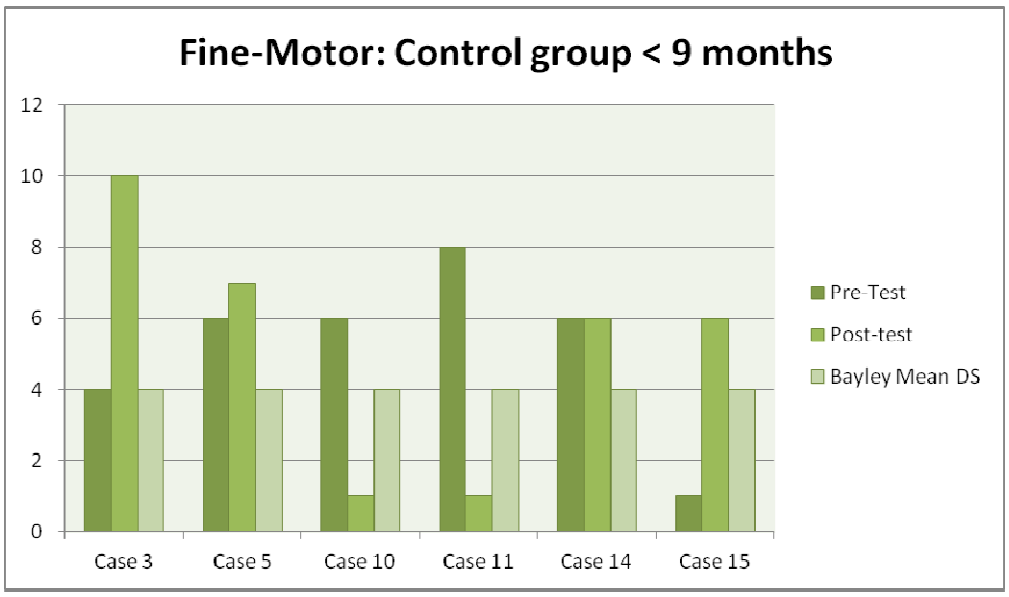


Figure 5.4: Individual differences in fine-motor development of 6 children <9 months: Control group

Figure 5.4 illustrates the pre-test and post-test scores of the <9-months control subgroup (participants J.3; J.5; J.10; J.11; J.14; J.15). This illustrates that the post-testing of four of the six participants scored higher than the Bayley Scales III mean scores for DS. Two participants performed poorer than the Bayley Scales III in the post-testing (Appendix J).

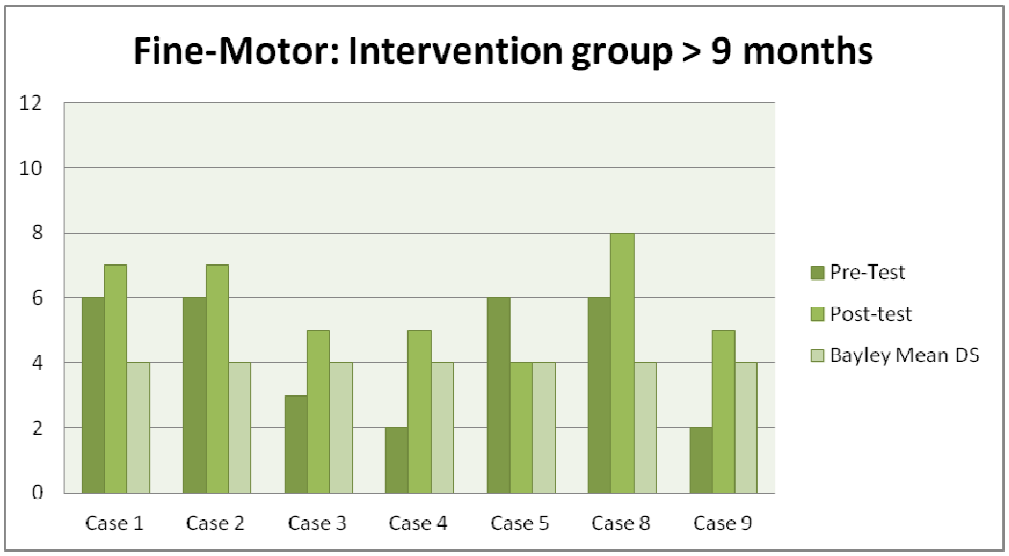


Figure 5.5: Individual differences in fine-motor development of 7 children >9 months: Intervention group

Figure 5.5 illustrates the pre-test and post-test scores of the >9-months intervention subgroup (participants I.1; I.2; I.3; I.4; I.5; I.8; I.9). Six of the seven participants' scores

increased and were higher than the Bayley Scales III mean scores. One participant's score decreased, but the score was still the same as the Bayley Scales III (Appendix I).

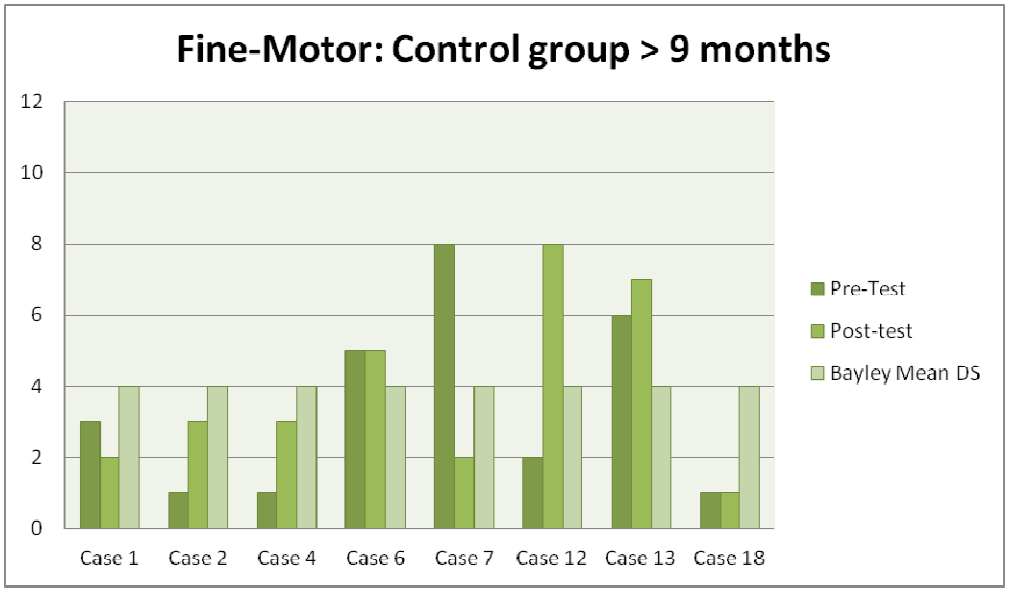


Figure 5.6: Individual differences in fine-motor development of 8 children >9 months: Control group

Figure 5.6 illustrates the pre-test and post-test scores of the >9-months control sub-group (participants J.1; J2; J.4; J.6; J.7; J.12; J.13; J.18). Three participants scored better than the Bayley Scales III mean scores on the post-test scores. Five participants scored poorer than the Bayley Scales III mean scores on the post-test scores (Appendix J).

The following graphs illustrate the gross-motor domain in the subgroups for both the intervention and control group.

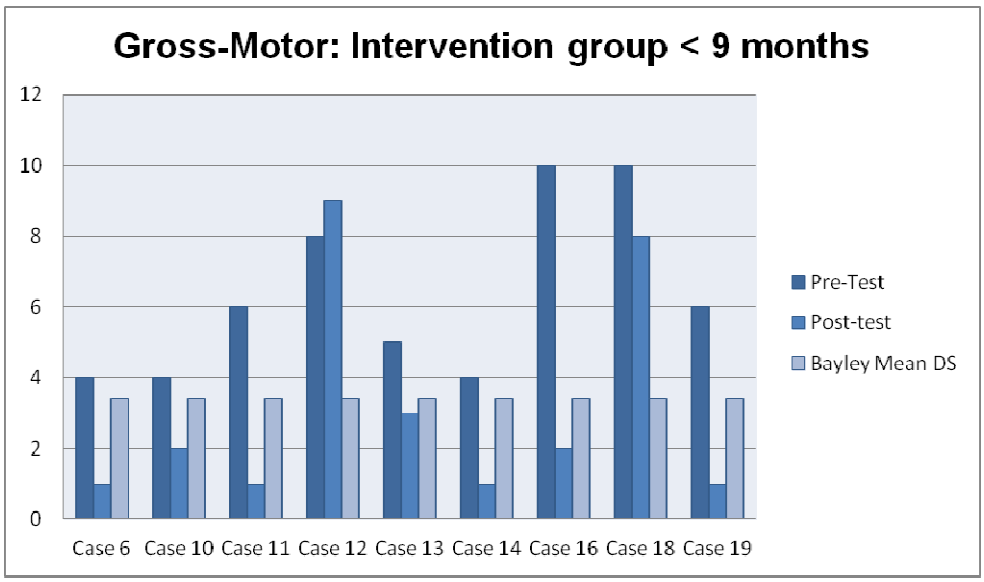


Figure 5.7: Individual differences in gross-motor development of 9 children <9 months: Intervention group

Figure 5.7 illustrates the individual scores of the intervention group <9 months. The scores declined for eight participants; only one participant showed an increase. Only two participants' post-test scores were higher than the Bayley Scales III mean scores.

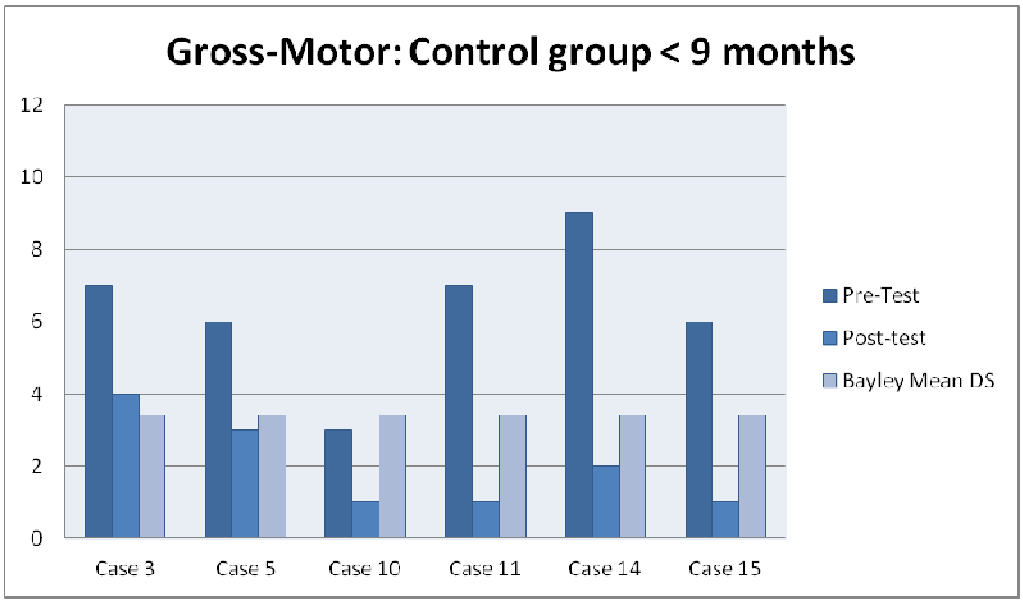


Figure 5.8: Individual differences in gross-motor development of 6 children <9 months: Control group

In Figure 5.8 it is shown that the control group scores for gross-motor domain in the subgroup <9 months declined for all six participants. Only one participant's post-test score was higher than the Bayley Scales III mean scores.

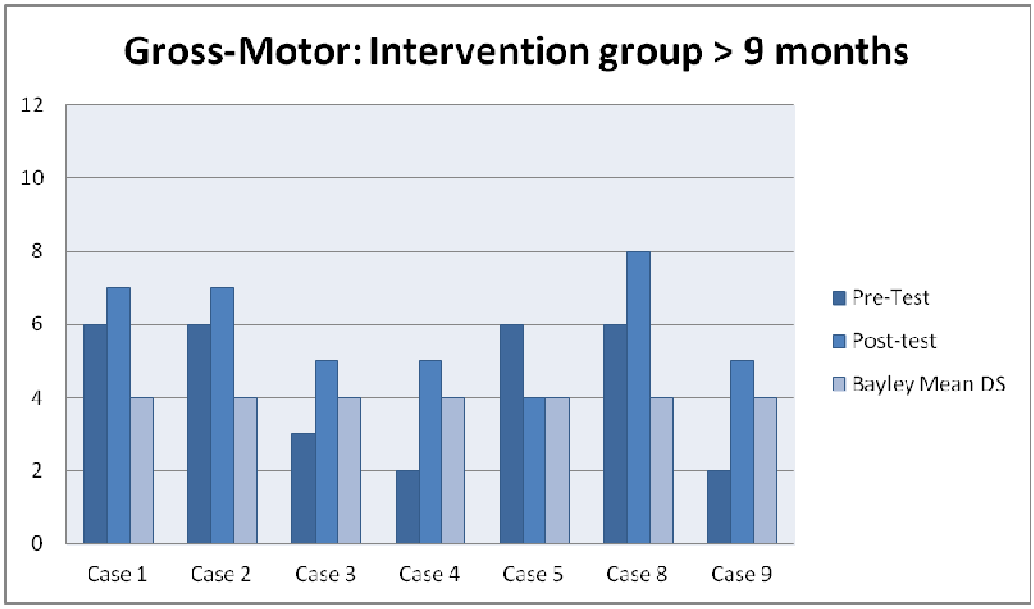


Figure 5.9: Individual differences in gross-motor development of 7 children >9 months: Intervention group

Figure 5.9 illustrates the pre-test and post-test scores of the intervention subgroup >9-months for the gross-motor domain (participants I.1; I.2; I.3; I.4; I.5; I.8; I.9). The scores showed an increase in six of the seven participants with post-test scores higher than the Bayley Scales III mean scores. Only one participant showed a decline in score, but it remained the same as the Bayley Scales III mean score.

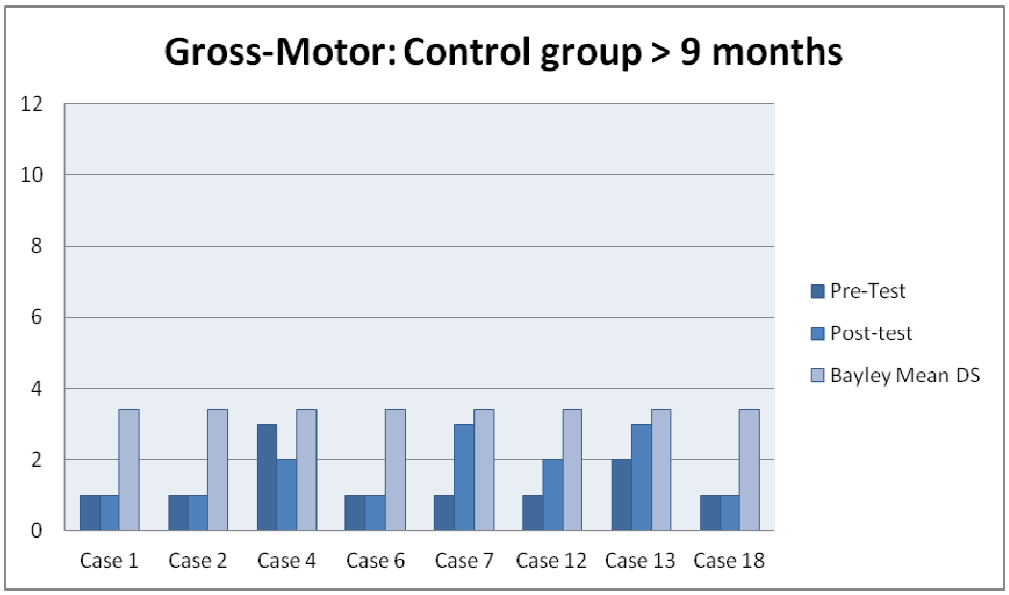


Figure 5.10: Individual differences in fine-motor development of 8 children >9 months: Control group

Figure 5.10 shows that in the subgroup >9 months for the control group, the participants' gross-motor ability remained the same for four of the eight participants. Three participants scored higher in the post-test and one participant's score declined. All the participants' post-test scores were below the Bayley Scales III mean scores.

A comparative illustration of the two subgroups was as follows:

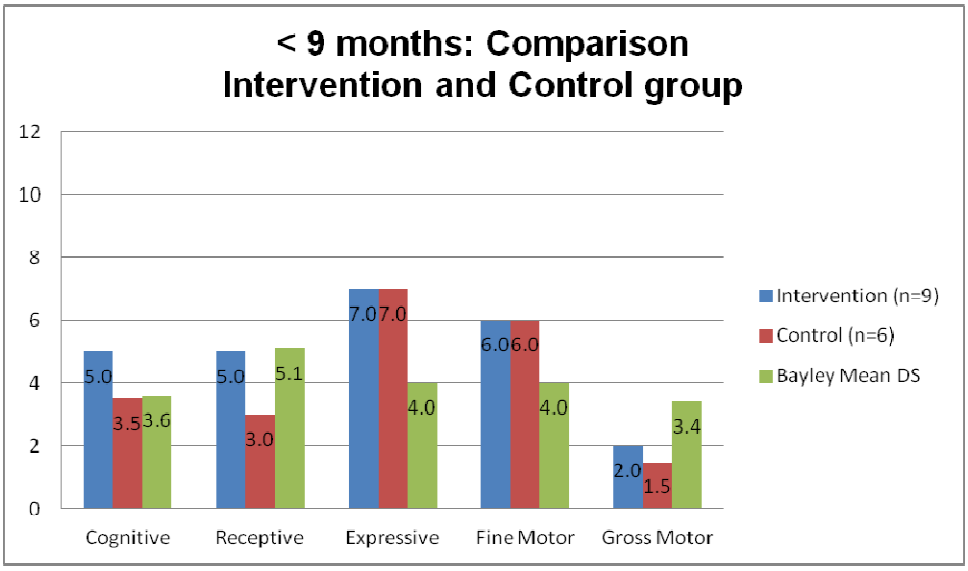


Figure 5.11: Comparison of post-test scores between intervention and control group <9 months group

Figure 5.11 shows variation between the domains for intervention participants and control participants <9 months. The intervention group scored higher than the control group in the cognitive, receptive-language and gross-motor domains. Both groups' expressive-language and fine-motor domain scores remained the same. Cognitive, expressive-language and fine-motor domains of the intervention group had higher scores in the post-test than the scores of the Bayley Scales III.

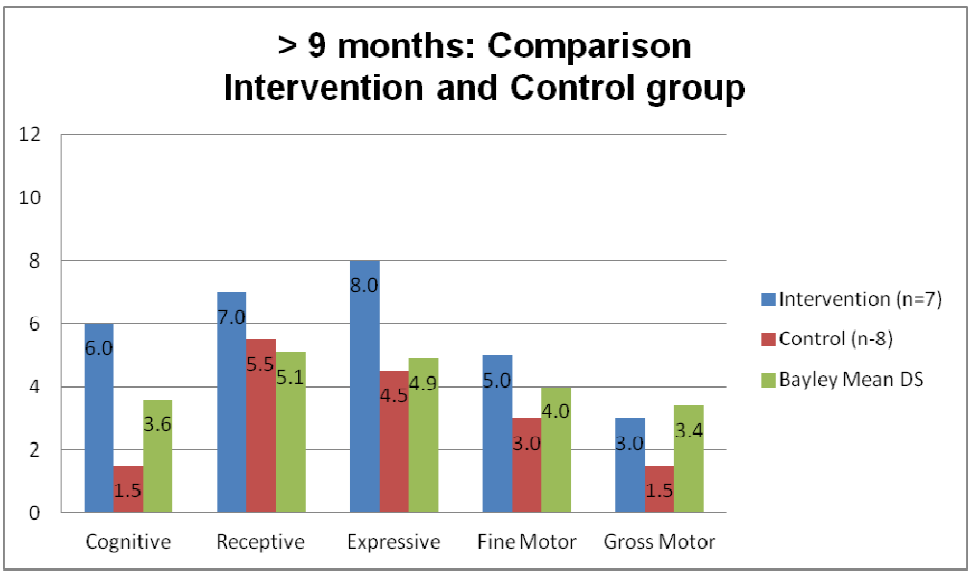


Figure 5.12: Comparison of post-test scores between intervention and control group >9 months group

The median scores are illustrated in Figure 5.12 for the subgroup >9 months. The cognitive, receptive, expressive and fine-motor domains median scores for the intervention group were higher than the control group and the Bayley Scales III mean scores. The intervention group scored higher in the gross-motor domain than the control group, but lower than the Bayley Scales III mean scores (**cf**. 4.3.7).

5.4 OBJECTIVE 2: To establish the duration of intervention required to achieve a positive outcome

5.4.1 DRSP Checklists

In Chapter 3, the DRSP was described in depth. The methodology to establish the duration of intervention with a possible positive outcome was described in the previous Chapter. The outcomes of the DRSP during the six-month intervention period are illustrated in Table 5.12 through to Table 5.18. Because of the small sample, the level descriptor scores were grouped into two groups namely, “could not master items independently (level descriptors 0–2)” and “could master items independently (level descriptors 3–4)” in the five domains for interpretive purposes. However, the tables reflect

all the individual level descriptor's scores as median scores for the performances in the domains.

Tables 5.12–5.18 illustrate the following:

- Each activity of the DRSP in the development age bands
- Median score after six months of DRSP intervention
- Number of participants (n) who could not perform activity at start of intervention
- Developmental domains
- Median number of sessions needed by the participants (M) to independently master the activities

Table 5.13: Activity Age band 0–3 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 0 - 3 Months													
DRSP activities		Developmental domains during intervention							After 6 months intervention (Median = 7 months)				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1A	Picking up your baby (1st part) (n=7)	2*											100%
1B	Picking up your baby (2nd part) (n=7)	2											100%
2A	Carrying your baby (n=6)	2											100%
2B	Carrying your baby (n=6)	2											100%
Tip	Mouth closure (n=3)	1			1								100%
3	"Mommy Talks" (n=7)			3	3								100%
4	"90 Degree Follow" (n=6)			2	2								100%
5	"Hello, Mommy loves you" (n=7)		3	3	3		3						100%
6	"Cover-the-Face" (n=7)		4		4		4						100%
7	"Mug in Middle" (n=7)	4	4	4	4								100%
8	"Spoon Watching" (n=7)	4		4	4								100%
9	"Armpit Roller" (n=7)	3	3	3	3								100%
Tip	Holding baby (n=6)	3				3							100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play

* Median number of sessions to perform an activity independently

The intervention, over a six-month period comprised 12 sessions for each participant. The participants' median age before the six-month intervention was two months. In Table 5.13, the development age band 0–3 months, and the activity participation of the seven participants are illustrated. Mastering of a cognitive skill happened after a median of three sessions, based on the median number of sessions per activity. The gross-motor activities were reached within a median of two sessions; fine-motor activities in a median of four sessions; play in a median of four sessions and language and social-emotional

development in three sessions. The median age of the participants after the six-month intervention was seven months, implying that even though the activities were designed for children's developmental age of 0–3 months, the participants were older. In this age band, the median number of sessions to perform activities independently were three, implying the participants needed six weeks to master activities.

Table 5.14: Activity Age band 3–6 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 3 - 6 Months													
DRSP activities		**Developmental domains during intervention**							**After 6 months intervention (Median = 9 months)**				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	Different ways of rolling (n=9)	10*									44.5%	33.3%	22.2%
2	"Side-Sitting" (n=9)	4	4									44.5%	55.5%
Tip	Arm support (n=9)		3									33.3%	66.7%
3	"Hands to midline" (n=8)	2	2	2	2	2	2					12.5%	87.5%
4	"Cover-the-Face" (n=8)		5	5	5	5	5						100.0%
5	"Mother's Face" (n=6)	2	2	2	2	2	2						100.0%
6	"Supported sitting on floor" (n=9)	3	3	3	3	3	3						100.0%
7	"Spoons in a Mug" (n=8)	5			5						25.0%	25.0%	50.0%
8	"Where's the Mug?" (n=9)	7	7	7	7	7	7			11.1%	55.6%		33.3%
9	"Cloth Ball" (n=8)	3	3	3	3				12.5%	12.5%	25.0%		50.0%
10	"Mug Tower" (n=9)	3	3	3	3				11.1%	55.5%			33.3%
11	"Leg Roller" (n=8)	1	1	1	1							12.5%	87.5%
12	"180 Degree Follow" (n=2)			#	#								100.0%
13	"Wha-Wha Sounds" (n=9)			3	3					22.2%	11.1%		66.7%
14	"Rock the Spoon" (n=9)	1		1			1						100.0%
15	"Spoon Sequence" (n=9)	1	1	1	1								100.0%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play
* Median number of sessions to perform an activity independently
# Instantaneous activity performance

In the age band 3–6 months the median age for the participants was three months before the six-month intervention. At the end of session 12, seven of the 12 gross-motor sub-items were mastered (mild help required or no problem), as illustrated in Table 5.14. Eight of the 11 fine-motor sub-items were mastered at the end of the 12 sessions, nine of the 12 cognitive items, eight of the 12 language, five of the six play sub-items and four of the five socio-emotional activities. The median age for the participants after the six-month intervention was nine months. In this age band, the median number of sessions to perform activities independently was three, implying that the participants needed six weeks to master activities.

Table 5.15: Activity Age band 6–9 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 6-9 Months													
DRSP activities		**Developmental domains during intervention**							**After 6 months intervention (Median = 9 months)**				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Midline Copying" (n=12)	2*	2	2	2					15.0%	23.0%	8.0%	46.0%
2	"Babies Name" (n=9)	2	2	2	2	2	2				15.0%	23.0%	54.0%
3	"Spoon Grasps" (n=9)	2	2	2								23.0%	62.0%
4	"Mug Stacking" (n=10)	4	4	4	4				15.0%	8.0%		8.0%	46.0%
5	"Spoon Transfers" (n=11)	3	3	3	3				30.0%	8.0%	8.0%		39.0%
6	"Look for Spoon" (n=9)	3	3	3	3						23.0%	8.0%	46.0%
7	"4 Foot" (n=13)	2	2							15.0%	15.0%	15.0%	55.0%
8	"On the Move" (n=12)	4	4	4	4				15.0%	15.0%	15.0%	23.0%	8.0%
Tip	Crawling (n=11)	4							15.0%	15.0%	15.0%	24.0%	8.0%
9	"Parachute" (n=10)	2	2	2	2	2	2		31.0%		8.0%		46.0%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play

* Median number of sessions to perform an activity independently

In the 6–9 months age band the number of participants as well as their ages per activity varied. From age band 0–3 and 3–6 months, three of the children participated in the activities of age band 6–9 months (**cf.** Table 5.15). This could influence the occurrence of insufficient skills to master activities within a certain age band (from unable to no problem). The total participants in this age band were 13. The median age before the six-month intervention was 6.5 months. The median number of sessions needed for mastering activities was different for all the developmental domains. The gross-motor activities required three sessions (with mild help or no problem) for the child to be able to perform the activities independently (**cf.** 3.3.2). The median age of the participants after the six-month intervention was nine months. In this age band, the median number of sessions to perform an activity independently was three, implying that participants needed six weeks to master activities. Illustrated in Table 5.15, 54% of the participants were able to perform the ten sub-items within the 12 sessions (mild help required to no problem).

Table 5.16: Activity Age band 9–12 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 9 - 12 Months													
DRSP activities		**Developmental domains during intervention**							**After 6 months intervention (Median = 16 months)**				
		GM	FM	COG	L	SE	PL ADL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Where are the Spoons?" (n=6)		4*	4	4		4						100.0%
2	"Tip the Mug" (n=7)		4	4	4								100.0%
3	"Where's Mommy" (n=5)	2	2	2	2	2	2						100.0%
4	"Mugs in Water" (n=7)	4	4	4	4	4	4				28.6%	14.3%	57.1%
5	"Cloth in Water" (n=7)	4	4	4	4	4	4				28.6%	14.3%	57.1%
6	"Words and Concepts" (n=7)		6	6	6		6				28.6%		71.4%
7	"Object Permanency" (n=5)		5	5	5							20.0%	80.0%
8	"Ta-Ta" (n=3)		#	#	#								100.0%
Tip	Kneeling to standing (n=7)	3				3					14.3%		85.7%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play, **ADL** = Activities of Daily Living

* Median number of sessions to perform an activity independently

Instantaneous activity performance

In the 9–12 months age band, the median age for the seven participants, before the six-month intervention, was ten months. The median number of sessions per activity was four out of 12 sessions (from <50% help, mild help required or no problem), as indicated in Table 5.16. The median age of the participants after the six-month intervention was 16 months.

Table 5.17: Activity Age band 12–18 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 12 - 18 Months													
DRSP activities		**Developmental domains during intervention**							**After 6 months intervention (Median = 18 months)**				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"On Top" (n=8)		7*	7	7					25.0%	37.5%		37.5%
2	"Put Spoons in Mug" (n=8)		8	8	8				25.0%		25.0%	12.5%	37.5%
3	"Sand Play" (n=6)	3	3	3	3		3		33.4%☒	33.4%	16.6%		16.6%
4	"Box" (n=6)	1	1	1	1		1				33.4%		66.6%
5	"Face" (n=8)		6	6	6				25.0%	12.5%	25.0%	37.5%	0.0%
6	"Background-Foreground" (n=8)		5	5	5						25.0%	12.5%	62.5%
7	"Cover the Spoon" (n=6)		5	5	5							33.4%	66.6%
8	"Hide & Seek" (n=8)		#		#	#	#						100.0%
Tip	Support-Walking (n=8)	2							12.5%		12.5%	12.5%	62.5%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play

* Median number of sessions to perform an activity independently

Instantaneous activity performance

☒Activity not introduced

In the 12–18 months age band, the median age for the eight participants before the six-month intervention was 12 months. The median number of sessions per activity was five out of 12 sessions, as indicated in Table 5.17. The median age of the participants after the six-month intervention was 18 months. At the end of the 12 sessions, 50% of the

participants were able to perform all the gross-motor items, 50% of the fine-motor and language items (mild help required or no problem). Even though the specific median score per session for example the “Sand Play” activity, was three; the activity was not introduced to three participants because they were from the age band 9–12 months and the activity was only introduced to the other two participants after the eight sessions.

Table 5.18: Activity Age band 18–24 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 18 - 24 Months													
DRSP activities		**Developmental domains during intervention**							**After 6 months intervention (Median = 23 months)**				
		GM	FM	COG	L	SE	PL ADL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	“Three Towers” (n=6)		3*	3	3				16.7%			16.7%	66.6%
2	“Bang-Clang” (n=4)		1	1	1								100.0%
3	“Water in Mugs” (n=5)		1	1	1	1	1		20%☒	20.0%	40.0%		20.0%
4	“Washing Hands” (n=5)	2	2	2	2		2		40%☒	20.0%	20.0%		20.0%
5	“This is Round” (n=5)		3	3	3				40%☒	40.0%			20.0%
6	“Sand-Circle” (n=6)	2	2	2	2				33.3%☒	33.3%			33.3%
7	“Scribble in Sand” (n=6)	3	3	3	3	3			33.3%☒			33.3%	33.3%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play, **ADL** = Activities of Daily Living

* Median number of sessions to perform an activity independently

☒Activity not introduced

In the 18–24 months age band, the median age for the six participants before the six-month intervention was 17 months. The median number of sessions per activity was two out of 12 sessions (from unable to no problem), as indicated in Table 5.18. The median age of the participants after the six-month intervention was 23 months. From age band 12–18 months two participants participated in the 18–24 months age band. Even though the specific median scores for example “Water in Mugs, Washing Hands, This is Round, Sand-Circle and Scribble in Sand” activities, were two or three, the activities were not introduced to two participants.

Table 5.19: Activity Age band 24–42 months: Median number of sessions needed to master DRSP activities independently during six-month intervention

Intervention Group Results: DRSP Activity Age Band: 24 - 42 Months													
DRSP activities		Developmental domains during intervention							After 6 months intervention (Median = 26 months)				
(n = 3)		GM	FM	COG	L	SE	PL ADL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Shapes: Circle"		3*	3	3						33.3%		66.7%
2	"Spoon-Circle"		X	X	X				33.3%		33.3%		33.3%
3	"Spoon-Square"		X	X	X		X		33.3%	33.3%	33.3%		
4	"Cloth-Square"		X	X	X				66.7%		33.3%		
5	"Spoon-Triangle"		X	X	X				66.7%	33.3%			
6	"Cloth-Triangle"		X	X	X				100.0%				
7	"PIR: Bridge"		X	X	X				33.3%		33.3%		33.3%
8	"On Top"		X	X	X				33.3%	33.3%			33.3%
9	"Top-to-Toe"	12	12	12	12	12	12				33.3%	33.3%	33.3%
10	"Train-Mugs"		1	1	1					33.3%			66.7%
11	"Centre Piece"		X	X	X				33.3%	33.3%			33.3%
12	"Spoon Turning"		X	X	X				66.7%		33.3%		
13	"Colors"	X	X	X	X		X		66.7%		33.3%		
14	"Body Parts"		3	3	3							33.3%	66.7%
15	"Mug Counting"		X	X	X				33.3%	33.3%		33.3%	
16	"Spoon Counting"		X	X	X		X		33.3%	33.3%		33.3%	
17	"Moe-ket-si"		7	7	7	7	7				33.3%		66.7%
18	"Sums"		X	X	X				100.0%				
19	"Size/Fractions"		X	X	X		X		66.7%	33.3%			
20	"Mug-a-Stone"		#	#	#	#	#					33.3%	66.7%
21	"Role-Play"	2	2	2	2	2	2					33.3%	66.7%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play, **ADL** = Activities of Daily Living

* Median number of sessions to perform an activity independently

Instantaneous activity performance

X Could not master activity independently after 12 sessions

In the 24–42 months age band, the median age for the three participants before the six-month intervention was 20 months. The median number of sessions per activity was more than 12 sessions, as indicated in Table 5.19. At the end of the 12 sessions, these three participants were able to perform (mild help required or no problem) all the gross-motor

items and the four social-emotional items were mastered independently in five of the 12 sessions. The 21 cognitive, language and fine-motor items were not mastered in the six-month period (unable, >50% help required or help <50%). The eight play items were not mastered in the six-month period. The median age of the participants after the six-month intervention was 26 months. In this age band, the participants needed more than 12 sessions (24 weeks) to independently master activities.

Table 5.20: Summary: Median score of sessions of mastering activities after six months

Summary of mastering DRSP activities by children with DS									
	Cognitive	Language	Fine Motor	Gross Motor	Socio-emotional	Play/ADL	Median*	Weeks	Months
0-3 Months	3	3	4	2	3	4	3	6	1.5
3-6 Months	3	3	3	3	3	3	3	6	1.5
6-9 Months	3	3	2	3	2	2	2.5	5	1.25
9-12 Months	4	4	4	4	4	4	4	8	2
12-18 Months	5	5	5	2	#	1	3.5	7	1.75
18-24 Months	2	2	2	2	2	2	2	4	1
24-42 Months	X	X	X	12	5	X	X	More than 24 weeks	
Median*	3	3	4	3	3	3	3		

* Session Median

\# Master during the first session

X Could not master activities independently after 12 sessions

Table 5.20 summarises the median number of intervention sessions required for a child with DS to master an activity in the specific domain for the age bands independently. Cognitive, language, gross-motor, social-emotional and play/ADL activities require a median of three, whereas fine-motor activities required a median of four. Intervention for the child with DS from birth to nine months would require a six-week period to achieve an activity independently. The 9–12 month age band would require eight weeks, the 12–18 months age band ten weeks, the 18–24 months age band four weeks and the 24–42

months age band would require more than a 24-week intervention period to master activities in the DRSP.

5.4.2 Session length

The duration of the sessions were timed and compared with the video recordings. The duration of a session for children with DS <18 months was 12–15 minutes. The duration of a session for children with DS >18 months ranged from 15 minutes to 40 minutes. This was used for the intervention time only and did not include time used for feedback and questions.

5.5 OBJECTIVE 3: To measure objectively to what extent the parents/caregivers are able to perform the required activities of the DRSP correctly and independently after instruction

5.5.1 Introduction

The DRSP checklist for the parent/caregiver was completed after each intervention session in the seven age bands, by using the level descriptors (**cf.** 4.5.4.1). In the introduction of this chapter, it was stipulated that the participants' parents were involved in the implementation of the activities. All 16 participants' parents accompanied them and no other caregivers were involved in the study.

This checklist was to determine if the parent understood the information on the specific developmental occupations and tasks. The handling techniques, positioning and structuring were explained, discussed and demonstrated to the parent. Each parent was afforded the opportunity to demonstrate the applicable activities of the DRSP, which their child should perform at home (**cf.** 3.3.2.2; 3.3.2.3; 3.3.2.4; 3.3.3).

Tables 5.19–5.25 illustrate the performance of the parents executing DRSP activities during the six-month intervention sessions.

Table 5.21: Activity Age band 0–3 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 0 - 3 Months													
DRSP activities		Developmental Domains during intervention							After 6 months intervention				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1A	Picking up your baby (1st part) (n=7)	3*				3							100%
1B	Picking up your baby (2nd part) (n=7)	3				3							100%
2A	Carrying your baby (n=6)	2											100%
2B	Carrying your baby (n=6)	2											100%
Tip	Mouth closure (n=1)	Δ			Δ								100%
3	"Mommy Talks" (n=2)			Δ	Δ								100%
4	"90 Degree Follow" (n=6)			2	2								100%
5	"Hello, Mommy loves you" (n=6)		1	1	1		1						100%
6	"Cover-the-Face" (n=2)		Δ		Δ		Δ						100%
7	"Mug in Middle" (n=7)	Δ	Δ	Δ	Δ								100%
8	"Spoon Watching" (n-7)	Δ		Δ	Δ								100%
9	"Armpit Roller" (n=3)	3	3	3	3								100%
Tip	Holding baby (n=7)	1				1							100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play

*Median number of sessions to perform an activity independently

Δ Mastered during the first session

In the age band 0–3 months, after six months intervention, the median number of sessions per activity differed as indicated in Table 5.21. The gross-motor activities were accomplished with a median of two sessions. The cognitive, fine-motor and play activities were accomplished at the end of the session and therefore with a median during or at the end of the first session (Δ/1). The language activities were accomplished during the first session. The social-emotional activities were accomplished with a median of three sessions.

Table 5.22: Activity Age band 3–6 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 3 - 6 Months													
DRSP activities		Developmental Domains during intervention							After 6 months intervention				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	Different ways of rolling (n=9)	2*											100%
2	"Side-Sitting" (n=8)	2	2										100%
Tip	Arm support (n=8)		2										100%
3	"Hands to midline" (n=3)	2	2	2	2	2	2						100%
4	"Cover-the-face" (n=1)		2	2	2	2	2						100%
5	"Mother's Face" (n=1)	2	2	2	2	2	2						100%
6	"Supported sitting on floor" (n=4)	2	2	2	2	2	2						100%
7	"Spoons in a Mug" (n=9)	2			2								100%
8	"Where's the Mug?" (n=9)	2	2	2	2	2	2						100%
9	"Cloth Ball" (n=9)	2	2	2	2								100%
10	"Mug Tower" (n=9)	2	2	2	2								100%
11	"Leg Roller" (n=3)	2	2	2	2								100%
12	"180 Degree Follow" (n=1)			2	2								100%
13	"Wha-Wha Sounds" (n=9)			2	2								100%
14	"Rock the Spoon" (n-9)	2		2			2						100%
15	"Spoon Sequence" (n=9)	2	2	2	2								100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play
*Median number of sessions to perform an activity independently

For the age band 3–6 months, after six months intervention, the median number of sessions per activity that enabled the parents to master activities is indicated in Table 5.22. The gross-motor, fine-motor, cognitive, language, social-emotional and play activities were accomplished with a median of two sessions.

Table 5.23: Activity Age band 6–9 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 6 - 9 Months													
DRSP activities		**Developmental Domains during intervention**							**After 6 months intervention**				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Midline Copying" (n=13)	Δ	Δ	Δ	Δ								100%
2	"Babies Name" (n=13)	Δ	Δ	Δ	Δ	Δ	Δ						100%
3	"Spoon Grasps" (n=13)	Δ	Δ	Δ									100%
4	"Mug Stacking" (n=13)	Δ	Δ	Δ	Δ								100%
5	"Spoon Transfers" (n=13)	Δ	Δ	Δ	Δ								100%
6	"Look for Spoon" (n=13)	Δ	Δ	Δ	Δ	Δ	Δ						100%
7	"4 Foot" (n=13)	2*	2										100%
8	"On the Move" (n=13)	3	3	3	3								100%
Tip	Crawling (n=13)	3										7.7%	92.3%
9	"Parachute" (n=13)	2	2	2	2	2	2						100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play

*Median number of sessions to perform an activity independently

Δ Mastered during the first session

In the age band 6–9 months, after six months intervention, all the developmental domain activities were accomplished within the first session (**cf.** Table 5.23).

Table 5.24: Activity Age band 9–12 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 9 - 12 Months													
DRSP activities		**Developmental Domains during intervention**							**After 6 months intervention**				
		GM	FM	COG	L	SE	PL ADL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Where are the Spoons?" (n=7)		1*	1	1		1						100%
2	"Tip the Mug" (n=7)		1	1	1								100%
3	"Where's Mommy?" (n=7)	Δ	Δ	Δ	Δ	Δ	Δ						100%
4	"Mugs in Water" (n=7)	1	1	1	1	1	1						100%
5	"Cloth in Water" (n=7)	1	1	1	1	1							100%
6	"Words and Concepts" (n=7)		2	2	2		2						100%
7	"Object Permanency" (n=7)		2	2	2								100%
8	"Ta-Ta" (n=7)		Δ	Δ	Δ								100%
Tip	Kneeling to standing (n=7)	3				3						12.5%	87.5%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play, **ADL** = Activities of Daily Living

*Median number of sessions to perform an activity independently

Δ Mastered during the first session

For the age band 9–12 months, after six months intervention, the median number of sessions per activity is indicated in Table 5.24. All activities were accomplished with a median of one session.

Table 5.25: Activity Age band 12–18 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 12 - 18 Months													
DRSP activities		Developmental Domains during intervention							After 6 months intervention				
		GM	FM	COG	L	SE	PL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"On Top" (n=8)		Δ	Δ	Δ								100%
2	"Put Spoons in Mug" (n=8)		Δ	Δ	Δ								100%
3	"Sand Play" (n=8)	1*	1	1	1		1						100%
4	"Box" (n=8)	2	2	2	2		2						100%
5	"Face" (n=8)		Δ	Δ	Δ								100%
6	"Background-Foreground" (n=8)		1	1	1								100%
7	"Cover the Spoon" (n=8)		Δ	Δ	Δ								100%
8	"Hide & Seek" (n=8)		Δ		Δ	Δ	Δ						100%
Tip	Support-Walking (n=8)	3											100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play

*Median number of sessions to perform an activity independently

Δ Mastered during the first session

For the age band 12–18 months, after six months intervention, the median number of sessions per activity is indicated in Table 5.25. The gross-motor activities were accomplished with a median of two sessions. Play activities were accomplished at the end of the first session. The social-emotional activities were accomplished within/during the first session as well as all the other developmental domain activities were accomplished during the first session.

Table 5.26: Activity Age band 18–24 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 18 - 24 Months													
DRSP activities		Developmental Domains during intervention							After 6 months intervention				
		GM	FM	COG	L	SE	PL ADL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Three Towers" (n=5)		1*	1	1								100%
2	"Bang-Clang" (n=5)		Δ	Δ	Δ								100%
3	"Water in Mugs" (n=5)		1	1	1	1	1						100%
4	"Washing Hands" (n=5)	Δ	Δ	Δ	Δ		Δ						100%
5	"This is Round" (n=5)		1	1	1								100%
6	"Sand-Circle" (n=5)	1	1	1	1								100%
7	"Scribble in Sand" (n=5)	1	1	1	1	1							100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play, **ADL** = Activities of Daily Living

*Median number of sessions to perform an activity independently

Δ Mastered during the first session

In the age band 18–42 months, after six months intervention, the activities in all the developmental domains were accomplished with a median of one session by the parents (**cf.** Table 5.26).

Table 5.27: Activity Age band 24–42 months: Median number of sessions needed to master transference of DRSP activities independently during six-month intervention

Parent Transfer: DRSP Activity Age Band: 24 - 42 Months													
DRSP activities		Developmental Domains during intervention							After 6 months intervention				
(n = 3)		GM	FM	COG	L	SE	PL ADL		Unable	Help required >50%	Help <50%	Mild help required 25%	No problem
1	"Shapes: Circle"		Δ	Δ	Δ								100%
2	"Spoon-Circle"		Δ	Δ	Δ								100%
3	"Spoon-Square"		Δ	Δ	Δ		Δ						100%
4	"Cloth-Square"	Δ	Δ	Δ	Δ								100%
5	"Spoon-Triangle"		Δ	Δ	Δ								100%
6	"Cloth-Triangle"		Δ	Δ	Δ								100%
7	"PIR: Bridge"		Δ	Δ	Δ								100%
8	"On Top"		Δ	Δ	Δ								100%
9	"Top-to-Toe"	Δ	Δ	Δ	Δ	Δ	Δ						100%
10	"Train-Mugs"		Δ	Δ	Δ								100%
11	"Centre Piece"		Δ	Δ	Δ								100%
12	"Spoon Turning"		Δ	Δ	Δ								100%
13	"Colors"	Δ	Δ	Δ	Δ		Δ						100%
14	"Body Parts"		Δ	Δ	Δ								100%
15	"Mug Counting"		Δ	Δ	Δ								100%
16	"Spoon Counting"		Δ	Δ	Δ		Δ						100%
17	"Moe-ket-si"		Δ	Δ	Δ	Δ	Δ						100%
18	"Sums"		Δ	Δ	Δ								100%
19	"Size/Fractions"		Δ	Δ	Δ		Δ						100%
20	"Mug-a-Stone"		Δ	Δ	Δ	Δ	Δ						100%
21	"Role-Play"	Δ	Δ	Δ	Δ	Δ	Δ						100%

Note: **GM** = Gross Motor, **FM** = Fine Motor, **COG** = Cognitive, **L** = Language, **SE** = Social-Emotional, **PL** = Play, **ADL** = Activities of Daily Living

Δ Mastered during the first session

In the age band 24–42 months, after six months intervention, the activities in all the developmental domains were accomplished by the parents during the first session (**cf.** Table 5.27).

Table 5.28: Summary timeframes for mastering activities by parents after six months

Summary of mastering DRSP activities by parents									
Age bands	Cognitive	Language	Fine Motor	Gross motor	Socio-emotional	Play/ADL	Median*	Weeks	Months
0-3 Months	Δ/1	Δ	Δ/1	2	3	Δ/1	Δ/1	0	0
3-6 Months	2	2	2	2	2	2	2	4	1
6-9 Months	Δ	Δ	Δ	Δ	Δ	Δ	Δ	0	0
9-12 Months	1	1	1	1	1	1	1	2	0.5
12-18 Months	Δ	Δ	Δ	2	Δ	1	Δ	0	0
18-24 Months	1	1	1	1	1	1	1	2	0.5
24-42 Months	Δ	Δ	Δ	Δ	Δ	Δ	Δ	0	0
Median*	1	Δ	Δ	1	1	1	Δ/1		

* Session Median
Δ Master during the first session

Table 5.28 summarises the parent's mastering of activities in all the domains. The time taken by parents to master all of the performance activities in the domains was during or at the end of the first session (Δ/1). In the age band 3–6 months the parents needed more assistance and therefore to master the activities took four weeks.

5.6 OBJECTIVE4: To determine parent/caregiver satisfaction with the DRSP and intervention process

The parents/caregivers completed a self-administered questionnaire with questions in two sections, to obtain their opinion. Twelve of the questions were related to the occupational therapist approach/client-centred approach, three relevant to the service approach and

two questions regarding the intervention area (**cf.** 3.3.4.3). The parents of the 16 children with DS in the intervention group were included in this objective. Only one parent per child, except for two fathers that accompanied the mothers, participated during intervention sessions. No caregivers were involved in the intervention group. Only one adult participant could read neither English nor Sesotho. An interpreter was at hand to help with any queries the parents may have had (**cf.** 4.6.1). The questionnaire was available in Afrikaans, English and Sesotho. Table 5.29 summarises the parents' responses. Fourteen (87,5%) of participants completed the questionnaire without any help and two (12,5%) needed an interpreter to complete the questionnaire (**cf.** Table 5.29).

Table 5.29: Parent Questionnaire (n=16)

	Questionnaire filled in by:			
	Client (parent/caregiver)			87,5%
	Interpreter			12,5%
	Assistance			
	Poor (Below your expectations) *Sastisfactory (Your expectations were met)* *Good (Your expectations were more than met)* *OT (occupational therapist)*	**Poor**	**Satis-factory**	**Good**
OT	How do you rate the explanation of what your Occupational Therapy treatment is supposed to achieve?		18,75%	81,25%
OT	What was the OT's response to your needs and points of view?		18,75%	81,25%
OT	How do you rate the treatment/intervention in terms of improving your child's functioning?		18,75%	81,25%
OT	Describe the OT's attitude towards you and your child.		18,75%	81,25%
Area	Describe the neatness and cleanliness of the Occupational Therapy area.		12,5%	87,5%
Area	How do you rate the level of safety within the Occupational Therapy area?		18,75%	81,25%
	Always (Your expectations were always met) *Sometimes (Your expectations were met)* *Never (Your expectations were never met)*	**Always**	**Sometimes**	**Never**
Service	Did your treatment sessions start on time?	87,5%	12,5%	
OT	If sometimes or never, OT responsible, explain		6,25%	
	If sometimes, Parent responsible, explain		6,25%	
	Were you given the opportunity to ask questions?	93,75%	6,25%	
Service	If there was a language barrier did the OT try to overcome/accommodate this problem?	100%		
OT	Was your baby's problem/diagnosis explained to you in a way you understood?	100%		
OT	Were you given the right to refuse treatment/intervention?	100%		
Service	Was your culture respected where applicable?	93,75%	6,25%	
OT	Was the OT friendly?	100%		
OT	Was the OT polite/respectful?	100%		
OT	Was the OT helpful?	100%		
OT	Was the OT understanding?	100%		
OT	Did you think the OT communicated well with other people involved in your baby's intervention?	100%		

No adult participant rated the questions applicable to the service, area and the occupational therapist as poorly. Twelve of the questions were related to the occupational therapist, three relevant to the service approach and two questions regarding the intervention area. The information obtained from the questionnaire indicated that 81,25%

(13) of the respondents rated the treatment/intervention as good to improve their child's functioning and 18,75% (3) were satisfied with the treatment/intervention.

Thirteen (81,25%) participants indicated that the occupational-therapy treatment was explained in such a manner that the supposed achievements were more than met and the other three (18,75%) indicated that their expectations were met.

Thirteen (81,25%) participants indicated the occupational therapist responded well to their needs and viewpoints and the remaining three (18,75%) were satisfied. According to thirteen (81,25%) participants, the occupational therapists' attitude towards them and their children were good and three (18,75%) described the attitude as satisfactory.

Fifteen (93,75%) participants indicated that they were afforded the opportunity to ask questions always, as opposed to one (6,25%) participant whose impression was that she only "sometimes" was afforded that opportunity.

All sixteen (100%) of the participants indicated that their child's problem and diagnosis were always explained in a manner that they could understand and that the occupational therapist was always understanding and helpful. They (100%) also further indicated that the approach of the occupational therapist was always polite and respectful and that she was always friendly. The occupational therapist's communication to other people involved with their child's intervention was rated as always good by all (100%) participants.

All sixteen adult (100%) participants indicated that they understood that they had the right to refuse the treatment or intervention.

The three questions relevant to the level of professionalism of the service rendered included the punctual start of sessions, language and cultural respect. One (6,25%) participant stated that she was sometimes responsible for the session not starting on time and one (6,25%) participant indicated it was sometimes the occupational therapists' fault for not starting on time with the intervention session. They felt that their culture was respected where applicable; 15 (93,75%) indicated that it was always respected and one (6,25%) only sometimes. No reason or explanation was given.

Two questions related to the physical area. Fourteen parents (87,5%) indicated that they were more than satisfied with the neatness and cleanliness of the occupational therapy

area. Two (12,5%) indicated that they were satisfied. The level of safety within the occupational therapy area was more than satisfactory for 13 (81,25%) participants and satisfactory for three (18,75%).

Only seven (43,75%) participants responded to the one-open ended question “Suggestions/Comments”. One participant (6,25%) indicated that “the OT is doing a good job with my daughter and I know that she is going to do very well. I’m glad to have her as my baby’s therapist”. One participant (6,25%) indicated that the OT was helpful and thanked the OT for the work. One participant (6,25%) indicated that the OT helped a lot and three (18,75%) were grateful for the improvement in their children and the professional way the OT worked with their children with DS.

5.7 CHAPTER SUMMARY

Chapter 5 summarised the results of the four objectives of the study. Objective one was described by using the pre-test and post-test data of the participants. The duration of intervention was discussed in objective two. Objective three was to determine if the parent understood the information on specific developmental matters of their child with DS during intervention. Lastly in objective four, a self-administered questionnaire was used to obtain the parents of the intervention group’s opinion on the intervention. These results will be discussed in the following chapter.

CHAPTER 6
DISCUSSION OF RESULTS

Without change, there is no innovation, creativity, or incentive for improvement. Those who initiate change will have a better opportunity to manage the change that is inevitable" William Pollard (Bolleurs 2012:2)

6.1 INTRODUCTION

All the results obtained during this research project were illustrated by means of tables and graphs in the previous chapter. In this chapter, the results obtained are discussed and interpreted with literature control for confirmation or contradiction. The discussion follows the same editorial sequence as in Chapter 5.

6.2 DEMOGRAPHIC INFORMATION OF PARTICIPANTS

In order to establish the effect of the DRSP on children with DS, a control group was necessary to make more reliable comparisons between the different treatment approaches. In a study (Lauteslager 2000:56) on the younger child with DS and early intervention did not involve a control group, partly because of the ethical considerations if they were not to receive any intervention (**cf.** 2.3.3.1). Regardless of the fact that a control group is a possible challenge, the researcher included a control group to attempt to execute a more reliable study and to investigate changes (Leedy & Ormrod 2010:223).

The demographic information of the participants was displayed in Table 5.1. The **sample** size in this study was small, but realistic (**cf.** 4.3.4.1). The intervention group's sample size determined the size of the control group (**cf.** 4.2.4.1). The age groups of the intervention group impacted further on this sampling process. It was difficult to enrol the exact age appropriate participants for the **control group** at the different sites (**cf.** 4.3.4.2). The initial plan was to match the control group to the intervention group, however this proved to be

too difficult as participants for the control group were recruited at the different sites. The control group's coordinator at site two could not recruit their outreach programme children with DS, as there were transport problems. The limited sample from site two was also the reason for recruiting at site three. By enrolling a control group, the researcher could establish and not only observe (Leedy & Ormrod 2010:223) an effect of the DRSP on children with DS. This led to the decision to embark on a quasi-experimental design utilising a non-randomised control group (**cf.** 4.3.1).

According to the study population for this study, a realistic sample for the intervention was predicted to be about 15 participants (**cf.** 4.3.4.1). The enrolment of the 15 intervention participants took six months (**cf.** Table 5.2). Only two referrals were sent to the BCIC in a period of six months after the closing of the intake, which indicated that the time allowed for the intake of intervention participants were not ended prematurely, and a longer enrolment period would have made little deference. Even in a study by Fewell and Glick (1996:235, 240) a small sample was represented with only eight children with DS out of the 44 participants, ranging from birth to two years.

The intervention group was equally distributed in relation to **gender**, whereas the control group was not equally distributed. The occupational therapist's primary concern when working with children is their ability to function within his/her context and not the gender. The foundational body-level components and the contextual factors interact and have an impact on the occupation-based life areas (Leubben *et al*. 2010:47). Play activities for the young child with DS presents the opportunity for language development, but no significant differences between the play activities for boys or girls with DS were found (**cf.** 3.3.2.1). In one study done for children with DS between one and five years of age, girls scored higher than boys for vocabulary and pragmatic language skills (Berglund *et al*. 2001:185). There was not sufficient evidence that there are differences in the gender of children with DS and it was not taken into account in this study. Parents may help children develop abilities to contradict these gender stereotypes (James n.d.:1/4).

The intervention group, as well as the control group, were not equally distributed in relation to home **language.** Language used by parents/caregivers may predict children's cognitive and language outcomes (e.g. making interested comments in response to what children say, asking questions, responding to vocalisations) (Lowry & Hanen n.d:1/3).The kind of interactions the child has with his/her parents are important to a child's

development (Lowry & Hanen n.d.:2/3). The home language spoken by the parents should not have played a significant role in the typical development of children with DS, and therefore it was not considered a confounding variable. It is therefore not the home languages that parents speak, but more the interaction between the child and the parent that is important. The control group was exposed to different therapist-implemented (**cf.** 2.7.1.1) programmes and not client-centred or parent-implemented development training as in the DRSP, which could have a negative influence on the interaction between the child and the parent. The involvement and education of the parent/caregiver, as well as the interaction with children with DS of the parent/caregiver (**cf.** 2.6.8) were elements in the protocol of the DRSP as an early-intervention programme (**cf.** 3.3.1.3), with no gender discrimination (**cf.** 3.3.2.1).

The distribution of the number of participants in each of the **age group categories** was similar; with the exception of the 0–3 months and 24–42 months clusters (**cf.** Table 5.1). In the 0–3 months category five participants were included in the intervention group while in the control group there were only two participants. This difference of an uneven age distribution of participants in the groups was expected to impact negatively on the results of the assessment of fine-motor and gross-motor development (**cf.** 2.3; 6.3.1.3.1; 6.3.1.3.2), but on assessment appeared to have had no significant impact (**cf.** Table 5.9). The control group's median scores were similar to the intervention group's median scores. In the age band 24–42 months no comparisons could be made as there were no participants in the control group. The age groups were used, because the DRSP has specified different age groups with different development expectations from the intervention participants.

The proportion of urban and rural surroundings at the **sites** for both groups were similar, as 12 participants resided in an urban environment and four participants in a rural environment for the intervention group and 11 participants resided in an urban environment and three in a rural environment for the control group. The age bands could not be compared according to the urban and rural sites. This distribution of urban and rural sites did not appear to influence the performance of the participants in either group.

According to Table 5.1, the control group followed different **therapy programmes**, whereas the intervention group received intervention on the DRSP only (**cf.** 4.3.3) which is a combination of parent-implemented developmental training and client-centred therapy

(**cf.** 2.7.1.2; 2.7.1.3; 3.3.1.3). No participants in the intervention group were enrolled in other therapies. The therapeutic intervention may have rendered security (haven) to the intervention group's parents. The compensation of the transport costs (**cf.** 4.8.6), due to the fact that 81% received care dependency grants (**cf.** 5.2.1), could have been a reason for their commitment to in the DRSP intervention programme. They were given the opportunity to attend other therapeutic approaches, but they chose to remain with the DRSP. However, the control group was exposed to different therapeutic programmes (**cf.** Table 5.1). These therapy approaches were therapist-implemented (**cf.** 2.7.1.1) and not specifically developed for children with DS, in comparison to the DRSP.

Due to the small sample sites' sizes and skewness of the data, it was not possible to perform analyses to adjust for baseline differences in demographic characteristics or in pre-test values.

There were three **withdrawals** or dropouts in the control group and one participant passed away (**cf.** 5.2). There were no withdrawals in the intervention group, and only two participants passed away. Therefore, attrition due to voluntary withdrawals was found in the control group only, which supports the findings by Del Giudice *et al*. (2006:57). Thus, parent-implemented developmental training programmes and client-centred therapy (**cf.** 2.7.1.2; 2.7.1.3) had fewer dropouts as opposed to therapist-implemented only programmes with the intervention of children with DS. The specific involvement of both the therapist and parents in the DRSP may be a reason that there was no attrition due to dropouts in the intervention group (**cf.** 6.5).

6.3 OBJECTIVE 1: To investigate the effect on developmental progress of the Developmental Resource Stimulation Programme (DRSP) in Down syndrome children younger than 42 months

6.3.1 Introduction

As discussed in Chapter 5 the Bayley Scales III was used for the pre-testing and post-testing of the two groups involved in this study. The intervention group's pre- and post-test

median scores showed higher scores than the Bayley Scales III mean scores for the DS population, except for gross-motor development (**cf.** Figure 5.1). The gross-motor development activities in the DRSP may have a high level of difficulty for children with DS, because of the principles of intervention approaches (**cf.** 2.7.1.1; 6.3.1.3.2). The fine-motor development of the control group was similar to the Bayley Scales III mean scores for the DS population (**cf.** Figure 5.2). The control group's cognitive, receptive language and gross-motor development post-test median scores were below the Bayley Scales III mean score. Possible reasons for these lower scores could be their therapist-implemented only intervention programmes where the parent is not fully involved with the intervention. The control group's expressive language development showed higher pre-test and post-test scores than the Bayley Scales III means score for the DS population. This is interesting and may reflect the social involvement of the parents and the benefit of speech therapy. The intervention group performed clinically better than the control group in three of the five developmental domains. This may imply that the DRSP has a positive impact on some of the developmental domains of the child with DS.

In the following section, the implications of the DRSP on the child with DS according to the different developmental domains will be discussed.

6.3.1.1 Cognitive developmental domain

According to the median changes depicted in Table 5.5 there was no change (0) for the intervention group and a decline in the median score of the control group (-0.5) occurred.

Analysis of the data confirmed that although there were positive post-test changes in the developmental patterns of this domain of the intervention group, it was not statistically significant. The data analysis of the control group showed no change between the pre-test and post-test score. The pre-test baseline scores of the two groups differed (control group 2.0 versus 5.0) which may imply that the control group had not received any directed cognitive development stimulation before the study commenced (**cf.** Table 5.1). This finding is difficult to explain for the children with DS who took part in the DSPI as this program includes a cognitive developmental domain in its developmental sequence performance inventory (**cf.** 2.6.9). Therefore, it would have been expected that the baseline pre-test scores should have been higher in the control group as 50% of the

participants were enrolled in the DSPI. It may be that the poorer performance of the remaining control group as compared to the intervention group at the pre-test may reflect socio-economic or cultural factors typical of those sites where they had been recruited. The occupational therapy received by seven of the intervention group participants prior to the study at the BCIC may explain the higher baseline scores in this group. However, the sample was small and the effect may not be significant.

Although the intervention group's pre-test and post-test scores showed an increase, the median change remained the same (**cf.** Table 5.5). Even though at first glance this was discouraging, it is important to point out that these findings did not replicate the declining scores described in the literature. The control group's performance echoed the findings in the published research and showed a slight decline in cognitive median scores (Chapman & Hesketh 2000:86; Fewell & Glick 1996:235, 240; Jarrold *et al.* 2000:240; Laws & Bishop 2004:441; Patterson *et al.* 2012:4; Tsao & Kindelberger 2009:428), with a description of "Extremely Low". The therapist-implemented programmes followed by the children, without the inclusive focus on cognitive abilities, may have been unable to stem the anticipated lack of progress or even the decline in cognitive abilities (**cf.** Table 5.5). Even though the child younger than three years is not expected to perform so many activities in a short course of six months according to typical development (**cf.** 2.3.3), the impact appeared to be more positive for the clinical outcomes of the cognitive domain through balanced occupational performance activities in the DRSP. The DRSP activities in the other developmental domains may also have indirectly impacted on the cognitive developmental domain. Therefore, early intervention with a holistic approach, including total parent participation and empowerment of the parents/caregivers, may have ultimately contributed to a clinical positive change (**cf.** 2.6.1) or at least it appears to have stemmed the anticipated decline.

According to Chapman and Hesketh (2000:87), there are learning delays at ages 0–2 years and then accelerated delays between ages 2–4 years, which may have resulted in the few published early-intervention programmes as the expected outcomes are were inconclusive. Therefore, this study supports the view that implementation of the DRSP should be from birth. An assumption could be made that positive outcomes or diminished observed deterioration may be expected if there is a specific focus on the abilities of the cognitive domain in the therapeutic intervention for the child with DS. The early-intervention process may have a more positive and long-lasting effect on the child with DS

in their present communities (Del Giudice *et al*. 2006:57; Hines & Bennett 1996:100; Mahoney *et al.* 2001:161). In accordance with this positive outcome of the cognitive domain, the parents/caregivers could have been encouraged and confident to implement the DRSP at home, as they could have experienced success with their child's development (**cf.** 2.6.8). The parent's dedicated implementation at home could therefore be rewarded by the improved development of their child with DS. Bayley (2006b:3) concludes that cognitive functions during the first year of life correlate with cognitive functioning later in life and this should be advocated more strongly (Silverman 2007:229). Although researchers (Crombie & Gunn 1998:254; Guralnick & Conlon 2007:512; Hines & Bennett 1996:97) have recommended early intervention and reported some success, these studies have been marred by methodological restraints, such as random control group assignments, limited sample descriptions and homogeneity in the syndrome has often been assumed.

Furthermore, the median score change which remained the same for the cognitive domain of the intervention group does not replicate previous findings of the DS phenotype of deficits in the cognitive domain (Chapman & Hesketh 2000:87; Silverman 2007:229). Patterson, Rapsey and Glue (2012:4) did a review of 13 articles published since 1990, which found that children with DS have a distinctive characteristic cognitive phenotype with low performances in IQ of 50 ("Extremely Low") at age 4-5 (Patterson *et al*. 2012:5). Researchers have also suggested that cognitive development is characterised by remarkable inter-individual differences (Tsao & Kindelberger 2009:428). In this current study the inter-individual differences in the cognitive domain are illustrated in the individual case studies of the intervention (Appendix I). In this current study regarding the cognitive domain did not show any gains of statistical significance.

Although this study did not investigate the level of intellectual disability which may have had an influence on the developmental domains; published literature confirms a decline in cognitive median scores identified with DS (Chapman & Hesketh 2000:86; Fewell & Glick 1996:235, 240; Jarrold, Baddeley & Hewes 2000:240; Laws & Bishop 2004:441; Patterson, Rapsey & Glue 2012:4; Tsao & Kindelberger 2009:428). A comparison of the cognitive domain's median score and descriptions as well as IQ could be made with the data available. The cognitive domain's median score for the 16 participants of the intervention group was 5.5, with a description of "Borderline" (IQ between 70 and 75) (**cf.** 2.2; Table 5.3). This is an indication that they scored even higher than is expected of the

typical DS individual with a standard IQ score between 50 and 70 (**cf.** 2.2). Even though this study did not investigate the level of intellectual disability the participants have, the intervention group's cognitive score was relatively high (IQ 70 and 75). Regardless of no statistical significance and statistical change for the median scores of the cognitive developmental domain, the results could be interpreted as positive. The DRSP may enhance cognitive development of the child with DS in future, in contradiction with current thinking. The control group's cognitive median score for the 14 participants was 2.0, with a description of "Extremely Low" (IQ Lower than 50) (**cf.** 2.2; Table 5.4), and in accordance with literature.

To obtain a better understanding of the intervention and control group's developmental trajectories, both groups were divided into two subgroups, namely a <9-months group and >9-months group (**cf.** 5.3.9).

The <9-months intervention group's median change showed that there was no change in the cognitive developmental domain, however the pre-test and post-test median scores showed an increase (from 4 to 5) (**cf.** Table 5.9). The <9-months control group's median change showed a decline (**cf.** Table 5.9), however the pre-test and post-test median scores showed also an increase. This decrease may be due to the small size (2) in the 0–3-months age band as opposed to the intervention group's five participants. As the literature (Chapman & Hesketh 2000:87) describes learning delays from ages 0–2 years, it could be concluded that the DRSP may have accomplished a positive clinical impact on the cognitive abilities, not only for infants with DS under nine months, but may even increase the cognitive abilities for the child with DS in the >9-months group (post-test median scores) (**cf.** Table 5.10; Table 5.12). The >9-months subgroup (**cf.** Table 5.10) of the intervention group scored higher than the control subgroup with a median post test score of six, which implies that the IQ standard score is expected to be 80 (Psychometric conversion table 2012:2/2). This may confirm that early referrals are beneficial to the development of the child with DS (**cf.** Preface) (**cf.** 2.6.1). The control group's median change in the >9-month subgroup showed a decline with the description of moderate to profound (**cf.** Table 5.10; Table 5.12).

Verbal short-term memory (Jarrold *et al.* 2000:240; Laws & Bishop 2004:441) appears to be impaired with only slight difference. This was contradicted by this study, since the

cognitive activities in the DRSP (Russell 2010:32, 38, 53) that specifically enhanced the short-term memory could be mastered by the children with DS (**cf.** 6.4.1).

Ultimately, an increase in the cognitive domain would not change the phenotype of the syndrome. However, the individual children in the intervention group showed variations in their phenotype and their cognitive abilities. According to the video recordings and DRSP checklists (process notes) these children's parents were fully involved and they focused throughout each intervention session. This could imply that the parents executed DRSP activities with precision at home to the benefit of their child with DS.

The findings in the current study may imply that more goal-specific activities predict better outcomes in this domain. The control group's six-month intervention showed a slight decline in their cognitive abilities. This could be the result of only therapist-implemented programmes without inclusion of specific cognitive development (**cf.** Table 5.5). The investment of the parent's involvement and participation could have made a difference (**cf.** 2.6.8). The assumption could be made that the median score changes of the intervention group, that remained the same contrary to the control group may be attributed to the fact that the DRSP with a combination of a client-centred therapy programme, parent-implemented developmental training and developmental domain activities may give the child with DS the opportunity for development in the cognitive domain.

6.3.1.2 Language developmental domain

The median score changes of the intervention group for both the language domains, namely receptive language and expressive language increased after a six-month DRSP intervention period, even though it was not statistically significant. The median post-test score (7.0) of the intervention group was what would have been expected of typically developing children of the respective ages (Bayley 2006b:108) (**cf.** 4.3.5.1). This may show that the activities allocated to the language developmental domain of the DRSP are effective. These results were in contradiction to the findings of language deficits in the literature (**cf.** 2.6.3) and were superior to that of the control group whose post-test median score in expressive language decreased (5.5). The limited increase observed in the control group was disappointing, since therapist-implemented programmes which included speech therapy were followed. The two group's baseline scores for expressive language

were the same (**cf**. Table 5.5). The limited increase in the control group's scores reflected the findings in published literature (Alexander 2011:117; Burgoyne 2009:3/6). According to research, intensive early intervention (Fewell & Glick 1996:238) does not have a statistically significant positive effect on the development of receptive and expressive language of children with DS (**cf.** 2.3.2). The current study did not show statistical significance, but the intervention group nearly showed typical development, as opposed to the lower scores of the control group. This indicated that the DRSP did have a positive outcome on the language domain of the participants.

According to Berglund (2001:180), there is a significant correlation between language and cognition (**cf.** 2.3.2), with delay more pronounced with regard to poor language skills, than decreased cognitive abilities of the children with DS. Interestingly, the literature findings suggest that speech disorders are not merely accounted for by a cognitive delay (Cleland, Wood, Hardcastle, Wishart & Timmins 2010:93; McCann, Wood, Hardcastle, Wishart & Timmins 2008:15). In the current study these two developmental domains both improved during the implementation of the DSRP for the intervention group with increased changes in the median scores of respectively 1.0 and 0.5 (**cf.** Table 5.5). In fact, contrary to what was expected the improvement in the language domain was even larger than the cognitive domain (**cf.** Table 5.5). This change could have been due to the active involvement of the parents and the effect of the DRSP. According to the video recordings, the parents actually mimicked the researcher when using words and conversations with their children with DS. Furthermore, literature (Tsao & Kindelberger 2009:431) suggested that although most children with DS display weak language abilities, their verbal performances increase with age. In a study done with typically developed children, cognitive and language outcomes were shown to improve when a parent/caregiver was highly responsive to their child's signals and interests (Pino 2000:330).

The DRSP's activities on language development are not divided into receptive and expressive language, but will be discussed separately.

6.3.1.2.1 Receptive Language

It is important to take note that the pre-test median scores were almost the same for both groups before the six-month intervention period. Regardless of absence of statistical

significance, the increased change in the median score of the receptive language of the intervention group is an indication that the DRSP could have had a positive clinical impact. The selection of the DRSP activities for the receptive language domain may be on par with typical development. Individuals with DS often have relatively stronger receptive language and comprehension than expressive capabilities throughout their lifespan. Receptive scores may have improved due to maternal language input (Pino 2000:335), which is more closely correlated with children's receptive language abilities than expressive abilities.

According to Table 5.5, the median score changes of the intervention group and control group's receptive language, after the respective interventions, showed an increase. There was no statistically significant change (p-value >0.05), but this information is of clinical importance. This increased median score for both groups of the receptive language domain is contradictory to the study done by Fewell and Glick (1996:238) who found a decline in those scores. The control group's increased scores could be that their parents, as the primary caretakers, tended to the child positively and that they interacted with their children with DS.

Literature (Fidler 2005:89; Fidler & Nadel 2007:266; Nilholm 2000:349; Silverman 2007:233), stated that children with DS have severe language delays, with stronger receptive language skills and weaker expressive language skills. This study, with a small sample reflects the opposite, since the intervention and control group pre-test scores showed no severe delays. Strategies and principles discussed in Chapter 3 indicate that the approaches necessary during intervention for children with DS may be beneficial to the improvement of receptive language (**cf.** 3.3.1.3; 3.3.3.2.1; 3.3.3.2.4). The DRSP demonstrates capabilities of involving the parents to enforce language development.

6.3.1.2.2 Expressive Language

The initial expressive language median score of the intervention group and control group were the same, but higher than the mean score of the Bayley Scales III for DS (**cf.** Table 5.5; Figure 5.1; Figure 5.2). These results reflect nearly typical developed children's scores and again is a contradiction to the reviewed literature (Berglund 2001:188; Fidler 2005:94; Stoel-Gammon 2001:96), which indicated that the language of a 36-month-old

child with DS is equivalent only to that of a 16-month typically developed child (**cf.** 2.3.2). The changes in median scores for both the groups were the same. It was expected that the control group would have performed better in this domain as four children with DS received speech therapy. The possibility exists that intervention sessions were not regularly attended by the control group, because it was the end of the winter. From personal experience, parents are not inclined to bring their children outdoors when it is too cold. The DRSP appears to have had a positive impact on the expressive language domain resulting in near typical development (**cf.** Table 5.5). The strategies and principles discussed in Chapter 3, that dictate the approaches necessary during intervention for children with DS may also be beneficial for the improvement of expressive language (**cf.** 3.3.1.3; 3.3.3.2.1; 3.3.3.2.4).

The positive trends of this current study should be taken into account during the development and evaluation of future interventions. The DRSP could be part of the expressive-language intervention, as the literature (McCann *et al.* 2008:13; Nilholm 2000:349; Tsao & Kindelberger 2009:427) describes that the expressive language of the child with DS is a major area of deficit and has a serious impact on the child with DS's development. Studies (Chapman & Hesketh 2000:87; Nilholm 1996:52) further indicate that these children have great delays with little or no improvement in their expressive language.

According to a study by Daunhauer and Fidler (2011:13), expressive language deficit may be a result of deficits in the motoric components of speech as well as deficits in the acquisition of complex expressive language forms. This study also contradicts these assumptions, which will be discussed in the following section.

6.3.1.3 Motor developmental domain

The researcher anticipated that the DRSP would positively influence the motor developmental domain with the balanced activities, but the same tendency as in the literature (Nilholm 1996:53) was observed in this current study with deficits (gross-motor development) or little improvement (fine-motor development). General movements were present in all the newborn babies and the researcher considered that it could predict better outcomes in the motor development of the children with DS in the intervention group, but it

did not reflect in the scores (**cf.** 2.3.3.1.2). Even though there was a decline in the gross-motor-development scores of both the intervention group and the control group, the intervention group's scores generally were better than that of the control group. This may indicate that the DRSP might have had a positive effect on the motor-development as opposed to the 50% of the control group receiving NDT physiotherapy (**cf.** Table 5.1) (**cf.** 6.2).

The researcher took the neuropathology and decreased myelination of the brain into consideration with the planning of the DRSP with set principles, anticipating that there will be challenges for the child with DS (**cf.** 2.3.3.1; 3.3.1.3). According to the literature (Derrington, Shapiro & Smith 1999:6/24; Fidler 2005:94; Jobling 1998:289; Spiker & Hopmann 1997:22/36), even with intervention there will be deficits or relative weaknesses and/or delimiters, but the treated children with DS were expected to perform better than a control group on both gross-motor and fine-motor domains. It must be realised that, even if no immediate improvements in the children with DS are observed, they still have potential to improve their motor skills with practice (Alton 2005:1/4; Latash 2007:969). There is literature (Sacks & Buckley 2003:137; Sourtiji *et al.* 2010:8), stating that older children with DS demonstrate a statistically strong correlation between motor and mental age (**cf.** 6.2). Early intervention may change this negative notion that motor development delay may indicate poorer results in children with DS's cognitive abilities (**cf.** Table 5.5). The poor performance in the motor developmental domain did not impact the cognitive domain, as the latter scores showed a positive trend.

Even with this negative overview, the opposite was demonstrated when comparisons were made between 12 of the participants' matching scores of the intervention and control groups. The data indicated that the intervention group scored higher than the control group in the post-test scores and the Bayley Scales III mean scores for DS in the motor development domain (Appendix I).

The separate discussion of the motor developmental domain into fine-motor development and gross-motor development will follow (**cf.** 2.3.3.1; 2.3.3.2; 4.3.5).

6.3.1.3.1 Fine-motor development

Both intervention and control groups showed positive median changes, but the intervention group (1.5) performed better than the control group (0.5) (**cf.** Table 5.5). To better understand the comprehensive fine-motor developmental domain the data of the study were divided into subgroups, namely <9-months (n=9 intervention/6 control) and >9-months (n=7 intervention/8 control) (Table 5.10).

The intervention group for the **<9-months subgroup** achieved the same median scores, with no decline (**cf.** Table 5.9). The control group's change in median score (0.5) showed a slight increase. This is contrary to the literature which shows declined scores in the fine-motor developmental domain (**cf.** 2.3.3.2). The DRSP may have had a positive impact on activities designed for fine-motor development of the intervention group (**cf.** 3.3.1.3). The control group's fine-motor development median score increased slightly (**cf.** Table 5.9) and this could have been due to their therapist-implemented programmes as well as parental involvement (**cf.** 2.6.8). Another explanation for the similar median scores of the intervention group as compared to the control group may be due to the fact that acquired behaviours with regard to motor development in three-month-old infants with DS, being entirely normal at birth, showed delays after six months only (Capone 2004:45; Fidler & Nadel 2007:264; Hines & Bennett 1996:100; Karimi *et al*. 2010:39; Nadel 2003:161; Piper *et al.* 1986:189). This fact may be important as four of the nine children with DS were younger than three months in the <9-month subgroup (Appendix I) and in the control group, two of the six children with DS were younger than three months in the <9-month subgroup (Appendix J).

Even though the control **>9-months subgroup** improved during the six-months, the intervention subgroup scores were higher (**cf.** Table 5.10; Table 5.12). No comparative studies could confirm this tendency of increased median scores in the intervention >9-months (2.0) and control >9-months (0.5) subgroups to. Children with DS's early development are typical in the early stages. Later developmental delays are present (Hines & Bennett 1996:100; Piper *et al.* 1986:189) (**cf.** 2.3.3.2). The higher scores achieved by the intervention group in comparison to the scores of the control group may have been due to the implementation of the DRSP. Eighty percent of the activities in the DRSP were designed to have a specific impact on the stimulation of fine-motor

development (**cf.** 6.4.3.1). The DRSP therefore, promoted fine-motor development, even if no statistically significant changes were established.

The activities promoting fine-motor developmental abilities, showed similar outcomes than the results of the Bayley Scales III, according to the DRSP checklist scoring. The age band 6–9 months promotes reaching and grasping specifically. These developmental performance activities were accomplished at the age of nine months in the intervention group, which is the typical development age for this activity performance (**cf.** Table 5.15). Activities for early manipulation are combined with weight-bearing activities, which are a requisite for manipulation and experience with objects to advance hand-object interaction and coordination (Heathcock *et al.* 2008:321; Russell 2010:13, 15, 17, 18, 26, 27) (**cf.** 3.3.2.4.2). During intervention the fine-motor developmental domain abilities could be clinically observed and therefore activities enhancing fine-motor abilities should be applied from an early age (Aparicio *et al*. 2009:636). The positive change in the fine-motor development, in the intervention group, as a possible result of the DRSP has not been replicated in the literature, which stipulates that reaching is severely delayed in infants with DS (Cobo-Lewis *et al.* 1996:464; Fidler *et al.* 2005:134). The intervention group's median pre-test score was 6.0 which implies no severe delay (**cf**. 5.5). The individual activities of the DRSP promote earlier developmental patterns in different domains to address these delays described in the literature (**cf.** 2.3.3.2). All the DRSP activities were designed to have an effect on the stimulation of sensory development (**cf.** Table 3.1). The DRSP included activities to stimulate all the senses, proprioception and tactile systems (**cf.** 2.3.4; 3.3.3.1.3), which may have had a positive influence on fine-motor development. As fine-motor functioning is matured only at the age of 11 years (**cf.** 2.3.3.2) the results of this domain in the study could be considered encouraging.

As an occupational therapist, the researcher placed emphasis on the fine-motor development and concentrated throughout the intervention on sensory development and principles for weight-bearing activities based on NDT principles while performing gross-motor activities (**cf.** 3.3.3.1.1; 3.3.3.2.2). This study could not replicate the findings (Castillo 2008:142; Dolva, Coster & Lilja 2004:627) of previous studies that acquisition of fine-motor skills are more delayed than gross-motor development (Sourtiji *et al*. 2010:5) (**cf.** 2.3.3.2).

6.3.1.3.2 Gross-motor development

The intervention and control groups' baselines varied for the pre-testing. The intervention group showed better scores than the control group despite the fact that 50% of the control group received physiotherapy prior to the study (**cf.** Table 5.1).

The decreased median score (-3.0) of the **<9-months subgroup's** gross-motor developmental domain (**cf.** Table 5.9) could have been the result of inflated pre-test median scores, since this subgroup included five participants younger than three months of age (**cf.** Table 5.1). Two participants showed Type 1 muscle tone (**cf**. Figure I.11; Figure I.15), one showed Type 3 muscle tone (**cf.** Figure I.14) and two showed Type 4 muscle tone (cf. Figure I.10; Figure I.16) (**cf**. 2.3.3.1) (Appendix I). This is an indication that three children with DS had lower muscle tone, less motor functioning and/or were weak in totality. The control <9-months subgroup also showed a declined median score (-4.0). Typical development in the motor developmental domain is observed during the first three months of the child with DS, and therefore this period is crucial for exposure to intervention (**cf.** 6.3.1.3.1) with early-parent involvement and basic developmental activity performances for gross-motor development (**cf.** 2.6.1; 2.6.4; 2.6.8).

The general negative outcome in the gross-motor developmental domain of the <9-months subgroup does not reflect the same scores on the DRSP checklists. One of the positive developmental outcomes was 'rolling' (**cf.** 2.3.3.1.1c). Rolling occurred at the early age of six months in 50% of the intervention children's development (**cf.** Table 5.13), where as Cobo-Lewis *et al.* (1996:464) describe severe delay with rolling occurring after 12 months. According to Table 2.2, 'rolling' occurs from seven months in typical developed children. This indicates that the DRSP may be beneficial. 'Side-sitting' (**cf.** Table 5.13) is not a component in any other early intervention programme described in literature (Lauteslager 2000:29). The DRSP specifically introduced the 'side-sitting' position, which enforces arm support and proprioseptive input necessary for crawling, balance and stability, followed by trunk rotation in transitional positions (**cf.** 2.3.1.1.1e, f).

A reason for the decrease in the gross-motor development scores for both groups (**cf.** Table 5.5) could have been because of the underlying neuropathology and phenotype of DS, which could have had a negative impact on gross-motor development. Another reason for the decrease could have been the parents' difficulty in mastering some of the

gross-motor activities to perform at home independently. Four parents took longer than four sessions, according to the video recordings to master these activities (**cf.** Table 5.27). A crucial part of the DRSP intervention was the parents' physical involvement with the implementation of the DRSP activities. Since 2000, studies demonstrated that parent involvement might have a positive impact on motor-intervention effectiveness (Mahoney, Robinson & Perales 2004:295). Lauteslarger (2000) also advocates holistic intervention in gross motor development with the involvement of the parent. Even though this study advocated parent involvement, the scores were disappointing. The intervention process may take longer than the allocated six months of this study to fully grasp and master techniques, as well as principles that could enhance their child with DS's development.

In the **>9-months group**, the gross-motor development of the intervention group improved (change in median score 1.0) during the six-months and performed better than the median score for the control-group (0.0) which stayed the same (**cf.** Table 5.10). This is also contradictory to the literature which describes that children with DS's early development display typical development and later (after 16 months) developmental delays are present (Capone 2004:50; Hines & Bennett 1996:100; Piper *et al.* 1986:189). The evidential decrease in scores for the gross-motor developmental domain adds to the accumulating evidence that the treatment methods and approaches currently used in early motor intervention are weak and fall short of expectations (Mahoney *et al.* 2004:295). As the researcher is trained in NDT principles and developmental skills (**cf.** 3.3.3.1.1; 3.3.3.1.2), these were applied in the DRSP. This may have resulted in the positive outcomes in the gross-motor development for the >9-months group.

The same positive tendency was shown in the gross-motor developmental domain of the >9-months subgroup scores on the DRSP checklists. The intervention group's median age for support-walking was 18 months (**cf.** Table 5.17). The walking median age of each participant was noted separately, since walking is such a monumental achievement for parents. The DRSP's gross-motor activities are fundamentally designed to stimulate walking eventually. The intervention group's median age for walking was 23 months, whereas the literature (Connolly *et al*. 1980:1408; Melyn & White 1973:544) indicates that walking may occur from 17 months to 74 months (**cf.** Table 2.2). Not one of the control group participants were walking at the post-test, according to the video recordings and the Bayley Scales III record forms. The literature (Connolly *et al*. 1980:1408; Melyn & White 1973:544) describe that there is a definite delay in walking and that the motor

development of the child with DS is usually significantly delayed. On average, they begin to walk about one year later than infants who are not disabled. This predicts that children with DS only walk at 28 months of age according to Sacks and Buckley (2003:136) and Ulrich *et al.* (2001:1) (**cf.** 2.6.4).

These positive gross-motor development trends may indicate that the DRSP had a positive clinical outcome on the development of the child with DS.

6.3.2 The Social-Emotional Scale

It is important to remember that an infant inherits a set of social-emotional characteristics and a style of interacting, but these are modified by parenting (Johnson & Blasco 1997:238) (**cf.** 2.3.4; 2.3.5; 4.3.5.1). According to the literature (Adamson, Deckner & Bakeman 2010:675; Moore, Oates, Hobson & Goodwin 2002:48), children with DS tend to have increased social development that continues into the preschool years. The social development of the child with DS was taken in to consideration during the development of the DRSP (**cf.** 2.3.5).

The scores improved for the intervention group, according to Table 5.7, but slightly declined for the control group. This is not surprising for the intervention group, because of the positive outcomes in the developmental domains. The parents' involvement could have contributed to this positive effect (**cf.** 2.6.8). The group of parents involved in the intervention group indicated that they were proud of their child's development and their achievements, according to the process notes. Another reason for the improved scores could have been that the parents of the intervention group, who filled in the questionnaire, had a better understanding of intervention and so of their child's abilities. Their expectations of their children would then also have been more realistic (Bruni *et al.* 2010:281). This correlates well with the scores in objective 4, where the participants indicated that the occupational therapist gave them the opportunity to ask questions and that information was given in a helpful way (**cf.** 6.6.2). The slight decline in the control group could be the result of therapist-implemented programmes with less positive parent involvement and less interaction between parent and child during intervention.

6.3.3 Adaptive Behaviour Scale

An important part of the child's evaluation is to learn how he/she interacts with people. It is important to know that every individual requires a repertoire of abilities and the DRSP promoted occupational performance activities to meet the daily demands and expectations of his/her environment.

Table 5.8 illustrates that the parents scored their children with DS high in communication, which could correlate with the scores in the language domain. The median score in the motor ability for both groups were lower at the post-testing as indicated by negative median change scores. The implication is that the parents of the intervention group understood their child and started to be more realistic about their child's ability during the intervention period, which should not necessarily be seen as negative. The intervention group's parents learned new handling techniques and were more assertive in their approach towards their child with DS. The scores that remained the same could be an indication of better insight in their child's development (Bruni *et al.* 2010:281).

The observation is made that the parent knows the child the best and should therefore provide behavioural information (Bayley 2006b:10). The adaptive behavioural skills are influenced by the cognitive and motor development, and therefore, according to the increased scores in these two developmental domains the intervention group should perform better with adaptive behavioural skills in future (Johnson & Blasco 1997:241). Chapman and Hesketh (2000:90) have made use of group comparisons, using the Adaptive Behaviour Scale, which revealed no differences in mean behavioural scores between the DS and control group. In 2009, one study (Kang, Han & Oh 2009:880) was done on adaptive skills in relation to motor-skill development, but only for the older child with DS from six to 12 years of age. This study indicates that there are inadequate results for convincing relations between these developmental skills. Motor-skill development was the most significant predictor of adaptive skills (Kang *et al*. 2009:882), all the more reason for that early intervention to be a priority, as it has an impact on the total development and well-being of the child and ultimately the adult with DS.

6.3.4 Summary of objective one

Despite expected individual gains, and the impression of improved outcomes for the child with DS on the DRSP, this was not supported by significant findings after statistical analysis. The gains made in both the intervention and control group, as well as the perceived deterioration in the motor developmental rate, were analysed and discussed against the backdrop of the DS typical developmental phenotype.

When the sample was split into below and above 9 months of age, evidence of a positive impact emerged. In the language, fine-motor and specifically >9-months gross-motor subgroup domains of the 16 participants in the intervention group an incline, compared to the control group with declined median scores. The cognitive domain scores remained the same. Regardless of no statistically significant improvements of development, the observed clinical changes according to the DRSP checklists and the median scores changes presented by the Bayley pre-test and post-test, are considered positive in this study. Statistical significance was not applicable for the study as the study sample was too small. The statistical changes in age were important as the children were six months older from pre-test age. There was a statistical difference in the cognitive and expressive language age in the control group (**cf.** Table 5.11).

As stipulated in Chapter 4 the evaluator is well trained in the use of the measurement instrument (**cf.** 4.7.2.4). This could have been helpful in the enhancement of the reliability of the evaluations, since it was executed professionally (Leedy & Ormrod 2010:93). The intervention group was unknown to the evaluator and the moderators, which contributed to the attempt to eliminate bias and could have added to the accuracy of the outcome of the study. The video recordings of the evaluations enhanced the validity of the measurements (**cf**. 4.3.6.2). By scoring the video recordings the moderators established, objectivity between the evaluator and the researcher during the evaluations and the DRSP check listing.

The assumption could be made from the results gathered in objective one that the DRSP consists of well-balanced performance activities and principles with a strong technical infusion of presentation and structuring (positioning and handling) strategies (**cf.** 3.1; 3.3.1.3).

6.4 OBJECTIVE 2: To establish the duration of intervention required to achieve a positive outcome

This study provided the researcher the opportunity to establish the specific duration and frequency of intervention required by a child with DS to execute an occupational performance activity.

In order for the infant participants to master skills, the parent participation and their mastering of the different developmental activities of the DRSP in each age band were important in this study (**cf.** 6.5). The mastering of the skills could be associated with the occupational therapist being part of the intervention process and that all parties were engaged (Pierce 2001:253).

The observation was made that with continuous use of DRSP, parents could execute the activities easily at home which resulted in excellent participation from their children during intervention sessions. The positive pre-test scores could have changed the perception of the parents and the intervention of their child with DS. As a result of the progression of the children and the changed perception of the parents, it is expected that parents will follow the DRSP successfully and independently as a home programme

6.4.1 Cognitive developmental domain

The DRSP consists of 85 activities, of which 69 (81%) were designed to stimulate cognitive development (**cf.** Table 3.1) (**cf.** 2.3.1; 2.6.2). The median number of sessions per activity in the cognitive developmental domain that enabled the intervention group to master the skills is three (**cf.** Table 5.20). This was considered to be acceptable, as there is no literature to compare these findings to. This mastering of cognitive skills could be that the DRSP was designed to enhance visio-spatial activities and other studies reflect the relative strengths in visio-spatial functioning (Daunhauer & Fidler 2011:11; Fidler 2005:89) (**cf.** 2.3.1).

A developmental age-appropriate activity analysis of each participant ensured that the child's activity performance could be met and the parents could engage with their children with pleasure while executing the activities at home (**cf.** 3.3.2.2). They were able to

achieve the activities, with the expected outcomes, with no difficulty. As the tools of the DRSP (**cf.** 3.3.2.1) are used by parents effortlessly daily with their child with DS it could have enhanced the mastering of the cognitive skills.

6.4.2 Language developmental domain

Although speech therapists are the primary provider of language skills intervention, the occupational therapist can be involved in the stimulation of this domain (Alexander 2011:117). The DRSP consists of 85 activities, of which 71 (84%) were designed to have a potential effect on the stimulation of the language development, but they were not specifically divided into receptive and expressive language domains. The median number of sessions per activity in the language developmental domain that enabled the participants to master the skills was three (**cf.** Table 5.20). This could be an indication that the activities DRSP were able to have a positive effect on language development.

6.4.3 Motor developmental domain

As previously motivated, the motor developmental domain was divided into fine-motor and gross-motor development (**cf.** 2.3.3.2; 6.3.1.3).

6.4.3.1 Fine-motor development

In objective one it was established that the intervention group showed increased scores in the fine-motor development (**cf.** Table 5.5). The DRSP consists of 85 activities, of which 68 (80%) were designed to have a specific impact on the stimulation of fine-motor development, with emphasis on correct positioning (**cf.** 2.3.3.1.1; 3.3.3.2.2). Fine-motor activities were well represented in the DRSP as research had demonstrated significant developmental delay in this domain (**cf.** 2.3.3.2). In order to enhance the occupational performance areas such as ADL and play, the possible deficits in the fine-motor domain as described in the literature (**cf.** 2.6.4) had to be addressed. These occupations included in the DRSP could have a positive effect on more play at home.

In the <9-months group 62% of activities were designed to stimulate fine-motor development and this reflects positively in the median scores that remained the same (**cf.** 6.3.1.3.1). In the >9-months group 96% of the activities were designed to stimulate fine-motor development with a positive effect as the intervention group showed a positive change in the median score. The mastering of the activities occasionally acquired a longer intervention period, but the end result was positive. In the 9–12 months age band participants would require eight weeks, the 12–18 months age band ten weeks, the 18–24 months age band four weeks and the 24–42 months age band would require more than a 24-week intervention period to master activities in the DRSP (**cf.** Table 5.20). This finding of the 24–42 months age band is in keeping with the literature and is probably a reflexion of the neuropathology and phenotype of DS (**cf.** 2.2; 2.3.3.2).

6.4.3.2 Gross-motor development

Of the 85 activities in the DRSP, 45 (53%) were specifically designed to have an impact on the stimulation of the gross-motor development. Even though more than half of the activities stimulated gross-motor development, accomplishment was still limited, but the activities require repetition in order to develop quality occupational performance. There should be repetition of the occupational performances to counteract any form of splinter skills that may occur later. The intervention group showed a significant decrease in their gross-motor developmental domain scores in the <9-months group regardless of the total of the 45 activities allocated by DRSP for gross-motor development, 80% are in the age-band 0–3 months and NDT principles were applied. A reason for the decline could be a larger group of participants younger than three months with inflated pre-test scores and literature (**cf.** 6.3.1.3.2) states that these children perform almost typically and then there is development decline. However, the median number of sessions per activity in the gross-motor developmental domain that enabled the participants to master the skills was three (**cf.** Table 5.20). In the 0–3 month age band participants would require four weeks, with the 3–6 and 6–9 months age bands six weeks intervention period to master activities in the DRSP (**cf.** Table 5.20). This indicated that the participants could execute the activities stipulated on the DRSP, but did not show positive outcomes when formally tested. The intervention sessions took place in an environment that became more familiar to the participants and the play activities may have become more enjoyable than during the strict principles which were followed during an evaluation session. The participants' parents

seemed uncomfortable in the evaluation sessions and this may have had a negative effect on the participants when they were expected to perform.

6.4.4 The Social-Emotional Scale

The intervention group showed a positive change in median scores on the social-emotional scale as illustrated in Table 5.7 (**cf.** 5.3.6). No specific/direct comparison was drawn between the parent questionnaire of the Bayley Scales III and the DRSP, however a positive trend was shown. The DRSP consists of 85 activities, of which 22 (26%) could have had an effect on the stimulation of social-emotional development. All the activities are designed to stimulate sensory stimulation. The median number of sessions per activity in the social-emotional developmental domain that enabled the participants to master the skills was three (**cf.** Table 5.20).

6.4.5 Session frequency and length

Over a period of six months, the DRSP was scored according to age bands, as explained in Chapter 5 (**cf.** 5.4) and the number and frequency of sessions as illustrated in Table 5.13–20 was determined. The length of a session was described in the previous chapters (**cf.** 2.6.4; 3.3.4.1; 5.4.2). The individual sessions established in this study were once every second week for a 42-month period for new-born babies with DS, with the length of a session 12–15 minutes for children <18 months and from 15 to 40 minutes for children >18 months. Individual differences should be taken into account in terms of length of sessions. Stipulated time allocations in an intervention programme may assist in total time management. A notable feature of this study was the establishment of the period of effective intervention required in the different domains (**cf.** Table 5.20). Contrary to this study with sessions every second week, Adamson *et al*. (2010:674) indicate that children with DS are included in intervention sessions two to five times only over a period of one year with visits occurring every one to three months.

According to the literature, there is a need to know, not only the effectiveness of an intervention programme, but also, when it should commence and what the duration of implementation should be (Dunst, Meter & Hamby 2011:2; Majenemer 1998:67). The

researcher, after an in-depth literature study and exploration of literature published or unpublished, could find no consensus. Dunst and Trivette (2009:167) reviewed 33 studies including children with autism, DS, intellectual and developmental disabilities, social-emotional disorders and physical disabilities. Interventions varied in terms of the length of time, the number, frequency and length of sessions. Interventions ranged from one to 16 months. The number of sessions ranged from one to more than 100. The individual sessions lasted between 15 minutes and/or four hours. A study (Novak, Cusick & Lannin 2009:e608) on cerebral palsy described an average frequency of twice a week for 16,5 minutes per session at home for eight weeks. In the Novak *et al.* (2009:e612) study, parent participation satisfaction was the key to the success, as in this study's outcomes. The frequency of the sessions ranged from twice a day, five days a week to just one session every two to four weeks (Novak *et al*. 2009:e609). This indicates that there is no generally accepted norm regarding frequency, session length and total duration of intervention in the literature.

6.4.6 Summary of objective two

This time management guideline presented in this current study could enable an occupational therapist in planning intervention sessions for children with DS within a specific timeframe. This could be more cost effective and parents could plan their own schedules more efficiently. Regarding the median number of sessions for mastering activities during a six month period the median of three sessions for all domains could be applicable. This may imply that developmental activities of children with DS could be mastered within a six-week period.

As it has been established that the parent's involvement is crucial, their participation should be measured (**cf.** 2.6.1; 2.6.8). The following objective was included to measure objectively the execution of activities correctly and independently by parents.

6.5 OBJECTIVE 3: To measure objectively to what extent the parents/caregivers are able to execute the required activities of the DRSP correctly and independently after instruction

According to the results obtained in this study, the conclusion can be made that the parents of the intervention group were able to execute the required activities of the DRSP correctly and independently after instruction.

The median number of sessions to master, correctly and independently, the majority of the DRSP activities was during the first session or one session (Δ/1). The 3–6 months age band was the only age band with a median number of two (**cf.** Table 5.28). From the documented individual checklists of parents, only four of the 16 parents took four sessions to master these gross-motor activities. The process notes on the DRSP checklist determined whether the parent understood the information during an intervention session and that the specific developmental issues were explained or demonstrated correctly by the researcher. The reason for taking two to four sessions to master gross-motor activities was that basic skills (3.3.1.2; 3.3.3.2) with significant principles of the motor developmental approaches such as NDT were applied. These parents had no prior knowledge of these principles of intervention. They also did not have any understanding of the reasoning supporting intervention, whereas occupational therapists, physiotherapists and speech therapists attend postgraduate NDT courses to improve their clinical practical skills (Mayston 2008:135). According to these findings the parents did well in mastering the activities.

There is literature available on parent-involvement and parent engagement of children with DS, but no direct results on the mastering of activities for parents during intervention.

The literature supports the principles of the DRSP by giving parents the opportunity to assist (VanLeit & Crowe 2002:407) and to engage their children with DS in daily occupational routines that could lead to positive changes. This could have lead to more independent mastering of DRSP activities, because parents could observe the positive changes in their child with DS. A further explanation of mastering the activities correctly and independently could have been that the researcher had the skills to assist each parent during the intervention sessions which describes a client-centred practice approach

(Pierce 2001:252) (**cf.** 2.7.1.3). Ultimately, the correct approach in the intervention of children with DS may lead to the correct and independent execution of intervention activities after instruction.

According to the ICF-CY and OTPF discussed in Chapter 2, there is a need for a shift in intervention focus in treating children with DS, with more emphasis placed on participation and on the acquisition of specific, functional skills (Rihtman, Tekuzener, Parush, Tenenbaum, Bachrach & Ornoy 2010:77). As the DRSP aimed to include stimulation of specific functional skills such as feeding it may enable parents to easily relate to such familiar functional skill activities to further assist them in mastering the activities correctly and independently.

There was one study that investigated whether parent-implemented developmental training could be of greater benefit to the young children with DS, compared to the therapist-implemented treatment, but it did not state or describe mastering of the activities involved with intervention by the parents. Unfortunately, the overall results of the study did not state clearly, but implied, that parent-implemented therapy could be more effective than therapist-implemented treatment (Del Giudice *et al*. 2006:56).

The results of the current study are supported by other studies that encourage the active involvement of parents in the intervention programme and opportunities to learn and provide parents with a sense of control and positive outcomes (Dunst & Trivette 2009:168; Guralnick & Conlon 2007:517; Ritzema *et al*. 2010:19/32). The BCIC acts as a family centre and the literature shows that family-centred sessions promote positive child outcomes and strengthen the parent-child interactions in ways that support and develop the parent's/caregiver's abilities to assist a child's learning in their natural environment throughout the day (Basu, Salisbury & Thorkildsen 2010:127). The assumption is made that if there are positive outcomes in the child's development, the parents indeed mastered the activities of the DRSP correctly and independently.

Brassard and Boehm (2007:3) advocate that parents had to be involved in the assessment process, not only to provide information about their child's development and needs, but also to gain an increased awareness of their own importance in their child's early development. The researcher assumed that, if parents were empowered to transfer

(master) and implement the correct intervention, this would improve their child with DS's development.

6.5.1 Summary of objective three

The most rewarding part of this study was assisting parents to be part of a process that was usually reserved for health professionals. Teaching and supporting parents with DS children to master these activities correctly and independently, was the pinnacle of this research for the researcher. The handling strategies in the DRSP were compiled and taught to the parents in such a way that could have rendered the positive outcomes of the mastering of the activities. The close involvement and accompaniment of the researcher seemed to empower the parents, which was the ultimate goal.

6.6 OBJECTIVE 4: To determine parent/caregiver satisfaction with the DRSP

According to the positive results (**cf.** Table 5.29) of this objective it indicated that the parents were satisfied with the intervention process. The DRSP was specifically designed for the parent to be involved in the intervention of their child with DS (**cf.** 2.6.8). According to the literature (Guralnick 2005:318; Ritzema *et al.* 2010:18/32), there is a significant positive correlation between parent ratings of family-centredness and their overall satisfaction with the programme and their child's outcomes.

To establish parent satisfaction the anonymous self-administered questionnaire was completed at the fourth intervention session. There was a concern that if the evaluation was postponed to the end of the intervention period parents might have felt obliged to evaluate the process positively. The purpose of the questionnaire was to obtain an objective, honest and unbiased opinion from the adult participants, where they could evaluate the intervention process and other factors, including service, occupational therapist approach and the area of intervention.

More than 80% (12 out of 16) of the participants agreed that the intervention had improved their child's functioning. The DRSP was developed to focus on the involvement of both

parent and child. Satisfied parents may eventually prove to experience long-term effects when implementing the DRSP with the DS population. These results are supported by research that 80% of parents with children with intellectual disability in the age group 0–35 months indicated that support assists them to deal more effectively with their problems (Kelly *et al*. 2007:6/12; Kelly, Zuckerman & Rosenblatt 2008:288). The results indicated that the overall impression of the participants with respect to the occupational therapist, service approach and area were satisfactory. This positive response was important, as the literature indicated that a satisfied parent portrayed better outcomes with intervention (**cf.** 2.6.8). The Hawthorne effect could have influenced the satisfaction of the parents because of their inclusion in the study and that they were given more attention during the study (**cf.** concept clarification).

6.6.1 Service

All cultural groups were respected and an ethical approach was followed during the DRSP sessions. It was sometimes impossible to keep strictly to time schedule for individual intervention sessions and this posed a problem when accommodating 13 parents on one day, especially with unreliable public transport. Time delays or waiting time may have been a cause of frustration. Coffee and tea were available for all adult participants whilst waiting for their intervention sessions, to accommodate delays and waiting time. A support group was established by the researcher and managed by the parents themselves also to utilise any delays in a constructive manner. Even with all these measures in place, one parent still complained that the sessions did not start on time.

One parent indicated that culture was only respected “sometimes”, meaning that she was not always assisted in her home (African) language. One could speculate that this particular participant had to complete a written Sesotho questionnaire and did not fully comprehend the question. The researcher is not proficient in an African language, and possibly the parent had expected to be accommodated in her own language. Unfortunately no indication was given prior to the study.

6.6.2 Occupational therapist approach

Twelve of the 18 questions in the questionnaire were pertinent to the occupational therapist's approach, in transferring information and skills during intervention. The overall results were positive regarding the occupational therapist approach.

The majority of the parents indicated that the occupational therapy treatment was explained in such a manner that the supposed developmental achievements were more than met. The written questionnaire could have been the reason for the three participants that did not score the highest score on the questionnaire. Regardless of knowledge of other therapy approaches, especially therapist-implemented treatment programmes (**cf.** 4.3.3), the parents indicated that they were satisfied with the DRSP.

Stressors have been identified that may influence the parent-child interaction. According to the literature one of the stressors is the details pertinent to a child's diagnosis, prognosis and behavioural issues, among the never-ending series of issues that arise, especially over the first three years of the child's life (Guralnick 2005:316; Guralnick & Conlon 2007:516). The information gathered from the questionnaire was supported by the literature. All 16 of the parents indicated that their child's problem and diagnosis were explained in such a manner that they could understand and that the occupational therapist was understanding and helpful. Another stressor that influences the parent-child interaction is that parents do not have the confidence and control involving their parenting role of gathering information on their child's needs (Guralnick 2005:316; Paige-Smith & Rix 2006:94). The parents indicated that the occupational therapist responded well to their needs and viewpoints and her attitude towards them and their children were more than satisfactory. Dunst (2002:143) supports this positive attitude of the parents that could result in a positive productive parent-child relationship. During the study, the researcher ensured that there was a good rapport between researcher and parents in order to create mutual trust, which is a basic principle of client-centred practice (**cf.** 2.7.1.3).

The results indicated that the parents were satisfied in gathering information on their child's needs as well as their own. The importance of question time should not be underestimated (**cf.** 2.7.1.3). The majority of the parents indicated that there was sufficient opportunity for asking questions regarding their child with DS and therefore not being

ignored. An earlier study (Bailey *et al*. 2004:892) found that 7% of parents felt that professionals ignored their opinions.

The occupational therapist's communication with the parents involved with their child's intervention was rated as always good by all the parents. All of the participants understood that they had the right to refuse the treatment or the intervention. They further indicated that the approach of the occupational therapist was polite and respectful and that she was friendly. This positive feedback indicated an overall satisfaction of the client-centred practice approach that emerged from the results.

6.6.3 The area of intervention

Two questions evaluated the parent's perception on where the intervention took place. Specific feedback regarding the area neatness, cleanliness and safety were asked which was indicated as satisfactory. No problems occurred and it seems that the area has been appropriate for the intervention.

6.6.4 Summary of objective four

The rationale of the DRSP was to collaborate with parents/caregivers and to integrate different therapeutic and teaching approaches to improve the development of the young child with DS. It has been found that collaboration and integration of services for vulnerable populations (Drummond 2005:3/5) are more effective, efficient and less costly than narrowly focused programmes.

The positive results regarding the service, occupational therapist approach and area were important and contributed to the success of this study. These outcomes are supported by Guralnick and Conlon (2007:518) who find that if parents have positive experiences, they are satisfied with early-intervention services. The study determined that the parents were satisfied with the DRSP intervention, including the activities and process.

6.7 CHAPTER SUMMARY

This chapter highlighted the trends of this intervention study using the DRSP. The results presented elucidate the need for specific intervention programmes such as the DRSP. The client-centred approach with involvement of the parents to enhance their child's development could have made a difference to the results. Limitations were observed during the study which will be discussed in the following chapter.

CHAPTER 7
CONCLUSIONS, RECOMMENDATIONS AND LIMITATIONS

"To be specific has many advantages that will minimise false expectations and stimulate new approaches while improving the outcomes for those who have been minimally responsive to existing intervention efforts." Guralnick (2005:318)

7.1 INTRODUCTION

This final chapter included the conclusions and recommendations aimed at further/future intervention studies, after considering the observed limitations and reflections on the study.

Down Syndrome has been the subject of many studies in varied fields such as immunology, genetics, neurophysiology and psychology. This interest may be attributed to the high incidence of DS and its well-known etiological factors according to the literature. Even though DS has been well studied, only one study on this age group of children with DS was found to determine whether parent-implemented developmental training was successful (**cf.** 2.6.7.3). Unfortunately the results were inconclusive. Therefore it is evident that a study where an attempt was made to quantify intervention in children with DS, as difficult as it may be, was of critical importance to inform on future directions that early intervention programmes, for these and other children with developmental defects, should follow.

The aim of this study, as described in chapter one, was to investigate the impact of the DRSP on DS children younger than 42 months in the South African context. The

objectives were the investigation of the impact of the DRSP on developmental progress on these children with DS, with the establishment of the duration of intervention required to achieve a positive outcome. The parent's participation was measured objectively to establish to what extent the parents/caregivers were able to perform the required activities of the DRSP correctly and independently after instruction. The final objective was to establish the satisfaction of the parental/caregiver with the DRSP.

Conclusions will follow after the discussion of limitations of the study in the following section.

7.2 LIMITATIONS OF THE STUDY

- Even as DS is the single most prevalent cause of intellectual disability occurring in approximately one in 700 births (Capone 2004:45; McIntosh *et al.* 2008:386), it was one of the challenges to get the right sample size for this population, namely in the Free State, South Africa. The small sample size and convenience sampling were limitations of this study. The initial consideration was that the study should proceed until the required number of 15 to 25 participants was included. Unfortunately, due to unforeseen circumstances, such as pregnancy of the evaluator, inadequate referrals and funds, the sample size could not be extended. Although the sample was small, the results indicated positive trends.

- The study population could not be matched. Even age matching was not possible, as the researcher did not have control over the inclusion of participants from the Down Syndrome Associations. The control group varied in terms of presence or absence of a specified intervention and the type of intervention administered. Ideally there should have been two control groups; those receiving intervention therapies such as speech, or occupational therapy and those not receiving neurodevelopmental therapies.

- Further variables which should be considered for matching would include the developmental levels. Other contextual variables could also influence interventions

or outcomes such as parent's education level, age, size of the family, the birth order of the child with DS and socio-economic status.

- The second part of the parent questionnaire could have been biased, regardless that it was compiled according to scientific principles. The older participants received occupational therapy, rendered at the BCIC before the study and this could have had an influence on the >9-months subgroup results. The parents knew the researcher and had respect for her. This could have inflated the positive frequency of the outcomes.

- The intervention was delineated to a six-month period, which could have influenced the results. An extended intervention period would make such a study more expensive and time consuming, but valid.

7.3 CONCLUSIONS

- Results indicated that, although there were no statistically significant findings, the children with DS, who followed the DRSP showed a positive trend in their developmental progress. It was demonstrated that the DRSP had a positive impact on the development in the receptive-language, expressive-language, fine-motor and >9-months gross-motor subgroup developmental domains, even though it was not statistically significant. The cognitive developmental domain scores remained the same. Sensory development, performance occupations and play were embedded in the developmental domains of the DRSP which proved to have a positive effect. It would give the impression that the involvement of the parents showed a positive trend concerning their child with DS's development and the DRSP represents parent-implemented developmental training and a client-centred therapy approach. The DRSP shows promise and might have clinical relevance in early intervention of children with DS.

- The study established a time management guideline including specific duration and frequency of executing an occupational performance activity by a child with DS. The recommendation for individual sessions established from this study could be

once every second week for the implementation and duration of the DRSP for newborn children with DS, with the suggested length of a session 12–15 minutes for children <18-months and 15–40 minutes for children >18-months.

- The DRSP enabled the parent to become more involved in the developmental process of their child with DS than traditional therapist-implemented approaches in the past and could assist in the collaboration between the occupational therapist and the parent/caregiver. It was established that parents/caregivers were able to master the required activities of the DRSP correctly and independently after instruction.

- The positive results of this study indicated that the parents were satisfied with the intervention process. The DRSP was specifically designed for the parent to be involved in the intervention of their child with DS and therefore, the importance of satisfied parents was essential.

7.4 RECOMMENDATIONS

- The DRSP activities manual consisted of a balanced number of activities allocated for all developmental domains. The implementation of the DRSP could be a valuable therapeutic tool. As the DRSP showed positive trends, it may be implemented in its present format and context. The lack of specific holistic early-intervention programmes that currently exist could be addressed.

- The early enrolment of children with DS into this programme may enable parents to help their child to develop to their full potential at an earlier age. The DRSP should be implemented at least up to the age of 42 months.

- The occupational therapist, as the interventionist, could be the ideal person to assist in the management of children with DS. The occupational therapist, who is equipped with a broader knowledge of activity analysis and the holistic therapeutic process to intervention of all the developmental domains, could be an appropriate principal team member. The DRSP could assist any occupational therapist by

using only this one programme, specifically developed to assist parents and children diagnosed with DS in the South African context. The KIT of the DRSP may accommodate parents of lower socio-economic status as it is affordable and consists of available household utensils. The DRSP could be implemented by occupational therapists that have a passion for working in the field of early intervention, especially DS. This personal factor will assist parents/caregivers to stay focused and motivated in the implementation of intervention for their child with DS. Input would be appreciated from other occupational therapists who implement the DRSP in order to strengthen this specific stimulation programme and form part of revised editions in future, as every child with DS is unique and their needs may be different.

- The DRSP should be promoted for the stimulation of the child with DS (birth to 42 months) in the South African context. Training in the DRSP is recommended at BCIC.

- Stipulated time allocations established in this study could assist in total time management in early-intervention programmes. Using the DRSP in occupational therapy intervention planning, a specific timeframe could be allocated to the early intervention, assisting parents to have additional control and insight in the intervention process. The DRSP could contribute to cost-effectiveness in therapy with ultimately better time management.

- The DRSP may be implemented in rural communities with children diagnosed with DS of lower socio-economic status, especially those who do not have the financial resources to visit a centre.

- Volunteers in organisations such as the Down syndrome association branches and support groups could be trained to use the DRSP. The DS branches and support groups should be able to assist parents, applying early intervention to children with DS. This would be more cost-effective.

- Within the South African context, resources are limited. Historically, all health professionals have been involved in the intervention team for children with DS. The

DRSP could alleviate the burden of both health professionals and families with children with DS. The use of the DRSP could create a better resource system for children with DS and be a solution to the constraints regarding resources.

- To enhance the therapeutic awareness of the assistance to the young child with DS, publications in accredited journals in South Africa, and internationally in regards with Africa should follow this study.

- The DRSP shows promise to be a useful intervention programme for children with DS. Therefore, it may also be useful in the management of early intervention for any other patients with intellectual disabilities or slow developers.

- Further Research:
- Research where other occupational therapists implement the DRSP to correlate their results with the present outcomes.
- Studies should be done to determine the rationale of the decline in the <9-months gross-motor domain. It should be determined whether it is a limitation of the DRSP or due to the time of intervention, the level of parent education or simply because of the phenotype of DS.
- Research is specifically needed to supply detailed descriptive accounts of motor and sensory development.
- As the Bayley Scales III is an expensive evaluation tool, the use of the DRSP checklists may be an appropriate way of assessing the progress in children with DS during early intervention. Research is needed to substantiate this recommendation.
- Sustainability of the skills promoted by the DRSP should be researched on a larger study population. Whether the children with DS will sustain their gains in the long run is an important question that will require follow-up studies.
- The DRSP checklist could be validated to be tested for reliability, sensitivity to detect change and content validity. This could be useful as parents would like to know if their child with DS is improving and clinicians can show them the results.

- Longitudinal follow-up would be needed to determine whether the benefits of the early intervention are maintained over time or if there is a “wash out” effect.

7.5 TO CONCLUDE

The aim of this study with its objectives was achieved. Intervention should focus on a child with DS’s strengths in order to counteract their weaknesses. This should be done with the family as an active agent, which ultimately produces a cascade of benefits. The results of this study suggest that the DRSP, an early-intervention programme specifically developed for the young child with DS, could be effective for improving developmental outcomes. Parent participation and utilisation of the DRSP at home was an important component of its success. Children with DS have the talents and strengths to enable them to rise above the difficulties and challenges of their condition.

At the conclusion of this chapter the researcher remains concerned that there is a great need to provide specific early intervention to assist the parent/caregiver of the child with DS. Early intervention for the young child with DS has proved to be a journey and not a destination.

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APPENDICES

APPENDIX A: Approval to conduct research

APPENDIX B: Information documents and consent documents

APPENDIX C: Development Resource Stimulation Programme (DRSP)

APPENDIX D: Relationship between DRSP, ICF-CY and OTPF

APPENDIX E: Bayley Scales of Infant and Toddler Development 3rd edition; Social-Emotional and Adaptive Behavior Questionnaire

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APPENDIX I: Case studies Intervention group

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APPENDIX K: Calculation of medians

APPENDIX L: Comparison between matching intervention and control group

Appendix A

Prof. A Stulting
Head School of Medicine: Faculty of Health Sciences
UFS

Dear Prof. A Stulting

APPROVAL TO CONDUCT RESEARCH: INVESTIGATION OF THE DEVELOPMENTAL RESOURCE STIMULATION PROGRAMME FOR THE CHILD WITH DOWN SYNDROME YOUNGER THAN 42 MONTHS.

I hereby request approval to conduct the above-mentioned research for a postgraduate qualification (PhD) in the School for Allied Health Professions.

The lack of specialised Down syndrome programmes in South Africa made this research a dire need. A specific outcomes-based programme is the answer, as children with Down syndrome have comparable (homogenic) problems and needs. A holistic approach for the management of children with Down syndrome from birth to 42 months of age in the South African context is needed. This lack of information made it a necessity for the researcher to present this population with a specialised programme. The Developmental Resource Stimulation Programme was developed by the researcher, (Russell 2010) and will be investigated in this study. The Developmental Resource Stimulation Programme is a unique occupational therapeutic, child-parent specific, one-on-one integrated programme specifically developed for children with Down syndrome. The purpose of this programme is to offer developmental stimulation to children with Down syndrome. The Department of Genetics and Paediatrics and Child Health at the School of Medicine refers patients with Down syndrome to the Bloemfontein Child Information Centre.

The protocol will be submitted to the Ethics Committee of the Faculty of Health Sciences for approval. Written informed consent from the parents of the children with Down syndrome will be requested from the researcher.

I trust that this request will be considered positively.

Yours sincerely

DC RUSSELL

Postgraduate student (PhD)
BLOEMFONTEIN CHILD INFORMATION CENTRE
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

Prof. André Venter
Head: Department Paediatric and Child Health
Faculty of Health Sciences, UFS

Dear Prof. Venter

APPROVAL TO CONDUCT RESEARCH: INVESTIGATION OF THE DEVELOPMENTAL RESOURCE STIMULATION PROGRAMME FOR THE CHILD WITH DOWN SYNDROME YOUNGER THAN 42 MONTHS

I hereby request approval to conduct the above-mentioned research for a postgraduate qualification (PhD) in the School for Allied Health Professions.

The lack of specialised Down syndrome programmes in South Africa made this research a dire need. A specific outcomes-based programme is the answer, as children with Down syndrome have comparable (homogenic) problems and needs. A holistic approach for the management of children with Down syndrome from birth to 42 months of age in the South African context is needed. This lack of information made it a necessity for the researcher to present this population with a specialised programme. The Developmental Resource Stimulation Programme was developed by the researcher, (Russell 2010) and will be investigated in this study. The Developmental Resource Stimulation Programme is a unique occupational therapeutic, child-parent specific, one-on-one integrated programme specifically developed for children with Down syndrome. The purpose of this programme is to offer developmental stimulation to children with Down syndrome.

The Department of Genetics and Paediatrics and Child Health at the School of Medicine refers patients with Down syndrome to the Bloemfontein Child Information Centre.

The protocol will be submitted to the Ethics Committee of the Faculty of Health Sciences for approval.

Written informed consent from the parents of the children with Down syndrome will be requested from the researcher.

I trust that this request will be considered positively.

Yours sincerely

DC RUSSELL
Postgraduate student (PhD)
BLOEMFONTEIN CHILD INFORMATION CENTRE
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH

Appendix B

Inligtingsbrief aan ouers**:**

ONDERSOEK VAN DIE "DEVELOPMENTAL RESOURCE STIMLATION PROGRAMME" VIR DIE KIND MET DOWN SINDROOM JONGER AS 42 MAANDE

Geagte Navorsingsdeelnemer

Ek, Dorothy Russell, gaan navorsing doen om 'n ontwikkelingstimulasieprogram, naamlik die "Developmental Resource Stimulation Programme", wat ek ontwikkel het vir die kind met Downsindroom jonger as 42 maande, te ondersoek. Die navorsing is deel van 'n nagraadse kwalifikasie (PhD) in die Skool vir Aanvullende Gesondheidsberoepe, Departement Arbeidsterapie.

Die rede vir hierdie navorsing is die tekort aan gespesialiseerde Downsindroom-programme in Suid-Afrika. *Aangesien die kinders met Downsindroom homogene probleme en behoeftes het, is 'n uitkomsgebaseerde program die oplossing om hierdie probleem aan te spreek. 'n Holistiese benadering in die hantering van die kinders met Downsindroom vanaf geboorte tot 42 maande in die Suid-Afrikaanse konteks is 'n behoefte. Die gebrek aan inligting het vir die navorser 'n noodsaaklikheid geword om 'n gespesialiseerde program vir hierdie populasie te ontwikkel. Die navorser (Russell 2010) het die "Developmental Resource Stimulation Programme" ontwikkel wat in die studie ondersoek sal word. Die program is 'n unieke arbeidsterapeutiese, kind-ouer-spesifiek, een-tot-een geïntegreerde program wat spesifiek ontwikkel is vir die kind met Downsindroom. Die doel van die program is om ontwikkelingstimulasie vir die kinders met Downsindroom aan te bied.

Die voorlegging van die protokol sal aan die Etiekkomitee van die Fakulteit Gesondheidswetenskappe gedoen word, vir goedkeuring.

Ek nooi u uit om deel te neem aan die navorsingstudie. As ouer van 'n kind met Downsindroom sal van u verwag word om die Bloemfontein Kinderinligtingsentrum elke tweede week vir ses maande te besoek. Elke sessie sal op video opgeneem word om te help met die puntetelling van die data van die stimulasieprogram en sal nie vir enige publikasie gebruik word nie. 'n Voortoets sal bepaal waar in die stimulasieprogram met intervensie begin sal word. Na afloop van ses maande van intervensie sal 'n natoets gedoen word. Hierdie is die eerste navorsing in Suid-Afrika van hierdie aard. Daar is geen risiko indien u deelneem aan die navorsingstudie nie. U en u baba sal vergoed word vir vervoer (taxi-geld) na en van die Kinderinligtingsentrum. Die voordeel om betrokke te wees by die studie is die verbetering van u kind se kwaliteit van ontwikkeling.

Kontakbesonderhede van navorser: DC Russell: 051-4441867/0833755058
Kontakbesonderhede van Sekretariaat van die Etiekkomitee: 051-4052812
Promoter: Dr R van Heerden: 051-4013078

Toestemmingsbrief aan ouers:

Toestemming tot deelname aan navorsing vir ouers van die babas met Downsindroom

Ek,……, gee hiermee my toestemming om deel te neem aan die navorsingsprojek. Ek verstaan dat dit deel uitmaak van ’n studie wat die “Developmental Resource Stimulation Programme (DRSP) ondersoek vir babas met Downsindroom. Die navorsing is deel van ’n nagraadse kwalifikasie (PhD) in die Skool van Aanvullende Gesondheidsberoepe, Departement Arbeidsterapie.

Die rede vir hierdie navorsing is die tekort aan gespesialiseerde Downsindroom-programme in Suid-Afrika. Aangesien die kinders met Downsindroom homogene probleme en behoeftes het, is ’n uitkomsgebaseerde program die oplossing om hierdie probleem aan te spreek. ’n Holistiese benadering in die hantering van die kinders met Downsindroom vanaf geboorte tot 42 maande in die Suid-Afrikaanse konteks is ’n behoefte. Die gebrek aan inligting het vir die navorser ’n noodsaaklikheid geword om ‘n gespesialiseerde program vir hierdie populasie te ontwikkel. Die navorser (Russell 2010) het die “Developmental Resource Stimulation Programme” ontwikkel wat ondersoek sal word in die studie. *Die program is ’n unieke arbeidsterapeutiese, kind-ouer-spesifiek, een-tot-een geïntegreerde program wat spesifiek ontwikkel is vir die kind met Downsindroom. Die doel van die program is om ontwikkelingstimulasie vir kinders met Downsindroom aan te bied.

Ek is ingelig oor die omvang van die navorsing en wat dit behels. Ek is gewillig om die Bloemfontein Kinderinligtingsentrum tweeweekliks vir ’n periode van ses maande te besoek. (Elke sessie sal 50 minute duur). Ek is ingelig dat elke sessie op video opgeneem sal word om te help met die puntetelling van die data van die stimulasieprogram en sal nie vir enige publikasie gebruik word nie. ’n Voortoets sal bepaal waar in die stimulasieprogram met intervensie begin sal word. Ek is bewus daarvan dat daar geen risiko is aan deelname aan die navorsingstudie nie. Ek is verder ingelig dat daar ’n vergoeding in die vorm van vervoer (taxi-geld) na en van die Kinderinligtingsentrum sal wees.

U kan die Sekretariaat van die Etiekkomitee van die Fakulteit Gesondheidswetenskappe, UV by telefoonnommer (051) 4052812 kontak indien u enige vrae het oor u regte as ’n proefpersoon.

U deelname aan hierdie navorsing is vrywillig, en u sal nie gepenaliseer word of voordele verbeur as u weier om deel te neem of besluit om deelname te enige tyd te staak nie.

As u instem om deel te neem, sal ’n ondertekende kopie van hierdie dokument sowel as die deelnemerinligtingsblad, wat ’n geskrewe opsomming van die navorsing is, aan u gegee word.

Die navorsingstudie, insluitende die bogenoemde inligting, is verbaal aan my beskryf. *Ek begryp wat my betrokkenheid by die studie beteken en ek stem vrywillig in om deel te neem.

Ek verstaan dat die inligting wat versamel word vir navorsings doeleindes gebruik gaan word en dat die inligting verkry in ’n professionele vaktydskrif gepubliseer mag word.

_____	_____
Naam van Ouer	Handtekening
_____	_____
Navorser	Datum

Information letter to parents**:**

INVESTIGATION OF THE DEVELOPMENTAL RESOURCE STIMULATION PROGRAMME FOR THE CHILD WITH DOWN SYNDROME YOUNGER THAN 42 MONTHS

Dear Participant

I, Dorothy Russell, will be doing research on the investigation of the Developmental Resource Stimulation Programme for the child with Down syndrome younger than 42 months. This research is a post-graduate qualification (PhD) in the School for Allied Health Professions.

The lack of specialised developmental Down syndrome programmes in South Africa made this research a dire need. A specific outcomes-based programme is the answer, as children with Down syndrome have comparable (homogenic) problems and needs. A holistic approach to the management of children with Down syndrome from birth to 42 months of age in the South African context is needed. This lack of information made it a necessity for the researcher to present this population with a specialised programme. The Developmental Resource Stimulation Programme was developed by the researcher, (Russell 2010) and will be investigated in this study. The Developmental Resource Stimulation Programme is a unique occupational therapeutic, child-parent specific, one-on-one, integrated programme specifically developed for children with Down syndrome. The purpose of this programme is to offer developmental stimulation to children with Down syndrome.

The protocol will be submitted to the Ethics Committee of the Faculty of Health Sciences for approval. Hereby I invite you to participate in this research study. You as the parent of a child with Down syndrome will be expected to visit the Bloemfontein Child Information Centre every second week for the next six months. All the sessions will be videotaped to help with the scoring of the data of the programme. A pre-test will determine at what level of the intervention stimulation programme should be started. The post-test will determine the effect of intervention after six months. This is the first research of this nature in South Africa. There is no risk involved in taking part in this research. Taxi fare for mother and baby will be the compensation to be part of the study. The benefit of being in the study will be enhancement in the quality of the development of your child.

Contact details of researcher: DC Russell: 051-4441867/0833755058
Contact details of REC Secretariat: 051-4052812
Promoter: Dr R van Heerden: 051-4013078

Consent parents:

Consent to participate in research for the parents of babies with Down syndrome

I, hereby give my consent to participate in the research project. I understand that it forms part of a study to investigate the Developmental Resource Stimulation Programme (DRSP) for babies with Down syndrome. This research is a post-graduate qualification (PhD) in the School for Allied Health Professions.

The lack of specialised developmental Down syndrome programmes in South Africa made this research a dire need. A specific outcomes-based programme is the answer, as children with Down syndrome have comparable (homogenic) problems and needs. A holistic approach to the management of children with Down syndrome from birth to 42 months of age in the South African context is needed. This lack of information made it a necessity for the researcher to present this population with a specialised programme. The Developmental Resource Stimulation Programme was developed by the researcher, (Russell 2010) and will be investigated in this study. The Developmental Resource Stimulation Programme is a unique occupational therapeutic, child-parent specific, one-on-one integrated programme specifically developed for children with Down syndrome. The purpose of this programme is to offer developmental stimulation to children with Down syndrome.

I am informed concerning the nature of the research and what it involves. I am prepared to visit the Bloemfontein Child Information Centre every second week for the next six months. (Each session will last 50 minutes.) I am informed that all the sessions will be videotaped to help with the scoring of the data of the programme. A pre-test will determine at what level of the intervention stimulation programme should be started. The post-test will determine the effect of intervention after 6 months. I am aware that there is no risk involved in taking part in this research. I am further informed that there will be compensation towards the taxi fare for mother and baby to be part of the study.

You may contact the Secretariat of the Ethics Committee of the Faculty of Health Sciences, UFS at telephone number (051) 4052812 if you have questions about you and your baby's rights as a research subject.

Your participation in this research is voluntary, and you will not be penalised or lose benefits if you refuse to participate or decide to terminate/withdraw from participation at any time.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information, has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate.

I understand that the information obtained will only be used for research purposes and that it might be published in a professional journal.

_____	_____
Name of Parent	Signature
_____	_____
Researcher	Date

Information letter in Sesotho to parents:

PATLISISO YA LENANEO LA MEHLODI YA NTSHETSOPELE YA HLABOLLO BAKENG SA NGWANA YA NANG LE DOWN SYNDROME YA KA TLASA DIKGWEDI TSE 42

Monkakarolo ya ratehang

Nna, Dorothy Russell, ke tla be ke etsa dipatlisiso ke batlisisa Lenaneo la Mehlodi ya Ntshetsopele ya Hlabollo bakeng sa ngwana ya nang le down syndrome ya ka tlasa dikgwedi tse 42. Dipatlisiso tsena ke boithuto ba kgau ya yunivesithi ya bongaka (PhD) Sekolong sa Diprofeshene tse Kopantsweng tsa Bophelo.

Tlhokeho ya maneneo a ntshetsopele a ikgethileng a Down syndrome mona Afrika Borwa ke yona e entseng hore boithuto bona bo etswe. Lenaneo le itshetlehileng ka diphetho ke lona karabo, hobane bana ba nang le Down Syndrome ba na le mathata le ditlhoko tse (tshwanang) tse bapisehang. Katamelo e feletseng bakeng sa ho laola bana ba nang le Down Syndrome ho tloha tswalong ho ya dikgweding tse 42 e a hlokeha maemong a Afrika Borwa. Tlhokeho ena e bakile hore mmatlisisi a rale lenaneo lena le ikgethileng bakeng sa setjhaba. Lenaneo la Mehlodi ya Ntshetsopele ya Hlabollo le ile la kgakolwa ke mmatlisisi (Russell 2010) mme le tla batlisiswa ho ya pele ka hara boithuto bona. Lenaneo la Mehlodi ya Ntshetsopele ya Hlabollo ke lenaneo le ikgethileng le kopantseng tsa tshebetso ya pholo, le shebanang le ngwana le mme, ka bonngwe ka bonngwe le radilweng ka ho ikgetha bakeng sa bana ba nang le Down Syndrome. Sepheo sa lenaneo lena ke ho fana ke ho fana ka hlabollo e tswelang pele baneng ba nang le Down Syndrome.

Repoto e tla fuwa Komiti ya tsa Boitshwaro ya Fakhalthi ya Mahlale a Bophelo bakeng sa ho tjhaellwa monwana.

Ka hook e o memela ho nka karolo boithutong bona ba dipatlisiso. Wena jwaloka motswadi wa ngwana ya nang le Down Syndrome ho lebeletswe hore o etele Bloemfontein Child Information Centre beke e nngwe le e nngwe ya bobedi ya kgwedi bakeng sa kgwedi tse 6. Dikopano kaofela di tla nkwa ka video ho thusa ho fana ka matshwao tlhahisoleseding e tla beng e fumanwe lenaneong lena. Teko ya pele ho dipatlisiso e tla lekanya hore na lenaneo la hlabollo le qalwe bohatong bofe. Teko e tla etswa ka morao e tla hlahisa kamora dikgwedi tse tsheletseng tsa haesale ho qalwa hore ditlamorao ke dife. Tsena ke dipatlisiso tsa pele tsa mofuta ona mona Afrika Borwa. Ha ho kotsi efe kapa efe ha o nka karolo boithutong bona ba dipatlisiso. Tefello ya taxi bakeng sa mme le lesea e tla ba tse lefellwang jwalo ka karolo ya boithuto. Molemo wa ho ba boithutong o tla bonahala ka boleng ba bophelo ha ngwana a tswelapele.

Dinomoro tsa mmatlisisi: DC Russell: 051-4441867/0833755058
Dinomoro tsa Mongodi wa Komiti ya Boitshwaro: 051-4052812
Moetapele: Dr R van Heerden: 051-4013078

Consent in Sesotho to parents:

Foromo ya tumelo ho tswa ho Batswadi ba bana ba nang le Down syndrome

Nna ……., ke fana ka tumelo ya hore ke tla nka karolo projekeng ya dipatlisiso. Ke utlwisisa hore e bopa karolo ya thuto ya ho batlisisa Lenaneo La Ntshetsopele ya Mohlodi wa Hlabollo bakeng sa bana ba nang le Down Syndome. Dipatlisiso tsena ke boithuto ba kgau ya yunivesithi ya bongaka (PhD) Sekolong sa Diprofeshene tse Kopantsweng tsa Bophelo.

Tlhokeho ya maneneo a ntshetsopele a ikgethileng a Down syndrome mona Afrika Borwa ke yona e entseng hore boithuto bona bo etswe. Lenaneo le itshetlehileng ka diphetho ke lona karabo, hobane bana ba nang le Down Syndrome ba na le mathata le ditlhoko tse (tshwanang) tse bapisehang. Katamelo e feletseng bakeng sa ho laola bana ba nang le Down Syndrome ho tloha tswalong ho ya dikgweding tse 42 e a hlokeha maemong a Afrika Borwa. Tlhokeho ena e bakile hore mmatlisisi a rale lenaneo lena le ikgethileng bakeng sa setjhaba. Lenaneo la Mehlodi ya Ntshetsopele ya Hlabollo le ile la kgakolwa ke mmatlisisi (Russell 2010) mme le tla batlisiswa ho ya pele ka hara boithuto bona. Lenaneo la Mehlodi ya Ntshetsopele ya Hlabollo ke lenaneo le ikgethileng le kopantseng tsa tshebetso ya pholo, le shebanang le ngwana le mme, ka bonngwe ka bonngwe le radilweng ka ho ikgetha bakeng sa bana ba nang le Down Syndrome. Sepheo sa lenaneo lena ke ho fana ke ho fana ka hlabollo e tswelang pele baneng ba nang le Down Syndrome.

Ke hlaloseditswe ka karolo ya patlisiso ena le hore ebile e akaretsa eng. Ke ikemiseditse ho etela Bloemfontein Child Information Centre beke e nngwe le e nngwe ya bobedi ya kgwedi, dikgwedi tse tsheletseng tse tlang. (Ketelo ka nngwe e tla ba metsotso e 50). Dikopano kaofela di tla nkwa ka video ho thusa ho fana ka matshwao tlhahisoleseding e tla beng e fumanwe lenaneong lena. Teko ya pele ho dipatlisiso e tla lekanya hore na lenaneo la hlabollo le qalwe bohatong bofe. Teko e tla etswa ka morao e tla hlahisa kamora dikgwedi tse tsheletseng tsa haesale ho qalwa hore ditlamorao ke dife. Ha ho kotsi efe kapa efe ha o nka karolo boithutong bona ba dipatlisiso. Tefello ya taxi bakeng sa mme le lesea e tla ba tse lefellwang jwalo ka karolo ya boithuto.

O ka ikgokahanya le Mongodi wa Komiti ya tsa Boitshwaro ya Fakhalthi ya Mahlale a Bophelo, UFS nomorong ya mohala ya (051) 4052812 ha o na le dipotso ka ha ditokelo tsa hao le tsa lesea la hao jwalo ka ha le tla ba bahlahlobiwa.

Ho nka karolo ha hao dipatlisisong tsena ke ka boithaopo, mme o k eke wa lefiswa kapa wa tingwa menyetla ha o ka hana ho nka karolo kapa wa etsa qeto ya ho emisa/ho ikgulela morao ka nako efe kapa efe.

Ha o dumela ho nka karolo, o tla fuwa khopi e saennweng ya tokomane ena le leqephe la tlhahisoleseding la monkakarolo, e leng kgutsufatso e ngotsweng ya dipatlisiso.

Boithuto bona ba dipatlisiso, ho kenyeleditswe tlhahisoleseding e ka hodimo ke bo hlaloseditswe ka molomo. Ke a utlwisisa hore seabo sa ka se bolelang boithutong bona mme ke dumela ka boithaopo ho nka karolo.

Ke utlwisisa hore tlhahisoleseding e tla fumanwa, e tla sebediswa feela bakeng sa dipatlisiso le hore e ka nna ya phatlalatswa ka hara buka ya diphatlalatso ya dipatlisiso.

_____ _____

Lebitso la Motswadi Tshaeno

_____ _____

Mmatlisisi Letsatsi

Appendix C

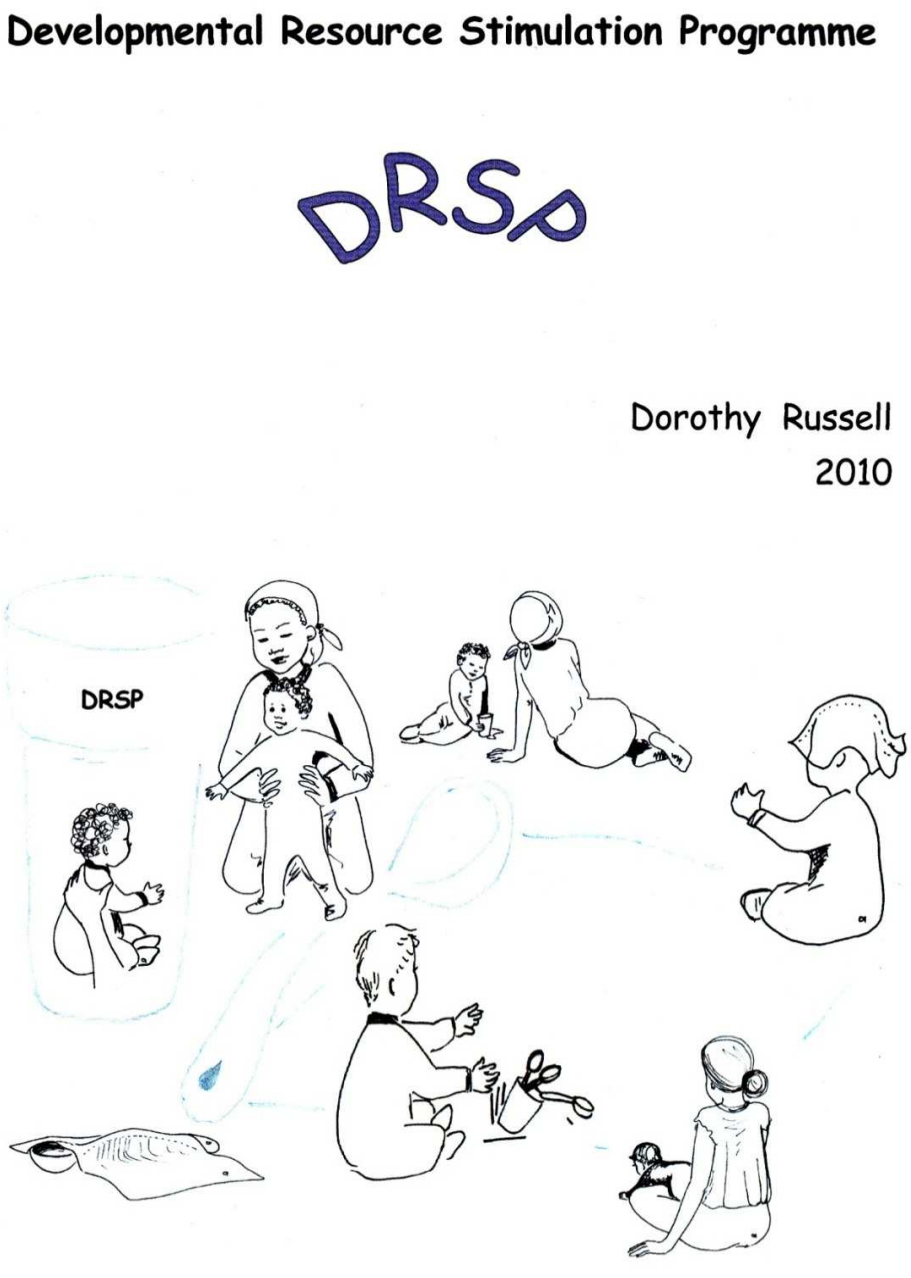

Figure C.1 DRSP Front page

Developmental Resource Stimulation Programme (DRSP): CONTENTS

0 – 3 Months

3 - 6 Months

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Figure C.2: DRSP Index page 1

Developmental Resource Stimulation Programme (DRSP): CONTENTS

6 - 9 Months

9 - 12 Months

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Figure C.3: DRSP Index page 2

Developmental Resource Stimulation Programme (DRSP): CONTENTS

12 - 18 Months

18 - 24 Months

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Figure C.4: DRSP Index page 3

Developmental Resource Stimulation Programme (DRSP): CONTENTS

24 - 42 Months

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Figure C.5: DRSP Index page 4

Figure C.6: DRSP page 11

Developmental Resource Stimulation Programme (DRSP) 0 – 3 Months

Activity	Position	Description	Outcomes	Materials
9 "Armpit Roller"	Tummy/Prone 	Mother makes a roller (cloth/baby blanket). Mother puts baby on top of the roller and baby bears his weight on his elbows. Hit the teaspoon against the mug to get attention.	Motor stimulation: head control, weight bearing on elbows Sensory stimulation: pro-prioception, touch Visual stimulation Auditory stimulation	Mug Teaspoons Cloth
Tip		Another method of holding a baby. Mother position her hands on baby's back and front of chest. Mother's hands are open, palms against baby's body. 	Motor stimulation: head control, sitting position	

Figure C:7: DRSP page 13

Developmental Resource Stimulation Programme (DRSP) 0 – 3 Months

Activity	Position	Description	Outcomes	Materials
6 "Cover-the-Face"	Back/Supine 	Mother puts open cloth on baby's face. She quickly removes it while talking to and smiling at him. Repeat several times. Mother says for instance: "You are beautiful and Mommy loves you."	Sensory stimulation – touch Auditory stimulation Play stimulation – joy	Cloth
7 "Mug in Middle"	Back/Supine 	Put mug in midline of baby. Take baby's hands and mother's hands over baby's hands around the mug while talking to him. Use sounds like ("a-a") to attract his attention. If the baby makes a specific sound – repeat his sounds.	Motor stimulation Sensory stimulation – touch Visual stimulation Auditory stimulation Speech stimulation	Mug
8 "Spoon watching"	Tummy/Prone 	Mother places the spoons in front of baby and encourages him to lift his head to see it. She bangs the spoons on the floor or table to get baby's attention.	Motor stimulation - head control Visual stimulation Auditory stimulation	Spoons

Figure C.8: DRSP page 15

Developmental Resource Stimulation Programme (DRSP) 3 – 6 Months

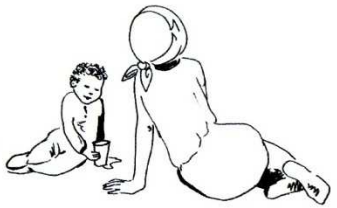
Activity	Position	Description	Outcomes	Materials
2 "Side-sitting"		Encourage baby to play with mugs on the side opposite to his feet. His hand and arm must cross the midline in order to reach the mug. Do this activity to the other side as well. Repeat 5 times. Keep on talking to baby and verbalize the actions.	Postural control Rotation Weight bearing on extended arms	Mugs
Tip		Place the baby in a supported position with his back against mother while on the floor. Use pressure on extended arms onto baby's upper legs. Mother may do this as often as possible.	Arm support	None
Tip		Place baby in supported position with his back against mother while on the floor. Use pressure on extended arms through the shoulders. Mother may do this as often as she wishes. Mother may also use her upper legs as a support.	Arm support	None

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Figure C.9: DRSP page 18

Developmental Resource Stimulation Programme (DRSP) 3 – 6 Months

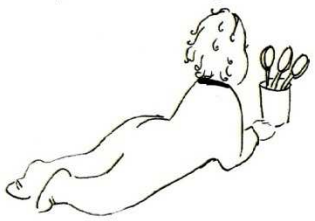
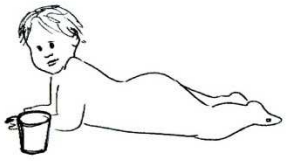
Activity	Position	Description	Outcomes	Materials
7 "Spoons in a Mug"	Tummy/Prone/Sitting 	Mother puts 2 or 3 spoons in a mug and shakes it at baby's one side without him seeing it. When baby hears the sound he should turn his head to the noise. Wait for baby's reaction and response.	Motor stimulation - head control, weight sifting, balance, equilibrium reactions Auditory stimulation	Mug Spoons
8 "Where's the Mug?"	Tummy/Prone  	Mother puts mugs in front and to the sides of baby. Baby reaches out to mugs while mother is singing to baby. (*see Appendix*) Mother puts a mug on left side of baby. Baby leans on left arm and reaches for mug with his right hand. Repeat above activity to right side. Mother talks to baby – e.g. "Where is the mug?" Mother repeats any sounds of the baby.	Motor stimulation: head control, reach, balance, hand-eye co-ordination, weight bearing and shifting, balance and equilibrium reactions Sensory stimulation touch, proprioception Auditory stimulation Visual stimulation Speech stimulation	Mugs

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Figure C.10: DRSP page 24

Developmental Resource Stimulation Programme (DRSP) 6 - 9 Months

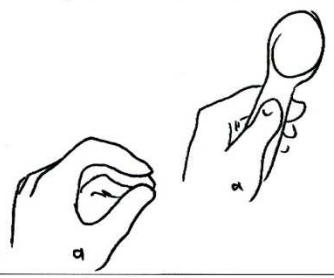
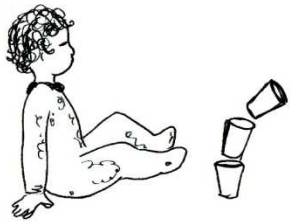
Activity	Position	Description	Outcomes	Materials
3 "Spoon Grasps"	Sitting/("Ankle chair") 	Mother puts spoons in front of baby. Baby tries to pick them up with his fingers and palm or his thumb and two fingers. If baby drops the spoon he may start to look for it.	Motor stimulation: sitting balance, hand function, eye-hand co-ordination Sensory stimulation: touch Visual stimulation	Spoons
4 "Mug Stacking"	Sitting/Mothers knee 	Mother stacks mugs in front of baby. She encourages baby to imitate her as she knocks them over. She says "boom". Mother puts mugs in front of baby. She hits the mugs like a drum with her hand. He will imitate action of mother. She makes appropriate sounds e.g. "boom, boom".	Motor stimulation: sitting balance, hand-eye and hand-hand co-ordination Sensory stimulation: touch Visual stimulation Auditory stimulation Speech stimulation	Mugs

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Figure C.11: DRSP page 26

Developmental Resource Stimulation Programme (DRSP) 6 - 9 Months

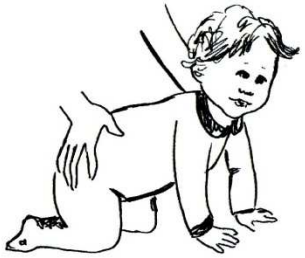
Activity	Position	Description	Outcomes	Materials
7 "4 Foot"	Side sitting to four foot kneeling 	Mother helps baby from side sitting position to four-foot-kneeling by supporting his shoulder and hip and helps him onto a four-foot kneeling position again. Mother supports baby again on his one shoulder and opposite hip in side sitting and moves slowly to four-foot kneeling position again. 	Motor stimulation: balance, four-foot kneeling, weight bearing, weight shift, eye-hand co-ordination Sensory stimulation: touch Auditory stimulation Visual stimulation Speech stimulation	None

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Figure C.12: DRSP page 29

Developmental Resource Stimulation Programme (DRSP) 9 - 12 Months

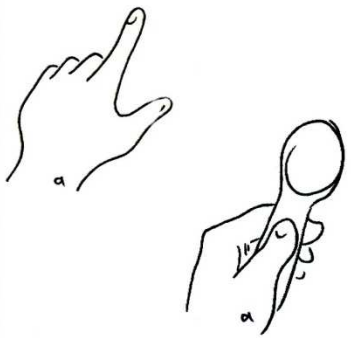
Activity	Position	Description	Outcomes	Materials
1 "Where are the Spoons?"	Sitting 	Mother puts spoons in front of baby. She asks: "Where's the spoon?" Baby points to spoon with his index finger (2nd finger). At first he holds it between two fingers and thumb, then between side of his index finger and thumb and finally between tips of his index finger and thumb (pincer grip). Baby will start to release spoon voluntarily.	Motor stimulation: balance, hand function, co-ordination Visual stimulation Sensory stimulation: touch Auditory stimulation Speech stimulation Cognitive stimulation: concentration Activities of daily living	Spoons
2 "Tip the Mug"	Sitting 	Mother puts spoons in mug and tips it over again while baby is looking. She puts spoons back into the mug. She encourages baby to take spoons out. Mother talks to baby e.g. "where is the spoon, mug" etc. Repeat 5 times. Baby may take a spoon out.	Motor stimulation: balance, hand function, eye-hand co-ordination Sensory stimulation: touch Visual stimulation Auditory stimulation Speech stimulation	Mug Spoons

Figure C.13: DRSP page 32

Developmental Resource Stimulation Programme (DRSP) 9 - 12 Months

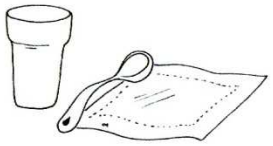
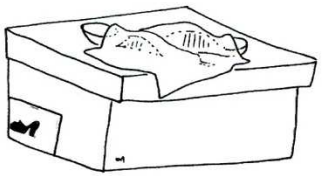
Activity	Position	Description	Outcomes	Materials
6 "Words and Concepts"	Lying on tummy/sitting or kneeling 	Mother puts the mug, spoon and cloth in front of baby. She points at each object and names it e.g. "This is a mug, I'm *drinking* out of a mug" and she demonstrates it. "This is a spoon, I'm *eating* with a spoon" and she demonstrates. "This is a cloth. I'm *washing* my face" and she demonstrates. Baby may use gestures as well as sounds.	Motor stimulation: balance, hand function, co-ordination Sensory stimulation Visual stimulation Auditory stimulation Perceptual stimulation: body image Speech stimulation: communication ADL(Activities of daily living): washing, eating, drinking	Mug Spoon Cloth
7 "Object Permanency"	Kneeling in front of a box/step/big stone 	Mother puts the spoons on top of box/step or big stone. Mother covers spoons with cloth and asks: "Where are the spoons?" and helps baby to find the spoons. Repeat as many times as wishes.	Motor stimulation: balance(kneeling), hand-eye co-ordination, hand function Sensory stimulation: touch Visual stimulation Auditory stimulation Cognitive stimulation: visual memory	Spoons Cloth

Figure C.14: DRSP page 37

Developmental Resource Stimulation Programme (DRSP) 12 - 18 Months

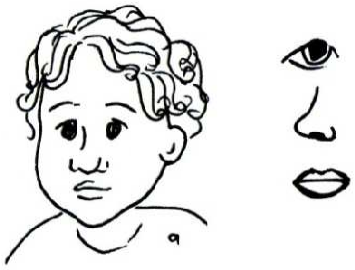
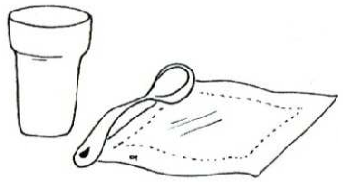
Activity	Position	Description	Outcomes	Materials
5 'Face'	Sitting or kneeling or standing in front of a container, box etc. 	Mother puts cloth on baby's head. Baby tries to remove cloth. Mother asks: "Where's Johnny's head? Where's mommy's head?" Mother asks baby to touch his nose, hair etc. If he does not react, take his hand and help him to touch these different body parts.	Motor stimulation: balance kneeling, standing, hand function, co-ordination Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: body image position in space	Cloth
6 'Background-Foreground'	Sitting/standing 	Mother encourages baby to pick up 2 objects and name them e.g. "give me the mug, spoon, cloth". Mother may sing a song. "... (childs name) is so wonderful, wonderful, wonderful."*(see Appendix)*	Motor stimulation: hand function, eye-hand co-ordination Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: Background-foreground	Mugs Teaspoons Cloth

Figure C.15: DRSP page 39

Developmental Resource Stimulation Programme (DRSP) 12 - 18 Months

Activity	Position	Description	Outcomes	Materials
Tip		Support baby against your body; assist him at the hips and/or under his arms. 'Kneel walk' with baby. Transfer his weight from side to side. 	Standing balance Walking	None

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Figure C.16: DRSP page 40

Developmental Resource Stimulation Programme (DRSP) 18 - 24 Months

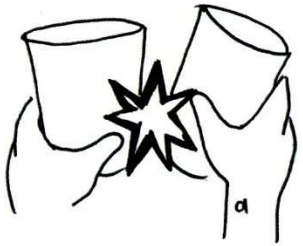
Activity	Position	Description	Outcomes	Materials
1 "Three Towers"	Sitting/Squatting position 	Child builds 3 mugs on top of each other. Breaks it down and rebuilds it. Later on the child may build up to 6 mugs high. (On top or inside)	Motor stimulation: balance in sitting/ squatting position, hand function, eye-hand co-ordination Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: position in space	Mugs
2 "Bang - Clang!"	Sitting/Squatting position 	Mother puts 2 mugs and 2 spoons in front of child. She encourages child to bang mugs together, and then the spoons. If necessary, mother helps child through these actions. She talks to child: "It is *my* mug or spoon." Child tries to imitate the words.	Motor stimulation: balance in kneeling, standing, hand function, eye-hand, hand-hand co-ordination Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: position in space	Mug Spoons

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Figure C.17: DRSP page 42

Developmental Resource Stimulation Programme (DRSP) 18 - 24 Months

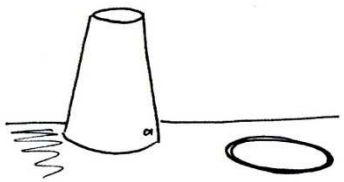
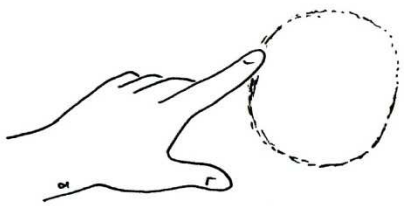
Activity	Position	Description	Outcomes	Materials
5 "This is Round"	Sitting/squatting 	Mother and child sit in front of wet sand. Mother demonstrates how to make a circle in the sand with the open side of the mug. Mother points with her finger to the round shape and says "It is round." Child imitates.	Motor stimulation: eye-hand co-ordination, hand function Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: shape	Mug Sand
6 "Sand-Circle"	Sitting/squatting 	She outlines the circle with her finger on the sand while saying: "It looks like a *ball*." She encourages child to say "*ball*".	Motor stimulation: balance in standing/squatting, eye-hand co-ordination Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: shape	Sand in baking tin or other kind of flat container

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Figure C.18: DRSP page 48

Developmental Resource Stimulation Programme (DRSP) 24 - 42 Months

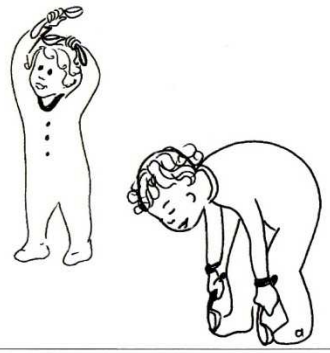
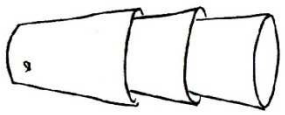
Activity	Position	Description	Outcomes	Materials
9 "Top-to-Toe"	Standing 	Child holds a spoon in each hand. (then cloth) Mother asks him to touch his head (top) and then his toes (bottom). She talks the whole time while the child is doing the activity. Repeat. Song: "Touch your *head, shoulder, knees* and *toes* holding cloth. *(see Appendix)*	Motor stimulation: eye-hand co-ordination, hand function Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: body image, laterality, position in space	Spoon Cloth
10 "Train-Mugs"	Sitting 	Mother builds a train with mugs (puts mugs into each other). Child imitates. She makes the sound of a train e.g. "chook, chook". Mother sings a song. *(see Appendix)*	Motor stimulation: eye-hand/hand-hand co-ordination, bilateral hand function Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: position in space	Mugs

Figure C.19: DRSP page 50

Developmental Resource Stimulation Programme (DRSP) 24 - 42 Months

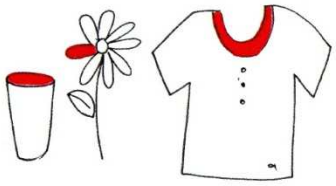
Activity	Position	Description	Outcomes	Materials
COLOUR **13** "Colors"	Sitting 	Mother shows child the red mug and encourages child to look for a matching colour in the room or outside and names the colour. She encourages the child to match the red mug with the other red object. She repeats the activity with other colours too and naming colours.	Motor stimulation Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: colour	Mugs
14 "Body Parts"	Sitting/standing 	Mother baths her child. She washes his face, his toes, his back, tummy etc. She demonstrates. After her mother has washed the child, the child has a turn to wash mother/ brother/sister/doll. Ask questions about body parts and their functions.	Motor stimulation: eye-hand co-ordination, hand function Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Perceptual stimulation: body image	Cloth

Figure C.20: DRSP page 54

Developmental Resource Stimulation Programme (DRSP) 24 - 42 Months

Activity	Position	Description	Outcomes	Materials
21 "Role-Play"	Sitting 	At this stage the child enjoys listening to stories, rhymes and music. Imaginary play begins e.g. tea party or house-house. Role play: "Oh, your food is delicious, may I have some please? Mommy helps to get the food. Do you know who let the maize grow? Answer for example may be: "The earth and farmers are wonderful and lets it happen." Sing a song for instance: "Life is so wonderful, (x3). Mommy loves you so much". *(see Appendix)*	Sensory stimulation Visual stimulation Auditory stimulation Speech stimulation Play stimulation	Mug Spoons

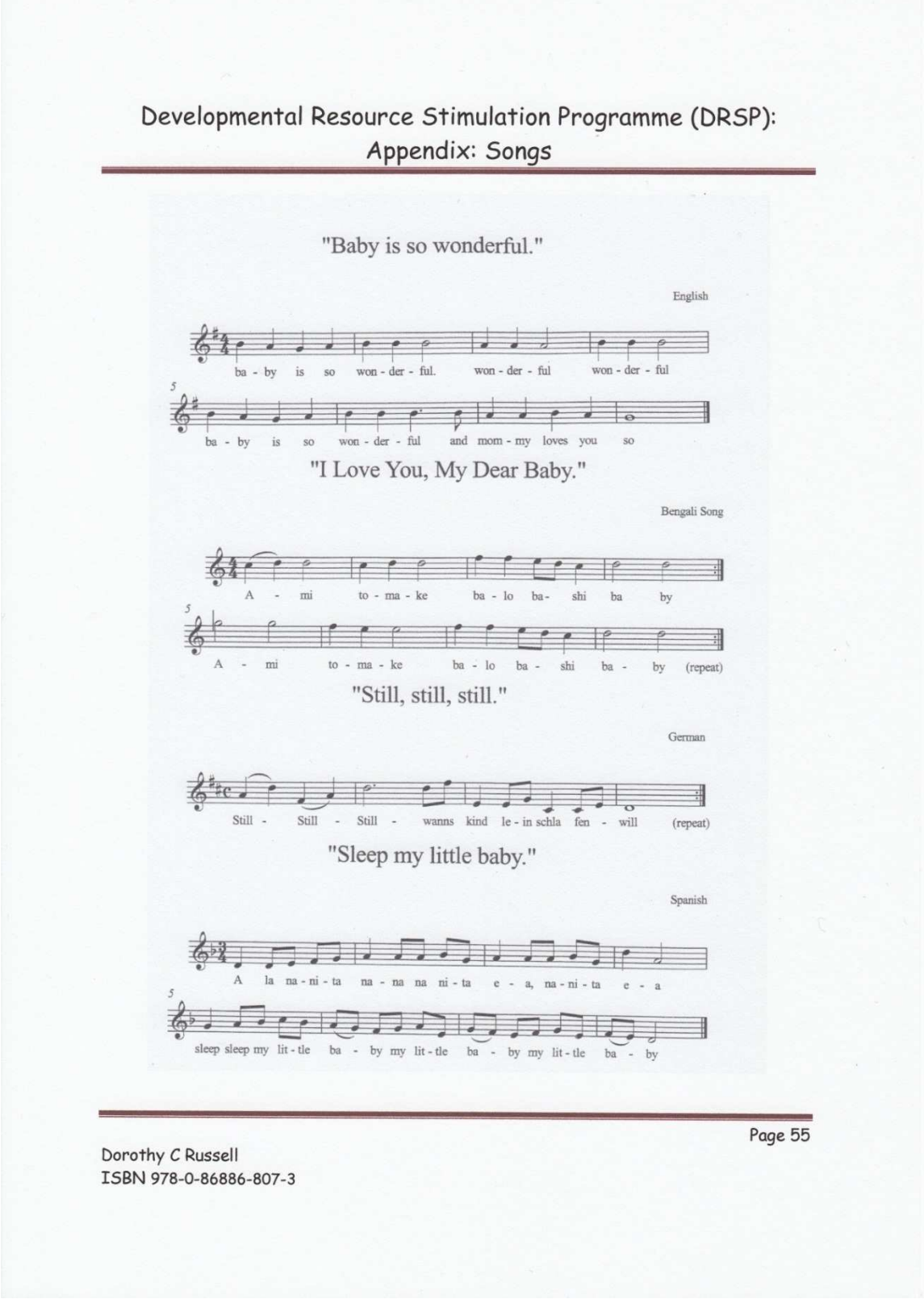


Figure C.21: DRSP Appendix

Appendix D

Table D.1: DRSP 0–3 months (compiled by researcher)

ICF (Kramer & Hinojosa 2010:34)	**DRSP Age group (Russell 2010:8-12)**	**OTPF** (Kramer & Hinojosa 2010:34)
Activities and Participation	**0-3 Months (10 Activities & 2 Tip's)**	**Areas of Occupation (Life Areas)**
Learning and applying knowledge	Picking up your baby; Carrying your baby; Mouth closure; Mommy Talks; "90 Degree Follow"; "Mug in Middle"; "Spoon watching"; Different ways of rolling; "Armpit roller"	Education
General tasks and demand (daily routine)	Picking up your baby; Carrying your baby; Mouth closure; Holding your baby; different ways of rolling	Instrumental activities of daily living
Mobility	Picking up your baby; Carrying your baby; Mouth closure; "Mug in Middle"; "Spoon watching"; Different ways of rolling; "Armpit roller"; Holding baby	*Performance skills* *Activity demands*
Self-care	Mouth closure; "Mug in Middle"	Activities of daily living
Interpersonal interactions and relationships	Mommy talks; "Hello, Mommy loves you"; "Cover-the-Face"	Social participation
Communication	Mommy Talks; "Hello, Mommy loves you"; "Mug in Middle"	
Community, social and civic life (play)	"Cover-the-Face"; "Hello, Mommy loves you"	
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	"90 Degree Follow"; "Mug in Middle"; "Spoon watching"	*Client factor*
Sensory	Mouth closure; "90 Degree Follow"; "Cover-the-Face"; "Spoon watching"; Different ways of rolling; "Armpit roller"	
Neuro-musculoskeletal and movement-related	Picking up your baby; Carrying your baby; Mouth closure; "Mug in Middle"; "Spoon watching"; Different ways of rolling; "Armpit roller"	*Performance skills* *Activity demands* *Performance patterns*
Voice and speech	"Mommy Talks"; "Hello, Mommy loves you"; "Cover-the-Face"	
Contextual Factors		**Context**
Support and relationships	Mouth closure; Holding baby	Physical, Personal
Attitudes	"Mommy Talks"; "Hello, Mommy loves you"; "Cover-the-Face"	Cultural, Social
Services, systems, and policies	BCIC - service	Cultural, Social, Personal

Table D.2: DRSP 3–6 months (compiled by researcher)

ICF	DRSP Age group (Russell 2010:13-21)	OTPF
Activities and Participation	**3 – 6 Months (15 Activities & 1 Tip)**	**Life Areas (Occupations)**
Learning and applying knowledge	Different ways of rolling; "Side-sitting"; Arm support Tips; 'Hands to Midline"; "Mother's Face"; Supported sitting on floor"; "Spoons in a Mug"; "Where's the Mug?" "Cloth Ball; "Mug Tower; "Rock the Spoon"; Spoon Sequence"	Education
General tasks and demand (daily routine)	Different ways of rolling; "Side-sitting";Arm support Tips; Supported sitting on floor"	Instrumental activities of daily living
Mobility	Different ways of rolling; "Side-sitting"; Arm support Tips; 'Hands to Midline"; Supported sitting on floor" "Where's the Mug?"; "Cloth Ball"; "Mug Tower"; "Rock the Spoon"; "Spoon Sequence"	*Performance skills* *Activitiy demands*
Interpersonal interactions and relationships	"Hands to Midline"; "Where's the Mug?"; "Mug Tower"; "180 Degree Follow"; "Wha-Wha Sounds"	Social participation
Communication	'Hands to Midline"; "Where's the Mug?" ; "Cloth Ball"; "Mug Tower"; "180 Degree Follow"; "Wha-Wha Sounds"; "Rock the Spoon"; "Spoon Sequence"	
Community, social and civic life (play)	'Hands to Midline"; "Cover-the-Face"; Mother's Face"; "Where's the Mug?" "Cloth Ball"; "Mug Tower"; "Rock the Spoon"; "Spoon Sequence"	
Self-care	"Hands to Midline"	Activities of daily living
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	"Hands to Midline"; "Mother's Face'; "Spoons in a Mug"; "Where's the Mug?"; "Cloth Ball"; "Mug Tower"; "180 Degree Follow"	*Client factor*
Sensory	Different ways of rolling; "Side-sitting"; Arm support Tips; 'Hands to Midline"; "Cover-the-Face"; "Mother's Face Supported sitting on floor";"Spoons in a Mug"; "Where's the Mug?"; "Cloth Ball"; "Mug Tower"; "180 Degree Follow"; "Wha-Wha Sounds"; "Rock the Spoon"; "Spoon Sequence"	
Neuro-musculoskeletal and movement-related	Different ways of rolling; "Side-sitting"; Arm support Tips; 'Hands to Midline" Supported sitting on floor"; "Spoons in a Mug"; "Where's the Mug?"; "Cloth Ball"; "Mug Tower"; "Rock the Spoon"; "Spoon Sequence"	*Performance skills* *Performance patterns*
Voice and speech	"Mother's Face", "Where's the Mug?", "Wha-Wha sounds"	
Contextual Factors		**Context**
Support and relationships	"Mother's Face"; "Supported sitting on floor"; "Leg Roller"	Physical, Personal
Attitudes	Arm support Tips; "Mother's Face"; "Supported sitting on floor"; "Leg Roller"; "Wha-Wha Sounds"	Cultural, Personal, Social
Services, systems, and policies	BCIC - service	Personal, Cultural, Social

Table D.3: DRSP 6–9 months (compiled by researcher)

ICF	DRSP Age group (Russell 2010:22-27)	OTPF
Activities and Participation	**6-9 Months (9 Activities & 1 Tip)**	**Areas of Occupation (Life Areas)**
Learning and applying knowledge	"Midline Copying"; "Babies Name"; "Spoon grasps"; "Mug Stacking"; "Spoon Transfers"; "Look for Spoon"; "4 Foot"; "On The Move" & Tip; "Parachute"	Education
Major life areas	"Look for Spoon"	
General tasks and demand (daily routine)	"Babies Name	*Activity demands*
Mobility	"Midline Copying"; "Babies name"; "Spoon grasps"; "Mug Stacking"; "Spoon Transfers"; "Look for Spoon"; "4 Foot"; "On The Move" & Tip; "Parachute"	*Performance skills* *Activity demands*
Interpersonal interactions and relationships	"Babies Name"; "Look for Spoon"	Social participation
Communication	"Babies Name"; "Mug Stacking"; "Spoon transfers"; "Look for Spoon"	
Community, social and civic life (play)	"Mug Stacking"	
Self-care	"Midline Copying"; "Spoon Transfers"	Activity of daily living
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	"Midline Copying"; "Babies Name"; "Mug Stacking"; "Look for Spoon"	*Client factor*
Sensory	"Midline Copying"; "Babies Name"; "Spoon grasps"; "Mug Stacking"; "Spoon Transfers"; "Look for Spoon"; "4 Foot"; "On The Move" & Tip; "Parachute"	
Neuro-musculoskeletal and movement-related	"Midline Copying"; "Babies Name"; "Spoon grasps"; "Mug Stacking"; "Spoon Transfers"; "Look for Spoon"; "4 Foot"; "On The Move" & Tip; "Parachute"	*Performance skills*
Contextual Factors		**Context**
Support and relationships	"Babies Name"	Personal
Attitudes	"Babies Name"; "4 Foot"; "On The Move" & Tip	Cultural, Social
Services, systems, and policies	BCIC - service	Cultural, Social, Personal

Table D.4: DRSP 9–12 months (compiled by researcher)

ICF	DRSP Age group (Russell 2010:28-33)	OTPF
Activities and Participation	**9 – 12 Months (9 Activities & 1 Tip)**	**Areas of Occupation (Life Areas)**
Learning and applying knowledge	"Where are the Spoons?"; "Tip the Mug"; "Where's Mommy?"; "Mugs in Water", "Cloth in Water"& Tip; "Words and Concepts"; "Object Permanency"; "Ta-Ta"; Tip	Education
Major life areas	"Words and Concepts"; "Object Permanency"	
Domestic life	"Where are the Spoons?"; "Words and Concepts"	
General tasks and demand (daily routine)	"Mugs in Water"; "Cloth in Water"; Tip-bath; "Words and Concepts"	Activities of daily living Instrumental activities of daily living
Mobility	"Where are the Spoons?"; "Tip the Mug"; "Where's Mommy?"; "Mugs in Water", "Cloth in Water" & Tip; "Words and Concepts"; "Object Permanency"; "Ta-Ta"; Tip	*Performance skills* *Activity demands*
Interpersonal interactions and relationships	"Where are the Spoons?"; Tip-bath; "Words and Concepts"; "Ta-Ta"	Social participation
Communication	Where are the Spoons?"; "Tip the Mug"; "Where's Mommy?"; "Mugs in Water", "Cloth in Water" & Tip; "Words and Concepts"; "Object Permanency"; "Ta-Ta"; Tip	
Community, social and civic life (play)	"Where's Mommy?"; "Mugs in Water"; ""Cloth in Water"	
Self-care	"Mugs in Water"; "Cloth in Water"; Tip-bath; "Words and Concepts"	Activities of daily living
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	Mugs in Water"; "Cloth in Water"; "Words and Concepts"; "Object Permanency"	*Client factor*
Sensory	"Where are the Spoons?"; "Tip the Mug"; "Where's Mommy?"; "Mugs in Water", "Cloth in Water" & Tip; "Words and Concepts"; "Object Permanency"; "Ta-Ta"; Tip	
Neuro-musculoskeletal and movement-related	"Where are the Spoons?"; "Tip the Mug"; "Where's Mommy?"; "Mugs in Water", "Cloth in Water" & Tip; "Words and Concepts"; "Object Permanency"; "Ta-Ta"; Tip	*Performance skills* *Performance patterns*
Contextual Factors		**Context**
Support and relationships	"Where's Mommy?"; Tip-bath	Physical, Personal
Attitudes	"Ta-Ta"; Kneeling-Tip	Cultural, Social
Services, systems, and policies	BCIC - service	Cultural, Social, Personal

Table D.5: DRSP 12–18 months (compiled by researcher)

ICF	DRSP Age group (Russell 2010:34-38)	OTPF
Activities and Participation	**12 – 18 Months (8 Activities & 1 Tip)**	**Areas of Occupation (Life Areas)**
Learning and applying knowledge	"On Top"; "Put Spoons in Mug"; "Sand Play"; "Box"; "Face"; "Background-Foreground", "Cover the Spoon"; "Hide & Seek"; Standing-Tip	Education
Domestic life	"Background-Foreground"	
Major life areas	"Background-Foreground"; "Cover the Spoon"	
General tasks and demand (daily routine)	"Put Spoons in Mug"; "Face"; "Background-Foreground"; "Hide & Seek"	
Mobility	On Top"; "Put Spoons in Mug"; "Sand Play"; "Box"; "Face"; "Background-Foreground", "Cover the Spoon"; Standing-Tip	*Performance skills* *Activity demands*
Interpersonal interactions and relationships	"On Top"; "Face";"Hide & Seek"	Social participation
Communication	"On Top"; "Put Spoons in Mug"; "Sand Play"; "Box"; "Face"; "Background-Foreground", "Cover the Spoon"; "Hide & Seek"; Standing-Tip	
Community, social and civic life (play)	"Sand Play"; "Box"; "Hide & Seek"	
Self-care	"Put Spoons in Mug"; "Face"	Activity of daily living
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	On Top"; "Put Spoons in Mug"; "Sand Play"; "Box"; "Face"; "Background-Foreground", "Cover the Spoon"	*Client factor*
Sensory	On Top"; "Put Spoons in Mug"; "Sand Play"; "Box"; "Face"; "Background-Foreground", "Cover the Spoon"; "Hide & Seek"; Standing-Tip	
Neuro-musculoskeletal and movement-related	On Top"; "Put Spoons in Mug"; "Sand Play"; "Box"; "Face"; "Background-Foreground", "Cover the Spoon"; Standing-Tip	*Performance skills* *Activity demands* *Performance patterns*
Support and relationships	"Hide & Seek"	Physical, Personal
Attitudes	"Box"; Standing-Tip	Cultural, Social
Services, systems, and policies	BCIC - service	Cultural, Social, Personal

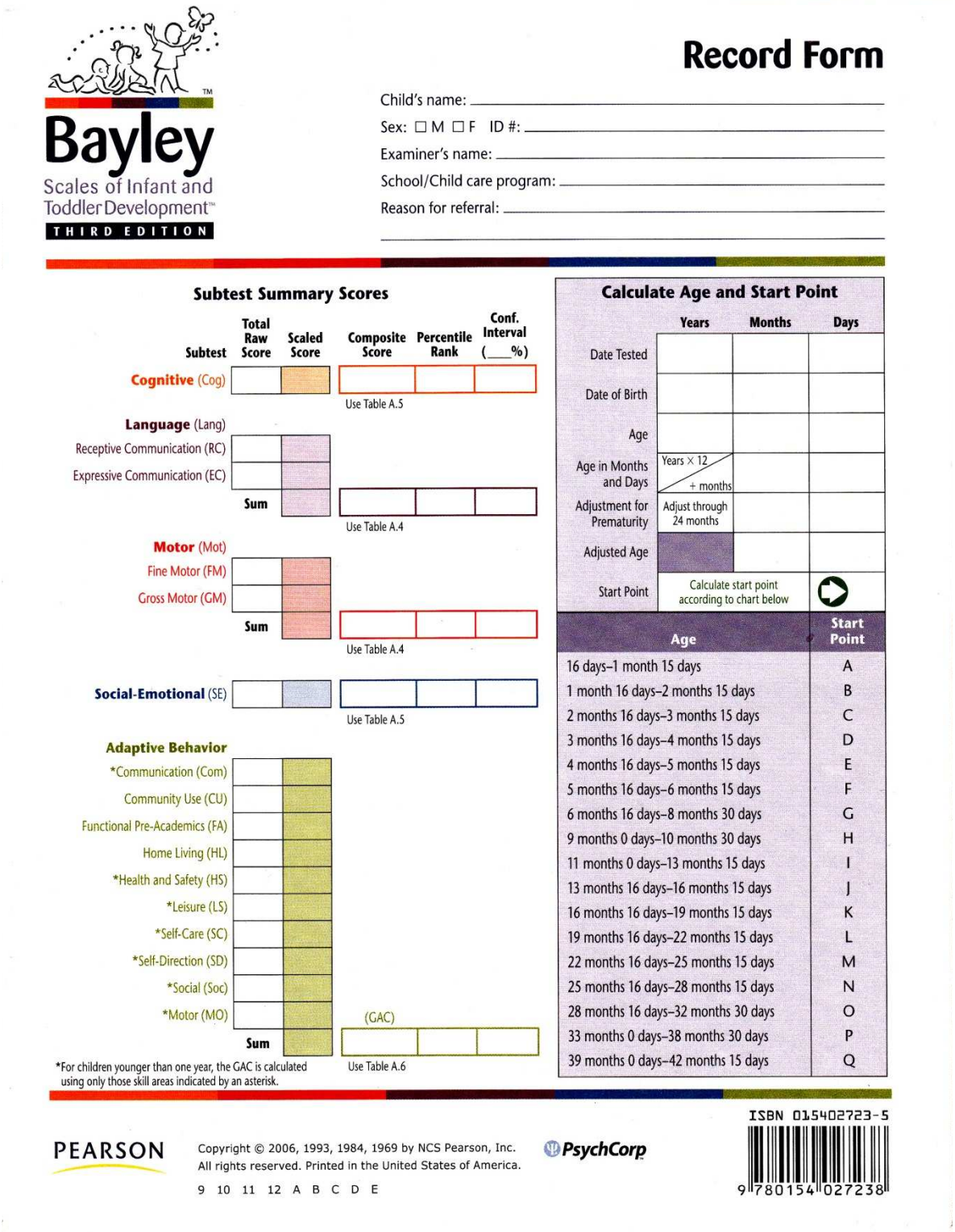
Table D.6: DRSP 18–24 months (compiled by researcher)

ICF	DRSP Age group (Russell 2010:39-42)	OTPF
Activities and Participation	**18 – 24 Months (7 Activities)**	**Areas of Occupation (Life Areas)**
Learning and applying knowledge	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "Washing Hands"; "This is Round", "Sand-Circle"; "Scribble in Sand"	Education
Major life areas	"Three Towers"; "Water in Mugs"; "This is Round"; "Sand-Circle"; "Scribble in Sand"	
General tasks and demand (daily routine)	"Water in Mugs"; "Washing hands"	Activities of daily living *Performance skills*
Mobility	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "Washing Hands"; "This is Round", "Sand-Circle"; "Scribble in Sand"	*Performance skills* *Performance patterns*
Interpersonal interactions and relationships	"Bang-Clang"; "Water in Mugs"; "Washing hands";"Scribble in Sand"	Social participation
Communication	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "Washing Hands"; "This is Round", "Sand-Circle"; "Scribble in Sand"	
Community, social and civic life (play)	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "Scribble in Sand"	
Self-care	"Washing Hands"	Activities of daily living
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "This is Round"; "Sand-Circle"; "Scribble in Sand"	*Client factor*
Sensory	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "Washing Hands"; "This is Round", "Sand-Circle"; "Scribble in Sand"	
Neuro-musculoskeletal and movement-related	"Three Towers"; "Bang-Clang"; "Water in Mugs"; "Washing Hands"; "This is Round", "Sand-Circle"; "Scribble in Sand"	*Performance skills* *Performance patterns*
Contextual Factors		**Context**
Support and relationships	"Washing hands"; "This is Round"; "Sand-Circle"; "Scribble in Sand"	Physical, Personal
Attitudes	"Bang-Clang"; "Water in Mugs"	Cultural, Social
Services, systems, and policies	BCIC - service	Cultural, Social, Personal

Table D.7: DRSP 24–42 months (compiled by researcher)

ICF	DRSP Age group (Russell 2010:43-53)	OTPF
Activities and Participation	**24 – 42 Months (21 Activities)**	**Areas of Occupation (Life Areas)**
Learning and applying know ledge	"Shapes: Circle"; "Spoon Circle"; "Spoon-Square"; "Cloth-Square"; "Spoon-Triangle"; "Position-In-Space: Bridge"; "On Top";"Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Spoon Turning"; "Colors"; "Body Parts"; 'Mug Counting"; "Spoon counting"; "Moe-ket-si"; "Sums"; "Size/Fractions"; "Mug-a-Stone"; "Role-Play"	Education
General tasks and demand (daily routine)	"On Top"; "Top-to-Toe"; "Centre Piece"; "Colors"; "Body Parts"; "Moe-ket-si"; "Role-Play"	
Major life areas	Shapes: Circle"; "Spoon Circle"; "Spoon-Square"; "Cloth-Square"; "Spoon-Triangle"; "Position-In-Space: Bridge"; "On Top"; "Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Spoon Turning"; "Colors"; "Body Parts"; 'Mug Counting"; "Spoon counting"; "Moe-ket-si"; "Sums"; "Size/Fractions"; "Mug-a-Stone"; "Role-Play"	
Mobility	"Position-In-Space: Bridge"; "Top-to-Toe"; "Train-Mugs"; "Colors"; "Body Parts"; "Moe-ket-si"; "Role-Play"	*Performance skills* *Activity demands*
Interpersonal interactions and relationships	"Top-to-Toe"; "Moe-ke-tsi"; "Role-Play"	Social participation
Communication	Shapes: Circle"; "Spoon Circle"; "Spoon-Square"; "Cloth-Square"; "Spoon-Triangle"; "Position-In-Space: Bridge"; "On Top"; "Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Spoon Turning"; "Colors"; "Body Parts"; 'Mug Counting"; "Spoon counting"; "Moe-ket-si"; "Sums"; "Size/Fractions"; "Mug-a-Stone"; "Role-Play"	
Community, social and civic life (play)	"Top-to-Toe"; "Train-Mugs"; "Spoon Turning"; "Spoon counting"; "Moe-ket-si"; "Mug-a-Stone"; "Role-Play"	
Domestic life	"Role-Play	
Self-care	"Body Parts"; "Role-Play"	Activities of daily living
Body Functions and Structures		**Foundational (Body-Level) Components**
Mental	Shapes: Circle"; "Spoon Circle"; "Spoon-Square"; "Cloth-Square"; "Spoon-Triangle"; "Position-In-Space: Bridge"; "On Top"; "Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Spoon Turning"; "Colors"; "Body Parts"; 'Mug Counting"; "Spoon counting"; "Moe-ket-si"; "Sums"; "Size/Fractions"; "Mug-a-Stone"; "Role-Play"	*Client factor*
Sensory	Shapes: Circle"; "Spoon Circle"; "Spoon-Square"; "Cloth-Square"; "Spoon-Triangle"; "Position-In-Space: Bridge"; "On Top"; "Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Spoon Turning"; "Body Parts"; 'Mug Counting"; "Spoon counting"; "Moe-ket-si"; "Sums"; "Size/Fractions"; "Mug-a-Stone"; "Role-Play"	
Neuro-musculoskeletal and movement-related	Shapes: Circle"; "Spoon Circle"; "Spoon-Square"; "Cloth-Square"; "Spoon-Triangle"; "Position-In-Space: Bridge"; "On Top"; "Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Spoon Turning";"Body Parts"; 'Mug Counting"; "Spoon counting"; "Moe ket-si"; "Sums"; "Size/Fractions"; "Mug-a-Stone"; "Role-Play"	*Performance skills* *Performance patterns*
Contextual Factors		**Context**
Support and relationships	"On Top"; "Top-to-Toe"; "Train-Mugs"; "Centre Piece"; "Colors"; "Body Parts"; "Moe-ket-si"; "Sums"; "Mug-a-Stone"; "Role-Play"	Physical, Personal
Attitudes	"Body Parts"; "Moe-ket-si"; "Sums"; "Mug-a-Stone"; "Role-Play"	Cultural, Social
Services, systems, and policies	BCIC - service	Cultural, Social, Personal

Appendix E



Bayley
Scales of Infant and Toddler Development™
THIRD EDITION

Record Form

Child's name: _____
Sex: ☐ M ☐ F ID #: _____
Examiner's name: _____
School/Child care program: _____
Reason for referral: _____
_____

Subtest Summary Scores

Subtest	Total Raw Score	Scaled Score	Composite Score	Percentile Rank	Conf. Interval (___%)
Cognitive (Cog)					
			Use Table A.5		
Language (Lang)					
Receptive Communication (RC)					
Expressive Communication (EC)					
Sum					
			Use Table A.4		
Motor (Mot)					
Fine Motor (FM)					
Gross Motor (GM)					
Sum					
			Use Table A.4		
Social-Emotional (SE)					
			Use Table A.5		
Adaptive Behavior					
*Communication (Com)					
Community Use (CU)					
Functional Pre-Academics (FA)					
Home Living (HL)					
*Health and Safety (HS)					
*Leisure (LS)					
*Self-Care (SC)					
*Self-Direction (SD)					
*Social (Soc)					
*Motor (MO)					
Sum			(GAC)		
			Use Table A.6		

*For children younger than one year, the GAC is calculated using only those skill areas indicated by an asterisk.

Calculate Age and Start Point

	Years	Months	Days
Date Tested			
Date of Birth			
Age			
Age in Months and Days	Years × 12 + months		
Adjustment for Prematurity	Adjust through 24 months		
Adjusted Age			
Start Point	Calculate start point according to chart below		

Age	Start Point
16 days–1 month 15 days	A
1 month 16 days–2 months 15 days	B
2 months 16 days–3 months 15 days	C
3 months 16 days–4 months 15 days	D
4 months 16 days–5 months 15 days	E
5 months 16 days–6 months 15 days	F
6 months 16 days–8 months 30 days	G
9 months 0 days–10 months 30 days	H
11 months 0 days–13 months 15 days	I
13 months 16 days–16 months 15 days	J
16 months 16 days–19 months 15 days	K
19 months 16 days–22 months 15 days	L
22 months 16 days–25 months 15 days	M
25 months 16 days–28 months 15 days	N
28 months 16 days–32 months 30 days	O
33 months 0 days–38 months 30 days	P
39 months 0 days–42 months 15 days	Q

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Figure E.1: Bayley Scales of Infant and Toddler Development 3rd edition

Cognitive Scale

Reversal Rule: The child must obtain scores of 1 on the first three consecutive items at the start point of any age to go forward. If the child obtains a score of zero on any of the first three items, go back to the start point for the previous age and administer those items.

Discontinue Rule: Stop administration when the child obtains scores of zero on five consecutive items.

Item	Materials	Score Criteria and Comments	Score
A 1. Calms When Picked Up	None	**Score:** Child calms when picked up by either you or caregiver.	1 0
2. Responds to Surroundings Series: Inspects	None	**Score:** Child freely turns eyes or head in visual exploration of surroundings.	1 0
B 3. Regards Object for 3 Seconds	Ring with string, ball, or other small object of interest	**Score:** Child gazes continuously at object for at least 3 seconds.	1 0
C 4. Habituates to Rattle	Rattle	Trials: 5 **Score:** Child displays orienting response to stimulus, then habituates during any of the remaining trials.	1 0
5. Discriminates Between Objects	Bell Stopwatch 5 seconds	**Score:** Child responds to bell by displaying a marked behavioral change within 5 seconds after you ring bell.	1 0
6. Recognizes Caregiver	None	**Score:** Child's expression changes to indicate recognition of the caregiver.	1 0
D 7. Becomes Excited in Anticipation	None	**Score:** Child displays anticipatory excitement.	1 0
8. Regards Object for 5 Seconds	Block or other small object of interest Stopwatch 5 seconds	**Score:** Child regards object continuously for at least 5 seconds.	1 0
9. Reacts to Disappearance of Face	None	**Score:** Child changes facial expression or displays other reaction to caregiver's disappearance.	1 0
10. Shifts Attention	Bell Rattle	Trials: 3 **Score:** Child's eyes move from one object to another in response to sound or movement of object(s).	1 0

2 20

Figure E.2: Cognitive Scale: Bayley Scales III

Language Scale

Receptive Communication Subtest

Reversal Rule: The child must obtain scores of 1 on the first three consecutive items at the start point of any age to go forward. If the child obtains a score of zero on any of the first three items, go back to the start point for the previous age and administer those items.

Discontinue Rule: Stop administration when the child obtains scores of zero on five consecutive items.

Item	Materials	Score Criteria and Comments	Score
1. Regards Person Momentarily	None	**Score:** Child fixes gaze on the person for at least 2 seconds.	1 0
2. Tolerates Attention	None	**Score:** Child tolerates attention and does not show signs of distress.	1 0
3. Calms When Spoken To	None	**Score:** Child calms when spoken to.	1 0
4. Reacts to Sounds in the Environment	Squeeze toy	**Score:** Child clearly reacts to the sound presented.	1 0
5. Responds to a Person's Voice	None	**Score:** Child clearly responds to the person's voice.	1 0
6. Searches With Head Turn	Bell Rattle	Trials: 2 **Score:** Child purposely turns head toward source of the sound.	1 0
7. Discriminates Sounds	Paper Rattle	**Score:** Child clearly responds to sound of the rattle.	1 0
8. Sustained Play With Objects	Objects of interest Stopwatch ● 60 seconds	**Score:** Child interacts with objects for at least 60 seconds.	1 0
9. Responds to Name	None	**Score:** Child turns head both times his or her name is called, but does not respond to unfamiliar name.	1 0
10. Interrupts Activity	Objects of interest	**Score:** Child looks up and briefly pauses during play when you call his or her name.	1 0
11. Recognizes 2 Familiar Words	None	**Score:** Child responds differentially to at least two familiar words.	1 0

Figure E.3: Language Scale: Receptive Communication Subtest: Bayley Scales III

Language Scale

Expressive Communication Subtest

Reversal Rule: The child must obtain scores of 1 on the first three consecutive items at the start point of any age to go forward. If the child obtains a score of zero on any of the first three items, go back to the start point for the previous age and administer those items.

Discontinue Rule: Stop administration when the child obtains scores of zero on five consecutive items.

	Item	Materials	Score Criteria and Comments	Score
A B C D	1. Undifferentiated Throaty Sounds	None	**Score:** Child produces soft, throaty, gurgling sounds.	1 0
	2. Social Smile	None	**Score:** Child smiles in response to speaker's attention.	1 0
E F G H	3. Vocalizes Mood	None	**Score:** Child produces vocalizations that express at least one mood.	1 0
	4. Undifferentiated Nasal Sounds	None	**Score:** Child produces nasal vocalizations.	1 0
	5. Social Vocalizing or Laughing	None	**Score:** Child vocalizes or laughs in response to speaker's attention.	1 0
	6. 2 Vowel Sounds	None	**Score:** Child vocalizes at least two different, distinct vowel sounds.	1 0
I	7. Gets Attention	None	**Score:** Child tries to get attention from you or others.	1 0
	8. 2 Consonant Sounds	Objects of interest	**Score:** Child produces at least two different, distinct consonant sounds.	1 0
	9. Uses Gestures	None	**Score:** Child uses at least one gesture to make wants known.	1 0
10/13 J	10. Consonant-Vowel Combination Series: 1 Combination	None	**Score:** Child imitates at least one repetitive consonant-vowel combination.	1 0
	11. Participates in Play Routine	Objects of interest	**Score:** Child actively participates in at least one play routine.	1 0

Figure E.4: Language Scale: Expressive Communication Subtest: Bayley Scales III

Motor Scale

Fine Motor Subtest

Reversal Rule: The child must obtain scores of 1 on the first three consecutive items at the start point of any age to go forward. If the child obtains a score of zero on any of the first three items, go back to the start point for the previous age and administer those items.

Discontinue Rule: Stop administration when the child obtains scores of zero on five consecutive items.

	Item	Materials	Score Criteria and Comments	Score
A B C	1. Hands Are Fisted	None	**Score:** Child's hands are fisted a majority of the time.	1 0
	2. Eyes Follow Moving Person	None	**Score:** Child's eyes follow moving person through midline to left and right.	1 0
	3. Eyes Follow Ring (Horizontal)	Ring with string	Trials: 3 **Score:** Child's eyes follow ring through one complete excursion.	1 0
	4. Eyes Follow Ring (Vertical)	Ring with string	Trials: 3 **Score:** Child's eyes follow ring through one complete excursion.	1 0
D	5. Attempts to Bring Hand to Mouth	None	**Score:** Child purposely attempts to place his or her hand in mouth.	1 0
	6. Retains Ring	Ring with string	**Score:** Child retains ring for at least 2 seconds.	1 0
	7. Eyes Follow Ring (Circular)	Ring with string	Trials: 3 **Score:** Child's eyes follow ring through one complete excursion (upper and lower halves of the circle).	1 0
	8. Head Follows Ring	Ring with string	Trials: 3 **Score:** Child turns his or her head to follow ring through one complete excursion.	1 0
	9. Eyes Follow Rolling Ball	Small ball	**Score:** Child's eyes follow ball as it moves past midline on both sides.	1 0
E	10. Keeps Hands Open	None	**Score:** Child holds his or her hands open most of the time when not attempting a task.	1 0

Figure E.5: Motor Scale: Fine Motor Subtest: Bayley Scales III

Motor Scale

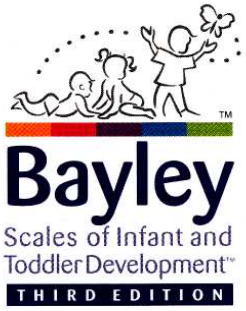
Gross Motor Subtest

Reversal Rule: The child must obtain scores of 1 on the first three consecutive items at the start point of any age to go forward. If the child obtains a score of zero on any of the first three items, go back to the start point for the previous age and administer those items.

Discontinue Rule: Stop administration when the child obtains a score of zero on five consecutive items.

	Item	Materials	Score Criteria and Comments	Score
A B	1. Thrusts Legs in Play	None	**Score:** Child randomly thrusts legs several times.	1 0
	2. Thrusts Arms in Play	None	**Score:** Child randomly thrusts arms several times.	1 0
3 4 9	3. Controls Head While Upright Series: Lifts Head	Stopwatch	**Score:** Child intermittently lifts head free of your shoulder without support. Time head held upright:	1 0
3 4 9	4. Controls Head While Upright Series: 3 Seconds	Stopwatch	**Score:** Child holds head erect for at least 3 seconds without support. Time head held upright:	1 0
C	5. Turns Head to Sides	Object of interest	**Score:** Child turns head from one side to the other by raising his or her head off the supporting surface enough to clear the nose. Child must be able to turn to both sides.	1 0
	6. Makes Crawling Movements	None	**Score:** Child makes any alternating crawling movements with his or her legs.	1 0
	7. Controls Head in Dorsal Suspension	None	**Score:** Child maintains head in midline or lifts head slightly.	1 0
	8. Controls Head in Ventral Suspension	None	**Score:** Child maintains head in midline or lifts head slightly.	1 0
3 4 9 D E	9. Controls Head While Upright Series: 15 Seconds	Stopwatch 15 seconds	**Score:** Child holds head erect and steady for at least 15 seconds without support. Time head held upright:	1 0

Figure E.6: Motor Scale: Gross Motor Subtest: Bayley Scales III



Social-Emotional and Adaptive Behavior Questionnaire

Child's name: _____

Sex: ☐ M ☐ F Age in months: _____

Completed by: _____

Relationship to child: _____

Examiner's name: _____

Does the child have any disabling conditions? ☐ Yes ☐ No

If yes, please describe: _____

_____

An important part of your child's evaluation is to learn about how he or she interacts with you (e.g., whether he or she can communicate with you or recognize others' feelings and emotions). It is also important to learn about the daily skills your child has that help him or her to get along both at home and away from home. Because you know your child so well, you are one of the best people to provide this type of information. The Social-Emotional Scale (part 1 of the following Questionnaire) asks about your child's social-emotional skills. The Adaptive Behavior Scale (part 2) asks about the different kinds of skills your child has.

The items cover a wide age range, and your child is not expected to show all the skills described in the items. It is important that you accurately give information about what skills your child does and does not have. Please note that the two scales require slightly different responses, so read the directions for each scale carefully and mark your rating for each item.

Your child's age affects your completion of both scales. The Social-Emotional Scale has specific stop points, depending on the age of your child. The examiner should indicate where you should stop. Depending on your child's age, you may complete all of the Adaptive Behavior Scale or only certain sections. Although the age-specific sections are clearly marked, the examiner should discuss this with you prior to completion of the Questionnaire.

Calculate Age

	Years	Months	Days
Date Tested			
Date of Birth			
Age			
Age in Months and Days	Years × 12 + months		
Adjustment for Prematurity	Adjust through 24 months		
Adjusted Age			

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Figure E.7: Social-Emotional and Adaptive Behavior Questionnaire

Social-Emotional Scale

Stanley I. Greenspan, M.D.

This scale is designed to measure how well your child has met certain social-emotional milestones for his or her age. Please note that this section has specific stop points, based on your child's age. For each question, circle the number in the column that best describes how often you observe the behavior in your child. Circle **only one** number for each question. Respond to all items until you reach the stop point for your child's age. If your child has not displayed the behavior, please circle 0 for **Can't tell**.

	Behavior Frequency					
	Can't tell	**None** of the time	**Some** of the time	**Half** of the time	**Most** of the time	**All** of the time
1. Takes a calm and enjoyable interest in most sounds.	0	1	2	3	4	5
2. You can easily get your child's attention without having to be very dramatic.	0	1	2	3	4	5
3. Takes a calm and enjoyable interest in most sights, including colorful or bright things.	0	1	2	3	4	5
4. You can easily get your child to look at things without them being very bright or colorful.	0	1	2	3	4	5
5. Calmly enjoys touching or being touched by different things.	0	1	2	3	4	5
6. You can easily get your child to respond to your touch without having to touch your child firmly to get his or her attention.	0	1	2	3	4	5
7. Likes to be swung around, danced with while in your arms, or quickly lifted up in the air.	0	1	2	3	4	5
8. You can easily get your child's attention by approaching him or her, or moving him or her around slowly.	0	1	2	3	4	5
For Sensory Processing Score calculations, total the scores for Items 1–8.						/40
9. You can help your child to calm down.	0	1	2	3	4	5
10. Looks at interesting sights, such as your face or a toy.	0	1	2	3	4	5
11. Looks at or turns toward interesting sounds.	0	1	2	3	4	5
Stop here if your child is 0–3 months old.					**Stage 1**	
12. Seems happy or pleased when he or she sees a favorite person (e.g., looks or smiles, makes sounds, or moves arms in a way that expresses joy or delight).	0	1	2	3	4	5
13. Responds to people talking or playing with him or her by making sounds or faces (e.g., happy sounds or a curious or annoyed look).	0	1	2	3	4	5
Stop here if your child is 4–5 months old.					**Stage 2**	
14. Reaches for or points at things, or makes distinct sounds to show you what he or she wants (e.g., reaches out to be picked up or points at a toy).	0	1	2	3	4	5
15. Exchanges two or more smiles, other looks, sounds, or actions (e.g., reaching, giving, or taking) with a favorite person.	0	1	2	3	4	5
Stop here if your child is 6–9 months old.					**Stage 3**	
16. Shows you that he or she understands your actions or gestures by making an appropriate gesture in return (e.g., makes a funny face back at you, looks at something you point to, stops doing something when you shake your head and use a firm voice to say "No!", or smiles and does more of something when you nod with a big smile and say "Yes!").	0	1	2	3	4	5
17. Uses many consecutive actions in a back-and-forth way to show you what he or she wants or to have fun with you (e.g., smiles, reaches out for a hug, and, when you hug, takes your hat, puts it on his or her head, and smiles proudly OR takes your hand, leads you to the refrigerator, tugs on the handle, and, after you open it, points to something he or she likes, such as food, a bottle of juice, or milk).	0	1	2	3	4	5
Stop here if your child is 10–14 months old.					**Stage 4a**	

Figure E.8: Social-Emotional Scale: Bayley Scales III

	Behavior Frequency					
	Can't tell	None of the time	Some of the time	Half of the time	Most of the time	All of the time
18. Copies or imitates many of your sounds, words, or actions while playing with you (e.g., if you make funny faces and sounds, he or she copies them).	0	1	2	3	4	5
19. Searches for something he or she wants by looking or getting you to look for it.	0	1	2	3	4	5
20. Shows you what he or she wants or needs by using a few actions in a row (e.g., leads you by the hand to open a door and then touches or bangs on the door).	0	1	2	3	4	5
21. Uses words or tries to use words when people talk with or play with him or her.	0	1	2	3	4	5
Stop here if your child is 15–18 months old.				**Stage 4b**		
22. Copies or imitates familiar make-believe play (e.g., feeds or hugs a doll).	0	1	2	3	4	5
23. Tells you what he or she wants with one or a few words (e.g., "Juice," "Open," or "Kiss").	0	1	2	3	4	5
24. Shows you he or she understands your simple verbal wish (e.g., "Please show me your toy.").	0	1	2	3	4	5
Stop here if your child is 19–24 months old.				**Stage 5a**		
25. Plays make-believe (e.g., feeds a doll, plays house, or pretends to be a TV or movie character) with you or others.	0	1	2	3	4	5
26. Uses words or pictures to tell you what he or she is interested in (e.g., "See truck!").	0	1	2	3	4	5
27. Uses words with one or more peers.	0	1	2	3	4	5
28. Uses words or pictures to show what he or she likes or dislikes (e.g., "Want that." or "No want.").	0	1	2	3	4	5
Stop here if your child is 25–30 months old.				**Stage 5b**		
29. Plays make-believe with one or more peers.	0	1	2	3	4	5
30. Plays make-believe with you or others where the story makes sense (e.g., has the bears go visit grandmother and then have a big lunch).	0	1	2	3	4	5
31. Uses phrases or sentences with you to ask a question about something he or she wants to do (e.g., "Mommy go out?" "What you doing outside?" or "Play?").	0	1	2	3	4	5
32. Can explain why he or she wants something or wants to do something (e.g., "Why do you want the juice?" "Because I'm thirsty.").	0	1	2	3	4	5
33. Describes his or her feelings to explain why he or she is doing something or wants something (e.g., "Because I'm happy/sad/excited.").	0	1	2	3	4	5
34. Plays make-believe with peers as well as adults where the story makes sense and has many parts to it (e.g., the children go to school, do work, have lunch, and meet an elephant on the way home).	0	1	2	3	4	5
35. Has conversations with adults and peers that make sense, with four or more back-and-forth exchanges about a variety of topics (e.g., feelings, foods, bedtimes, friends, or school).	0	1	2	3	4	5
Stop here if your child is 31–42 months old.				**Stage 6**		

Social-Emotional Total Raw Score (Items 1–35) /175

Figure E.9: Adaptive Behavior Scale: Bayley Scales III

Adaptive Behavior Scale

Part 2 is designed to measure important behaviors a child displays at home, school, and in other settings. The behaviors included range from those suitable for infants to those suitable for young children. Some items may seem too difficult for infants while others may seem too easy for young children. Therefore, the child is likely to display some but not all behaviors included in this scale.

The Adaptive Behavior Scale includes 10 skill areas. Please read and answer ALL items in the appropriate skill areas, according to the following guidelines:

Age of child:	Complete:
Younger than 1 year old	Communication, Health and Safety, Leisure, Self-Care, Self-Direction, Social, and Motor skill areas only
1–3½ years old	All 10 skill areas

Rate the child according to how often he or she **correctly** performs a behavior, when the behavior needs to be displayed. The rating you choose should reflect the frequency with which the child performs the behavior **when it is needed**. The child should be able to perform the activity or behavior **without help** unless otherwise indicated in the item. Record your response for each item by circling one of the following:

0 Is Not Able

1 Never or **Almost Never When Needed**

2 Sometimes When Needed

3 Always or **Almost Always When Needed**

Then evaluate whether you have observed the behavior or if you are guessing about the frequency of its occurrence. If your rating is based on a guess, put a check (✓) in the box marked **Check If You Guessed**. If your answer is based on observation or direct knowledge, leave this column blank.

The following example shows how to complete the Adaptive Behavior Scale:

	Behavior Frequency				
	Is not able	Never when needed	Sometimes when needed	Always when needed	Check if you guessed
3. Rolls from stomach to side.	0	1	2	(3)	☐
4. Shakes rattle or other toys.	0	1	(2)	3	☑
5. Reaches for objects such as a bottle or toy.	(0)	1	2	3	☐

In the example above, the child being rated **Always** (or Almost Always) rolls from stomach to side when needed; **Sometimes** shakes a rattle or other toys; and **Is Not Able** to reach for objects such as a bottle or toy. The ratings of Items 3 and 5 are based on observation or direct knowledge; therefore the **Check If You Guessed** column is left blank. The rater guessed on Item 4, so the **Check If You Guessed** column is marked.

Figure E.10: Adaptive Behavior Scale: Bayley Scales III

The following table is provided to further assist you.

Rating	The child:
0 **Is Not Able**	• cannot perform the behavior; • is too young to have tried the behavior; or • has a physical condition that prevents the behavior.
1 **Never** or **Almost Never** **When Needed**	**has the ability to perform the behavior, but** • never or almost never does it when needed; or • never or almost never does it on his or her own without being reminded.
2 **Sometimes** **When** **Needed**	**has the ability to perform the behavior, and** • only does it sometimes when needed; • sometimes does it without help, but sometimes needs help; or • sometimes does it on his or her own, but sometimes needs to be reminded.
3 **Always** or **Almost Always** **When Needed**	**has the ability to perform the behavior, and** • displays the behavior most or all of the time without being reminded; or • displayed the behavior at a younger age, but has now outgrown it.

Column	Check this column if:
Check **If You** **Guessed**	• your rating was an estimate. • you have never seen the child in a situation in which the behavior is needed. • the child has not had the opportunity to perform the behavior.

If you do not understand an item or feel it would be helpful to discuss an item with the assessment professional, mark the item and make a brief note of your concerns on page 15 of this Questionnaire.

Communication

	Behavior Frequency				
	Is not able	**Never** when needed	**Sometimes** when needed	**Always** when needed	**Check** if you guessed
1. Looks at others' faces when they are talking.	0	1	2	3	☐
2. Laughs when a parent or other person laughs.	0	1	2	3	☐
3. Raises and lowers voice to express different feelings or needs.	0	1	2	3	☐
4. Cries or fusses when upset.	0	1	2	3	☐
5. Raises voice to get attention.	0	1	2	3	☐
6. Says the names of other people (e.g., Mama, Daddy, or friends' names).	0	1	2	3	☐
7. Shakes head or says "Yes" or "No" in response to a simple question (e.g., "Do you want something to drink?").	0	1	2	3	☐
8. Points to common items in a room when asked (e.g., "Show me the TV.").	0	1	2	3	☐
9. Listens closely for at least one minute when people talk.	0	1	2	3	☐
10. Repeats words others say (e.g., says "baby" when an adult says "baby").	0	1	2	3	☐
11. Says the name of an object clearly enough so that others recognize it (e.g., ball, dog, or cup).	0	1	2	3	☐
12. Follows simple commands (e.g., "No." or "Come here.").	0	1	2	3	☐
13. Follows simple directions that include *over* or *under* (e.g., "Put your hands over your head.").	0	1	2	3	☐
14. Sings all or part of the words to songs.	0	1	2	3	☐
15. Makes plurals of words by adding an *-s* (e.g., shoes, socks, or dogs).	0	1	2	3	☐
16. Names 20 or more familiar objects.	0	1	2	3	☐
17. Uses sentences with a noun and a verb.	0	1	2	3	☐
18. Speaks in sentences of six or more words.	0	1	2	3	☐

continued

Figure E.11: Adaptive Behavior Scale: Bayley Scales III

Functional Pre-Academics

Do not complete the Functional Pre-Academics skill area if the child being rated is younger than one year.

	Behavior Frequency				
	Is not able	Never when needed	Sometimes when needed	Always when needed	Check if you guessed
1. Points to pictures in books when asked (e.g., points to a horse or cow).	0	1	2	3	☐
2. Holds crayon or pencil with point down when using paper.	0	1	2	3	☐
3. States his or her age in years when asked.	0	1	2	3	☐
4. Counts three or more objects.	0	1	2	3	☐
5. Attempts to imitate simple drawings (e.g., copying a line or circle).	0	1	2	3	☐
6. Sings the alphabet song.	0	1	2	3	☐
7. Names six or more colors including red, blue, and yellow.	0	1	2	3	☐
8. Recites nursery rhymes from memory.	0	1	2	3	☐
9. Identifies at least two numbers from a group of numbers.	0	1	2	3	☐
10. Names four or more shapes (e.g., circle, square, rectangle, and triangle).	0	1	2	3	☐
11. Reads own name when printed.	0	1	2	3	☐
12. Counts 10 or more objects without using fingers.	0	1	2	3	☐
13. Draws a recognizable face including two eyes, a nose, mouth, and hair.	0	1	2	3	☐
14. Names at least two letters when shown own name.	0	1	2	3	☐
15. Names most letters when shown the alphabet.	0	1	2	3	☐
16. Counts from 1 to 20.	0	1	2	3	☐
17. Prints at least two letters in own name.	0	1	2	3	☐
18. Reads and obeys common signs (e.g., *Do Not Enter, Exit,* or *Stop*).	0	1	2	3	☐
19. States the days of the week in order.	0	1	2	3	☐
20. Writes numbers 1 to 10.	0	1	2	3	☐
21. Tells what day comes before another (e.g., "Wednesday comes before Thursday.").	0	1	2	3	☐
22. Writes his or her first and last names.	0	1	2	3	☐
23. States time and day of favorite television shows.	0	1	2	3	☐
Total Raw Score (Functional Pre-Academics Items 1–23)			/ 69		Total Guessed

Home Living

Do not complete the Home Living skill area if the child being rated is younger than one year.

1. Removes cookies, chips, or other food from a box or bag.	0	1	2	3	☐
2. Turns television on and off.	0	1	2	3	☐
3. Shows concern when he or she spills something (e.g., says "Oh no!" or tells an adult).	0	1	2	3	☐
4. Points to the place where his or her clothes are stored.	0	1	2	3	☐
5. Uses wall switch to turn lights on and off, even if a chair or stool is needed.	0	1	2	3	☐
6. Assists other people with putting away toys, games, and other items.	0	1	2	3	☐
7. Picks up and throws away trash or paper at home.	0	1	2	3	☐
8. Does simple errand when asked (e.g., runs to get a towel for a spill).	0	1	2	3	☐
9. Attempts to wipe up spills, even if an adult must help.	0	1	2	3	☐
10. Refrains from kicking or hitting furniture.	0	1	2	3	☐
11. Gets own snacks from cabinet or pantry.	0	1	2	3	☐
12. Offers to help a parent or other adult with tasks.	0	1	2	3	☐

continued

Figure E.12: Adaptive Behavior Scale: Bayley Scales III

Health and Safety *continued*

	Behavior Frequency				
	Is not able	Never when needed	Sometimes when needed	Always when needed	Check if you guessed
22. Carries hot containers safely and carefully.	0	1	2	3	☐
23. Uses electrical outlets or sockets safely.	0	1	2	3	☐
24. Cares for his or her minor injuries (e.g., paper cuts, knee scrapes, or nosebleeds).	0	1	2	3	☐
Total Raw Score (Health and Safety Items 1–24)				/72	Total Guessed

Leisure

1. Plays with a single toy or game for at least one minute.	0	1	2	3	☐
2. Plays alone with toys, games, or other fun activities.	0	1	2	3	☐
3. Looks at pictures in books or magazines with an adult.	0	1	2	3	☐
4. Watches for a few minutes as people play with toys or games.	0	1	2	3	☐
5. Plays simple games like "peek-a-boo" or rolls a ball to others.	0	1	2	3	☐
6. Chooses a game or toy during playtime.	0	1	2	3	☐
7. Plays with a single toy or game for more than five minutes.	0	1	2	3	☐
8. Plays on playground equipment with an adult.	0	1	2	3	☐
9. Plays with toys, games, or other fun items with other people.	0	1	2	3	☐
10. Plays with other children when asked.	0	1	2	3	☐
11. Plays on playground equipment.	0	1	2	3	☐
12. Asks to be read to from a favorite book.	0	1	2	3	☐
13. Attends fun activities at another's home.	0	1	2	3	☐
14. Plays simple games with playmates without adult supervision.	0	1	2	3	☐
15. Invites others to join him or her in playing games and other fun activities.	0	1	2	3	☐
16. Participates in a specific fun activity on a routine basis (e.g., listening to a certain type of music or playing a favorite computer game).	0	1	2	3	☐
17. Waits for his or her own turn in games and other fun activities.	0	1	2	3	☐
18. Saves things of interest (e.g., rocks, feathers, or pictures).	0	1	2	3	☐
19. Invites others home for a fun activity.	0	1	2	3	☐
20. Plays simple board games.	0	1	2	3	☐
21. Follows the rules in games.	0	1	2	3	☐
22. Participates in an organized program for a sport or hobby (e.g., takes a music class or practices basketball).	0	1	2	3	☐
Total Raw Score (Leisure Items 1–22)				/66	Total Guessed

Self-Care

1. Swallows liquids with no difficulty.	0	1	2	3	☐
2. Nurses, drinks, or eats willingly, with little encouragement.	0	1	2	3	☐
3. Swallows soft, strained, or mashed food (e.g., baby food or applesauce).	0	1	2	3	☐
4. Sleeps through most of the night, waking no more than one or two times.	0	1	2	3	☐
5. Opens mouth when offered food on a spoon.	0	1	2	3	☐
6. Feeds himself or herself crackers, cookies, dry cereal, or other finger foods.	0	1	2	3	☐
7. Drinks from a cup or glass, even if another person must hold it.	0	1	2	3	☐

continued

Figure E.13: Adaptive Behavior Scale: Bayley Scales III

Self-Direction *continued*

	Behavior Frequency				
	Is not able	Never when needed	Sometimes when needed	Always when needed	Check if you guessed
18. Controls temper when a parent or other adult takes a toy or object away.	0	1	2	3	☐
19. Works on one home or school activity for at least 15 minutes.	0	1	2	3	☐
20. Stops a fun activity, without complaints, when told that time is up.	0	1	2	3	☐
21. Controls temper when disagreeing with friends.	0	1	2	3	☐
22. Follows a routine without being reminded (e.g., brushing teeth before bedtime or regularly feeding a pet).	0	1	2	3	☐
23. Asks permission before playing with another child's toy or game.	0	1	2	3	☐
24. Chooses own clothes almost every day.	0	1	2	3	☐
25. Discusses ways to solve conflicts with others (e.g., "You can have this now if I can have it later.").	0	1	2	3	☐
Total Raw Score (Self-Direction Items 1–25)			/75		Total Guessed

Social

1. Smiles when he or she sees parent.	0	1	2	3	☐
2. Squeals or laughs when happy or delighted.	0	1	2	3	☐
3. Relaxes body when held (e.g., snuggles).	0	1	2	3	☐
4. Lifts arms to express a desire to be picked up.	0	1	2	3	☐
5. Shows a sense of humor (e.g., laughs when someone acts silly).	0	1	2	3	☐
6. Displays a special closeness or relationship to parent (e.g., acts happy when parent returns).	0	1	2	3	☐
7. Responds differently to familiar and unfamiliar persons (e.g., is less warm to an unfamiliar person).	0	1	2	3	☐
8. Hugs and kisses parents or others.	0	1	2	3	☐
9. Runs to greet special family members and friends.	0	1	2	3	☐
10. Imitates actions of adults (e.g., pretends to clean house or drive a car).	0	1	2	3	☐
11. Shares toys willingly with others.	0	1	2	3	☐
12. Greets other children (e.g., says "Hi").	0	1	2	3	☐
13. Says "Thank you" when given a gift.	0	1	2	3	☐
14. Shows sympathy for others when they are sad or upset.	0	1	2	3	☐
15. Seeks friendship with others in his or her age group.	0	1	2	3	☐
16. Responds appropriately when introduced to others (e.g., says "Hello").	0	1	2	3	☐
17. Moves out of another person's way without being asked.	0	1	2	3	☐
18. Offers assistance to others (e.g., offers to carry packages or put away food).	0	1	2	3	☐
19. Says when he or she feels happy, sad, scared, or angry.	0	1	2	3	☐
20. States when others seem happy, sad, scared, or angry.	0	1	2	3	☐
21. Apologizes if he or she hurts the feelings of others.	0	1	2	3	☐
22. Places reasonable demands on friends (e.g., does not become upset when a friend plays with another friend).	0	1	2	3	☐
23. Refrains from saying something that might embarrass or hurt others.	0	1	2	3	☐
24. Personally makes or buys gifts for family members on major holidays.	0	1	2	3	☐
Total Raw Score (Social Items 1–24)			/72		Total Guessed

Figure E.14: Adaptive Behavior Scale: Bayley Scales III

Appendix E/1

Data Appendix E/1							
PRE-TEST & POST-TEST							
Bayley Scaled Scores							
Client Code							1- 2
Date of Birth							3- 8
Age in days and months							9- 12
	Days		Month		Year		
Date of Test							13- 18
	S Score		Months		Days		
Cognitive							19- 24
Language	S Score		Months		Days		
Receptive Communication							25- 30
Expressive Communication							31- 36
Motor	S Score		Months		Days		
Fine Motor							37- 42
Gross Motor							43- 48
					S Score		
Social-Emotional							49- 50
Adaptive Behavior					S Score		
Communication							51- 52
Community Use							53- 54
Functional Pre-Academics							55- 56
Home Living							57- 58
Health and Safety							59- 60
Leisure							61- 62
Self-Care							63- 64
Self-Direction							65- 66
Social-Emotional							67- 68
Motor							69- 70
Sum							71- 73

Figure E/1.1: Data Sheet for Pre- and post-test of Bayley Scales III

Appendix E/2

External Moderator's Report

Client Code				
Age in months				
Test: Date				

	Acceptable	Unacceptable: Reasons
Cognitive		
Language		
Receptive Communication		
Expressive Communication		
Motor		
Fine Motor		
Gross Motor		
Social-Emotional Questionnaire		
Adaptive Behavior Questionnaire		

Signed by:
Date:

Figure E/2.1: Data Sheet for Pre- and post-test of Bayley Scales III

Appendix F

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	0 - 3 Months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1A	Picking up your baby (1st part)										
1B	Picking up your baby (2nd part)										
2A	Carrying your baby										
2B	Carrying your baby										
Tip	Mouth closure										
3	"Mommy Talks"										
4	"90 Degree Follow"										
5	"Hello, Mommy loves you"										
6	"Peek-a-Boo"										
7	"Mug in Middle"										
8	"Spoon Watching"										
9	"Armpit Roller"										
Tip	Holding baby										

Figure F.1: Process Score Sheet: DRSP Checklist for children with DS age band 0-3 months

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	3 - 6 Months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	Different ways of rolling										
2	"Side-Sitting"										
Tip	Arm support										
3	"Hands to midline"										
4	"Peek-a-Boo"										
5	"Mother's Face"										
6	"Supported sitting on floor"										
7	"Spoons in a Mug"										
8	"Where's the Mug?"										
9	"Cloth Ball"										
10	"Mug Tower"										
11	"Leg Roller"										
12	"180 Degree Follow"										
13	"Wha-Wha Sounds"										
14	"Rock the Spoon"										
15	"Spoon Sequence"										

Figure F.2: Process Score Sheet: DRSP Checklist for children with DS age band 3-6 months

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	6 - 9 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Midline Copying"										
2	"Babies Name"										
3	"Spoon Grasps"										
4	"Mug Stacking"										
5	"Spoon Transfers"										
6	"Look for Spoon"										
7	"4 Foot"										
8	"On the Move"										
Tip	Crawling										
9	"Parachute"										

Figure F.3: Process Score Sheet: DRSP Checklist for children with DS age band 6-9 months

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	9-12 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Where are the Spoons?"										
2	"Tip the Mug"										
3	"Where's Mommy"										
4	"Mugs in Water"										
5	"Cloth in Water"										
6	"Words and Concepts"										
7	"Object Permanency"										
8	"Ta-Ta"										
Tip	Kneeling to standing										

Figure F.4: Process Score Sheet: DRSP Checklist for children with DS age band 9-12 months

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	12 - 18 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"On Top"										
2	"Put Spoons in Mug"										
3	"Sand Play"										
4	"Box"										
5	"Face"										
6	"Background-Foreground"										
7	"Cover the Spoon"										
8	"Hide & Seek"										
Tip	Support-Walking										

Figure F.5: Process Score Sheet: DRSP Checklist for children with DS age band 12-18 months

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	18 - 24 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Three Towers"										
2	"Bang-Clang"										
3	"Water in Mugs"										
4	"Washing Hands"										
5	"This is Round"										
6	"Sand-Circle"										
7	"Scribble in Sand"										

Figure F.6: Process Score Sheet: DRSP Checklist for children with DS age band 18-24 months

Data Appendix F

Intervention Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% of time
4 = No problem, No difficulty, Fully independent

	24 - 42 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Shapes: Circle"										
2	"Spoon-Circle"										
3	"Spoon-Square"										
4	"Cloth-Square"										
5	"Spoon-Triangle"										
6	"Cloth-Triangle"										
7	"PIR: Bridge"										
8	"On Top"										
9	"Top-to-Toe"										
10	"Train-Mugs"										
11	"Centre Piece"										
12	"Spoon Turning"										
13	"Colors"										
14	"Body Parts"										
15	"Mug Counting"										
16	"Spoon Counting"										
17	"Moe-ket-si"										
18	"Sums"										
19	"Size/Fractions"										
20	"Mug-a-Stone"										
21	"Role-Play"										

Figure F.7: Process Score Sheet: DRSP Checklist for children with DS age band 24-42 months

Appendix F/1

	Data Appendix F/1														
	Client Code														
	DRSP Checklist													1	2
	0-3 Months/ Sessions	1	2	3	4	5	6	7	8	9	10	11	12		
1	Picking up your baby (1st part)													3 -	14
2	Picking up your baby (2nd part)													15 -	26
3	Carrying your baby													27 -	38
4	Mouth closure													39 -	50
5	"Mommy Talks"													51 -	62
6	"90 Degree Follow"													63 -	74
7	"Hello, Mommy loves you"													75 -	86
8	"Cover the Face"													1 -	12
9	"Mug in Middle"													13 -	24
10	"Spoon Watching"													25 -	36
11	"Armpit Roller"													37 -	48
12	Holding baby													49 -	60
	0=Unable 1=Help more 50% 2=Help less 50% 3=Mild help 25% 4=No problem														

Figure F/1.1: Data sheet: DRSP Checklist for children with DS age band 0-3 months

	Data Appendix F/1														
	Client Code														
	DRSP Checklist													1	2
	3-6 months/ Sessions	1	2	3	4	5	6	7	8	9	10	11	12		
1	Different ways of rolling													3 - 14	
2	"Side-Sitting"													15 - 26	
3	Arm support													27 - 38	
4	"Hands to midline"													39 - 50	
5	"Cover the Face"													51 - 62	
6	"Mother's Face"													63 - 74	
7	"Supported sitting on floor"													75 - 86	
8	"Spoons in a Mug"													1 - 12	
9	"Where's the Mug?"													13 - 24	
10	"Cloth Ball"													25 - 36	
11	"Mug Tower"													37 - 48	
12	"Leg Roller"													49 - 60	
13	"180 Degree Follow"													61 - 72	
14	"Wha-Wha Sounds"													73 - 84	
15	"Rock the Spoon"													1 - 12	
16	"Spoon Sequence"													13 - 24	
	0=Unable 1=Help more 50% 2=Help less 50% 3=Mild help 25% 4=No problem														

Figure F/1.2: Data sheet: DRSP Checklist for children with DS age band 3-6 months

	Data Appendix F/1														
	Client Code														
	DRSP Checklist													1	2
	6-9 months/ Sessions	1	2	3	4	5	6	7	8	9	10	11	12		
1	"Midline Copying"													3 -	14
2	"Babies Name"													15 -	26
3	"Spoon Grasps"													27 -	38
4	"Mug Stacking"													39 -	50
5	"Spoon Transfers"													51 -	62
6	"Look for Spoon"													63 -	74
7	"4 Foot"													75 -	86
8	"On the Move"													1 -	12
9	Crawling													13 -	24
10	"Parachute"													25 -	36

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure F/1.3: Data sheet: DRSP Checklist for children with DS age band 6-9 months

	Data Appendix F/1														
	Client Code														
	DRSP Checklist													1	2
	9-12 months/ Sessions	1	2	3	4	5	6	7	8	9	10	11	12		
1	"Where are the Spoons?"													3 -	14
2	"Tip the Mug"													15 -	26
3	"Where's Mommy"													27 -	38
4	"Mugs in Water"													39 -	50
5	"Cloth in Water"													51 -	62
6	"Words and Concepts"													63 -	74
7	"Object Permanency"													75 -	86
8	"Ta-Ta"													1 -	12
9	Kneeling to standing													13 -	24

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure F/1.4: Data sheet: DRSP Checklist for children with DS age band 9-12 months

	Data Appendix F/1													
	Client Code													
	DRSP Checklist												1	2
1	**12-18 months/ Sessions**	1	2	3	4	5	6	7	8	9	10	11	12	
2	"On Top"													3 - 14
3	"Put Spoons in Mug"													15 - 26
4	"Sand Play"													27 - 38
5	"Box"													39 - 50
6	"Face"													51 - 62
7	"Background-Foreground"													63 - 74
8	"Cover the Spoon"													75 - 86
9	"Hide & Seek"													1 - 12
10	Support-Walking													13 - 24
	0=Unable 1=Help more 50% 2=Help less 50% 3=Mild help 25% 4=No problem													

Figure F/1.5: Data sheet: DRSP Checklist for children with DS age band 12-18 months

	Data Appendix F/1													
	Client Code													
	DRSP Checklist												1	2
1	**18-24 months/ Sessions**	1	2	3	4	5	6	7	8	9	10	11	12	
2	"Three Towers"													3 - 14
3	"Bang-Clang"													15 - 26
4	"Water in Mugs"													27 - 38
5	"Washing Hands"													39 - 50
6	"This is Round"													51 - 62
7	"Sand-Circle"													63 - 74
8	"Scribble in Sand"													75 - 86

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure F/1.6: Data sheet: DRSP Checklist for children with DS age band 18-24 months

	Data Appendix F/1														
	Client Code														
	DRSP Checklist													1	2
	24-42 months/ Sessions	1	2	3	4	5	6	7	8	9	10	11	12		
1	"Shapes: Circle"													3 - 14	
2	"Spoon-Circle"													15 - 26	
3	"Spoon-Square"													27 - 38	
4	"Cloth-Square"													39 - 50	
5	"Spoon-Triangle"													51 - 62	
6	"Cloth-Triangle"													63 - 74	
7	"PIR: Bridge"													75 - 86	
8	"On Top"													1- 12	
9	"Top-to-Toe"													13- 24	
10	"Train-Mugs"													25- 36	
11	"Centre Piece"													37- 48	
12	"Spoon Turning"													49- 60	
13	"Colors"													61- 72	
14	"Body Parts"													73- 84	
15	"Mug Counting"													1- 12	
16	"Spoon Counting"													13- 24	
16	"Moe-ket-si"													25- 36	
18	"Sums"													37- 48	
19	"Size/Fractions"													49- 60	
20	"Mug-a-Stone"													61- 72	
21	"Role-Play"													73- 84	

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure F/1.7: Data sheet: DRSP Checklist for children with DS age band 24-42 months

Appendix G

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% all of the time
4 = No problem, No difficulty, Fully independent

	0 - 3 Months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1A	Picking up your baby (1st part)										
1B	Picking up your baby (2nd part)										
2A	Carrying your baby										
2B	Carrying your baby										
Tip	Mouth closure										
3	"Mommy Talks"										
4	"90 Degree Follow"										
5	"Hello, Mommy loves you"										
6	"Peek-a-Boo"										
7	"Mug in Middle"										
8	"Spoon Watching"										
9	"Armpit Roller"										
Tip	Holding baby										

Figure G.1: Process Score sheet: DRSP Checklist for parents/caregiver: DS child age band 0-3 months

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% all of the time
4 = No problem, No difficulty, Fully independent

	3 - 6 Months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	Different ways of rolling										
2	"Side-Sitting"										
Tip	Arm support										
3	"Hands to midline"										
4	"Peek-a-Boo"										
5	"Mother's Face"										
6	"Supported sitting on floor"										
7	"Spoons in a Mug"										
8	"Where's the Mug?"										
9	"Cloth Ball"										
10	"Mug Tower"										
11	"Leg Roller"										
12	"180 Degree Follow"										
13	"Wha-Wha Sounds"										
14	"Rock the Spoon"										
15	"Spoon Sequence"										

Figure G.2: Process Score sheet: DRSP Checklist for parents/caregivers: DS child age band 3-6 months

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% aal of the time
4 = No problem, No difficulty, Fully independent

	6 - 9 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Midline Copying"										
2	"Babies Name"										
3	"Spoon Grasps"										
4	"Mug Stacking"										
5	"Spoon Transfers"										
6	"Look for Spoon"										
7	"4 Foot"										
8	"On the Move"										
Tip	Crawling										
9	"Parachute"										

Figure G.3: Process Score sheet: DRSP Checklist for parents/caregivers: DS child age band 6-9 months

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% all of the time
4 = No problem, No difficulty, Fully independent

	9 - 12 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Where are the Spoons?"										
2	"Tip the Mug"										
3	"Where's Mommy"										
4	"Mugs in Water"										
5	"Cloth in Water"										
6	"Words and Concepts"										
7	"Object Permanency"										
8	"Ta-Ta"										
Tip	Kneeling to standing										

Figure G.4: Process Score sheet: DRSP Checklist for parents/caregivers: DS child age band 9-12 months

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% all of the time
4 = No problem, No difficulty, Fully independent

	12 - 18 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"On Top"										
2	"Put Spoons in Mug"										
3	"Sand Play"										
4	"Box"										
5	"Face"										
6	"Background-Foreground"										
7	"Cover the Spoon"										
8	"Hide & Seek"										
Tip	Support-Walking										

Figure G.5: Process Score sheet: DRSP Checklist for parents/caregivers: DS child age band 12-18 months

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% all of the time
4 = No problem, No difficulty, Fully independent

	18 - 24 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Three Towers"										
2	"Bang-Clang"										
3	"Water in Mugs"										
4	"Washing Hands"										
5	"This is Round"										
6	"Sand-Circle"										
7	"Scribble in Sand"										

Figure G.6: Process Score sheet: DRSP Checklist for parents/caregivers: DS child age band 18-24 months

Data Appendix G

Parents/Caregivers Process: DRSP Checklist

Patient: DOB: No.:

0 = Unable to perform task, Complete facilitation, Complete difficulty up to 95%
1 = Help required, Substantial facilitation, Severe difficulty more than 50%
2 = Help required, Moderate facilitation, Moderate difficulty less than 50%
3 = Mild facilitation, Mild difficulty 25% all of the time
4 = No problem, No difficulty, Fully independent

	24 - 42 months	Date	Child	Date	Child	Date	Child	Date	Child	Date	Child
1	"Shapes: Circle"										
2	"Spoon-Circle"										
3	"Spoon-Square"										
4	"Cloth-Square"										
5	"Spoon-Triangle"										
6	"Cloth-Triangle"										
7	"PIR: Bridge"										
8	"On Top"										
9	"Top-to-Toe"										
10	"Train-Mugs"										
11	"Centre Piece"										
12	"Spoon Turning"										
13	"Colors"										
14	"Body Parts"										
15	"Mug Counting"										
16	"Spoon Counting"										
17	"Moe-ket-si"										
18	"Sums"										
19	"Size/Fractions"										
20	"Mug-a-Stone"										
21	"Role-Play"										

Figure G.7: Process Score sheet: DRSP Checklist for parents/caregivers: DS child age band 24-42 months

Appendix G/1

	Data Appendix G/1														
	Client Code														
	DRSP Checklist													1	2
	0-3 Months	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date		
1	Picking up your baby (1st part)													3 - 14	
2	Picking up your baby (2nd part)													15 - 26	
3	Carrying your baby													27 - 38	
4	Mouth closure													39 - 50	
5	"Mommy Talks"													51 - 62	
6	"90 Degree Follow"													63 - 74	
7	"Hello, Mommy loves you"													75 - 86	
8	"Cover the Face"													1 - 12	
9	"Mug in Middle"													13 - 24	
10	"Spoon Watching"													25 - 36	
11	"Armpit Roller"													37 - 48	
12	Holding baby													49 - 60	
	0=Unable 1=Help more 50% 2=Help less 50% 3=Mild help 25% 4=No problem														

Figure G/1.1: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 0-3 months

	Data Appendix G/1														
	Client Code														
	DRSP Checklist													1	2
	3-6 months	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date		
1	Different ways of rolling													3 -	14
2	“Side-Sitting”													15 -	26
3	Arm support													27 -	38
4	“Hands to midline”													39 -	50
5	“Cover the Face”													51 -	62
6	“Mother’s Face”													63 -	74
7	“Supported sitting on floor”													75 -	86
8	“Spoons in a Mug”													1 -	12
9	“Where’s the Mug?”													13 -	24
10	“Cloth Ball”													25 -	36
11	“Mug Tower”													37 -	48
12	“Leg Roller”													49 -	60
13	“180 Degree Follow”													61 -	72
14	“Wha-Wha Sounds”													73 -	84
15	“Rock the Spoon”													1 -	12
16	“Spoon Sequence”													13 -	24
	0=Unable 1=Help more 50% 2=Help less 50% 3=Mild help 25% 4=No problem														

Figure G/1.2: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 3-6 months

Data Appendix G/1

Client Code

DRSP Checklist

1 2

	6-9 months	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	
1	"Midline Copying"													3 - 14
2	"Babies Name"													15 - 26
3	"Spoon Grasps"													27 - 38
4	"Mug Stacking"													39 - 50
5	"Spoon Transfers"													51 - 62
6	"Look for Spoon"													63 - 74
7	"4 Foot"													75 - 86
8	"On the Move"													1 - 12
9	Crawling													13 - 24
10	"Parachute"													25 - 36

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure G/1.3: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 6-9 months

	Data Appendix G/1													
	Client Code													
	DRSP Checklist												1	2
	9-12 months	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	
1	"Where are the Spoons?"													3 - 14
2	"Tip the Mug"													15 - 26
3	"Where's Mommy"													27 - 38
4	"Mugs in Water"													39 - 50
5	"Cloth in Water"													51 - 62
6	"Words and Concepts"													63 - 74
7	"Object Permanency"													75 - 86
8	"Ta-Ta"													1 - 12
9	Kneeling to standing													13 - 24

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure G/1.4: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 9-12 months

	Data Appendix G/1													
	Client Code													
	DRSP Checklist												1	2
1	**12-18 months**	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	
2	"On Top"												3 -	14
3	"Put Spoons in Mug"												15 -	26
4	"Sand Play"												27 -	38
5	"Box"												39 -	50
6	"Face"												51 -	62
7	"Background-Foreground"												63 -	74
8	"Cover the Spoon"												75 -	86
9	"Hide & Seek"												1 -	12
10	Support-Walking												13 -	24
	0=Unable 1=Help more 50% 2=Help less 50% 3=Mild help 25% 4=No problem													

Figure G/1.5: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 12-18 month

	Data Appendix G/1													
	Client Code													
	DRSP Checklist												1	2
1	**18-24 months**	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	
2	"Three Towers"												3 -	14
3	"Bang-Clang"												15 -	26
4	"Water in Mugs"												27 -	38
5	"Washing Hands"												39 -	50
6	"This is Round"												51 -	62
7	"Sand-Circle"												63 -	74
8	"Scribble in Sand"												75 -	86

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure G/1.6: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 18-24 months

	Data Appendix G/1													
	Client Code													
	DRSP Checklist												1	2
	24-42 months	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	Date	
1	"Shapes: Circle"													3 - 14
2	"Spoon-Circle"													15 - 26
3	"Spoon-Square"													27 - 38
4	"Cloth-Square"													39 - 50
5	"Spoon-Triangle"													51 - 62
6	"Cloth-Triangle"													63 - 74
7	"PIR: Bridge"													75 - 86
8	"On Top"													1- 12
9	"Top-to-Toe"													13- 24
10	"Train-Mugs"													25- 36
11	"Centre Piece"													37- 48
12	"Spoon Turning"													49- 60
13	"Colors"													61- 72
14	"Body Parts"													73- 84
15	"Mug Counting"													1- 12
16	"Spoon Counting"													13- 24
16	"Moe-ket-si"													25- 36
18	"Sums"													37- 48
19	"Size/Fractions"													49- 60
20	"Mug-a-Stone"													61- 72
21	"Role-Play"													73- 84

0=Unable
1=Help more 50%
2=Help less 50%
3=Mild help 25%
4=No problem

Figure G/1.7: Data sheet: DRSP Checklist for parents/caregivers: DS child age band 24-42 months

Appendix H

	Data Appendix H					
	Parent Audit Tool					
	Client Code (study subject number)					1 - 2
	Questionnaire filled in by: *client /interpreter/ assistance*					3
	Poor (Below your expectations) Satisfactory (Your expectations were met) Good (Your expectations were more than met)					
	OT = Occupational Therapist	1 Poor	2 Satis-factory	3 Good		
1	How do you rate the explanation of what your Occupational Therapy treatment is supposed to achieve?					4
2	What was the OT's response to your needs and points of view?					5
3	How do you rate the treatment/intervention in terms of improving your child's functioning?					6
4	Describe the OT's attitude towards you and your child.					7
5	Describe the neatness and cleanliness of the Occupational Therapy area.					8
6	How do you rate the level of safety within the Occupational Therapy area?					9
		1 Always	2 Sometimes	3 Never		
7	Did your treatment sessions start on time?					10
8	If sometimes or never, OT responsible, explain					11
	If sometimes, Parent responsible, explain					12
9	Were you given the opportunity to ask questions?					13
10	If there was a language barrier did the OT try to overcome/accommodate this problem?					14
11	Was your baby's problem/diagnosis explained to you in a way you understood?					15
12	Were you given the right to refuse treatment/intervention?					16
13	Was your culture respected where applicable?					17
14	Was the OT friendly?					18
15	Was the OT polite/respectful?					19
16	Was the OT helpful?					20
17	Was the OT understanding?					21
18	Did you think the OT communicated well with other people involved in your baby's intervention?					22
	Suggestions/Comments:					23-24

Figure H.1: Parent Audit Tool in English

	Data Appendix H					
	Ouer Ouditinstrument					
	Kliënt Kode (studie nommer)					1 - 2
	Vraelys ingevul deur: *kliënt / vertaler / assistant*					3
	Swak (Onder verwagting) Bevredigend (voldoen aan verwagtinge) Goed (Meer as net voldoen aan verwagtinge)					
	AT = Arbeidsterapeut	1 Swak	2 Bevredigend	3 Goed		
1	Is Arbeidsterapie behandeling verstaanbaar verduidelik en die proses daarvan?					4
2	Hoe het AT gereageer op u behoeftes en verwagtinge?					5
3	Hoe kan die behandeling/intervensie geevalueer word vir die vordering van u kind se funksionering?					6
4	Beskryf die houding van die AT teenoor u en u baba?					7
5	Beskryf die netheid en sindelikheid van die Arbeidserapie area.					8
6	Beoordeel die veiligheidsvlak binne die Arbeidsterapie area.					9
		1 Altyd	2 Soms	3 Nooit		
7	Het die intervensiesessie op tyd begin?					10
8	Indien soms of nooit, AT verantwoordelik daarvoor? Bespreek					11
	Indien soms, Ouer verantwoordelik daarvoor? Bespreek					12
9	Was daar geleentheid vir vrae vra?					13
10	Indien daar 'n taalindernis was, het die AT poging aangewend om dit aan te spreek/oorkom/akkommodeer?					14
11	Is u baba se probleem/diagnose verstaanbaar verduidelik?					15
12	Is u die opsie gegee om terapie/intervensie te weier?					16
13	Is u kultuur met die nodige toepaslike respek behandel?					17
14	Was die AT vriendelik?					18
15	Was die AT hoflik/respekvol?					19
16	Was die AT behulpsaam?					20
17	Het die AT begrip getoon?					21
18	Dink u dat die AT goed kommunikeer met ander mense wat met u baba se intervensie betrokke was?					22
	Voorstelle/Kommentaar:					23-24

Figure H.2: Parent Audit Tool in Afrikaans

	Data Appendix H					
	Mokudi se hlahlobang ya basebedisis					
	Mosebedisi Code (study subject number)					1 - 2
	Tlatsitswe la dipotso ke: *mosebedisi/toloko/tlelereke*					3
	E a fokola (Ha e a fihlella ditebello tsa hao) E a kgotsofatsa (E fetile ditebello tsa hao) E ntle (Ditebello tsa hao di kgotsofaditswe le ho feta)					
	OT = Occupational Therapist	1 E a fokola	2 E a kgotsofatsa	3 E ntle		
1	E be o bona tlhaloso ya kalafo ya tshebetso e reretsweng phekolo e fihlella seo e neng e se reretswe?					4
2	Karabo e bile efe ditlhokong le dintlhakemong tsa hao?					5
3	E be o bona kalafo e ntlafatsa ho fola ha hao ha ngwana?					6
4	Hlalosa boitshwaro ba mosebeletsi wa tshebetso e reretsweng phekolo ho wena ha ngwana?					7
5	Hlalosa makgethe le bohlweki ba sebaka sa tshebetso e reretsweng phekolo?					8
6	E be o bona boemo ba polokeho sebakeng sa tshebetso e reretsweng phekolo bo le jwang?					9
		1 Always	2 Sometimes	3 Never		
7	E be Tshebetso ya hao ya kalafo e qadile ka nako?					10
8	Ebang ho se jwalo – na o ile wa hlalosetswa lebaka, OT lata?					11
	Batswadi ba fihlile lata?					12
9	E be o ile wa nehwa monyetla wa ho botsa dipotso?					13
10	Ebang ho ne ho na le bothata ba puo na mosebeletsi w a tshebetso e reretsw eng phekolo o ile a leka ho rarolla bothata bona?					14
11	E be o ile wa hlalosetswa bothata/bohloko ba hao/ngwana ka tsela eo o e utlwisisang?					15
12	E be o ile wa nehwa tokelo ya ho hana kalafo?					16
13	E be setso sa hao se ile sa hlomphuwa moo ho neng ho hlokeha teng?					17
14	E be mosebeletsi wa tshebetso e reretsweng phekolo o ne a tletse setswalle?					18
15	E be mosebeletsi wa tshebetso e reretsweng phekolo o ne a na le tlhompho?					19
16	E be mosebeletsi wa tshebetso e reretsweng phekolo o ne mme a thusa?					20
17	E be o nahana hore mosebeletsi w a tshebetso e reretsw eng phekolo o ne a buisana hantle le batho ba bang ba kalafong le w ena?					21
18	E be o ile w a hlokomedisw a ka Molaotheo w a Ditokelo tsa Mokudi o pepesitsw eng ka ngw ana sebakeng seo?					22
	Ditlhahiso/Maikutlo					23-24

Figure H.3: Parent Audit Tool in SeSotho

Appendix I

I.1 Afrikaans-speaking girl with DS aged 34 months 3 days after a six-month intervention period

According to Figure I.1, the mean scores for this participant showed an increase in the cognitive and motor domains and the same mean scores for the language domain. This little girl punctually attended all 12 treatment sessions over six months. The dedication of her mother made this possible. At every session, early in the mornings at 7:30, the girl and her mother came into the treatment area with a smile and enthusiasm and walked straight to the table. Interestingly, she would not tolerate repeating an activity during the session. When she had completed a task, she would wait rather impatiently for the next activity.

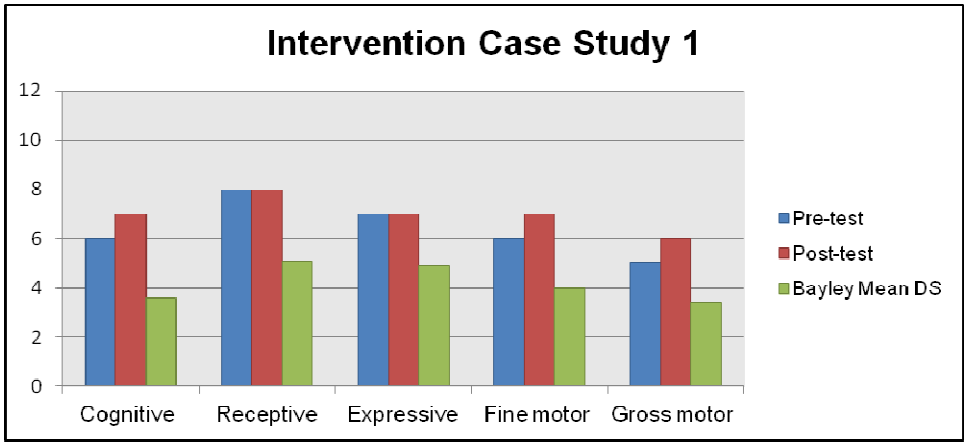

Figure I.1: Participant 1 of intervention group 34 months 3 days

I.2 English-speaking girl with DS aged 23 months and 23 days after a six-month intervention period

The cognitive and motor domains improved during the six months. Figure I.2 illustrates a slight decrease in the language domain, but the scores were what would be expected of typical development. This girl completed her 12 sessions, attended with her parents, in a six-month period accompanied sometimes by a nanny on Saturday afternoons. She was at the developmental stage where throwing objects from the table was her activity of choice. By the end of the six months, she was throwing fewer objects and completing more activities. Her speech development advanced to two-word utterances.

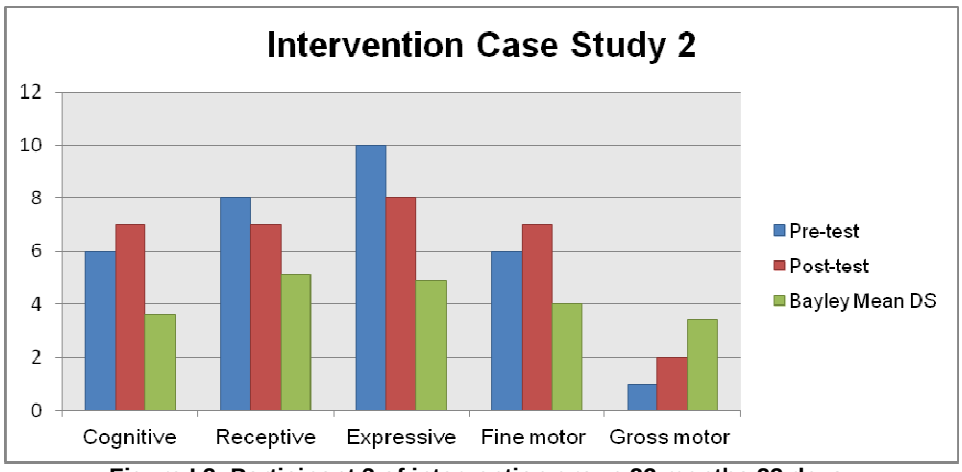

Figure I.2: Participant 2 of intervention group 23 months 23 days

I.3 Xhosa-speaking girl with DS aged 26 months 9 days after a six-month intervention period

The median score in the cognitive domain remained the same and the other domain's mean scores indicated an improvement. This Xhosa girl was always very friendly, with a lot of incomprehensible words, but she loved babbling, as if one could understand every word. Her health, especially respiratory, was a problem and therefore six sessions had to be rescheduled during the six-month intervention period. Standing was her position of choice during the intervention sessions and the sessions were adapted accordingly. She started walking at the end of the six months.

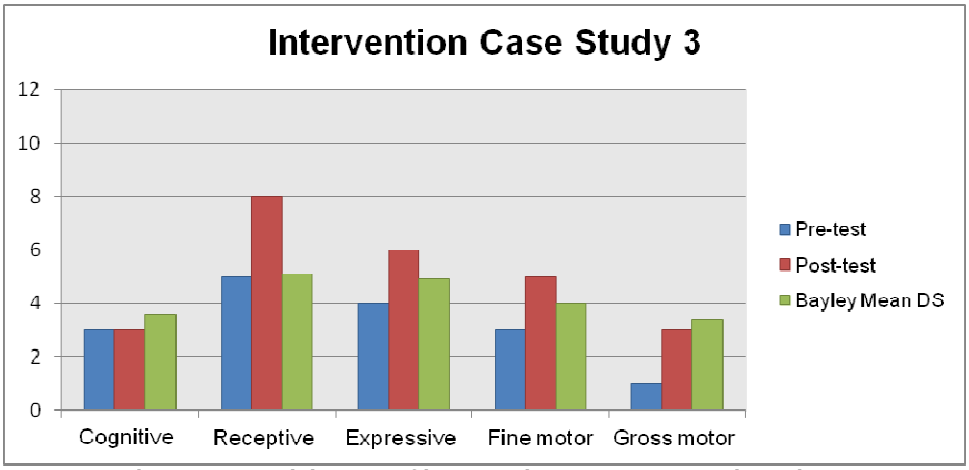

Figure I.3: Participant 3 of intervention group 26 months 9 days

I.4 Sesotho-speaking boy with DS aged 23 months 24 days after a six-month intervention period

According to Figure I.4, the mean scores remained the same for the cognitive, receptive and gross-motor domains. The expressive language showed a decrease. The fine-motor domain showed an increase in the mean score. This busy boy kept the intervention sessions interesting! He was born at 32 weeks gestation with a low birth weight. He started off playing with the spoons only. After the intervention period of six months he played with all the equipment of the DRSP activities. His concentration during the period improved and he could attend to the activities supplied in the sessions. His crawling pattern was well coordinated and the quality of his gross-motor movements had improved.

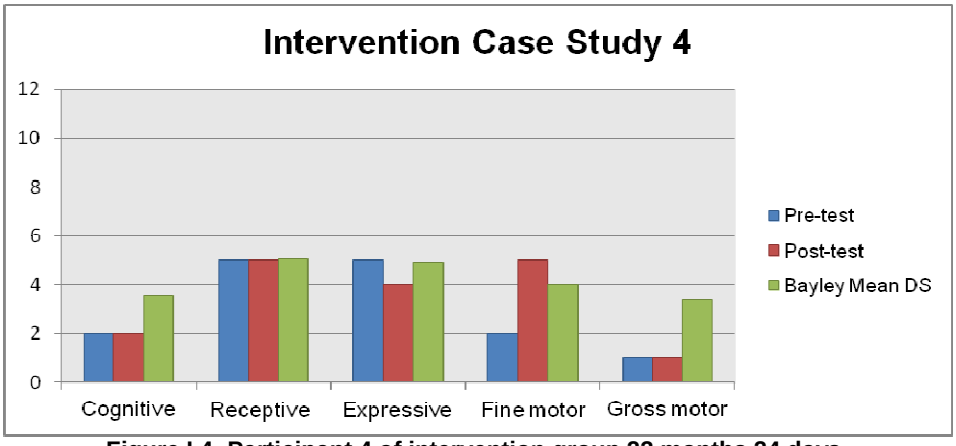

Figure I.4: Participant 4 of intervention group 23 months 24 days

I.5 Sesotho-speaking boy with DS aged 18 months 22 days after a six-month intervention period

Figure I.5 illustrates a decline in cognitive and fine-motor domain mean scores. The language-domain mean scores improved, with the gross-motor that showed the same mean scores after a six-month intervention period. This Sotho boy also improved during the six-month intervention period, but at a slower pace. He was born with a congenital hand deformity, with syndactuli of three fingers of both hands. Over the period, arm-support activities were a problem. He preferred to sit only and not to manipulate objects. Halfway through the DRSP he started to manipulate the mugs, teaspoons and cloth. His muscle tone was type three (very low) and therefore the gross-motor activities took up a lot of the sessions at the beginning of the intervention. He started weight-bearing activities such as four-foot kneeling at the end of the six-

month period. He was the only child in the study that was very adamant when he did not want to participate, by shaking his head immediately. His mother remained positive through this non-compliant period of him.

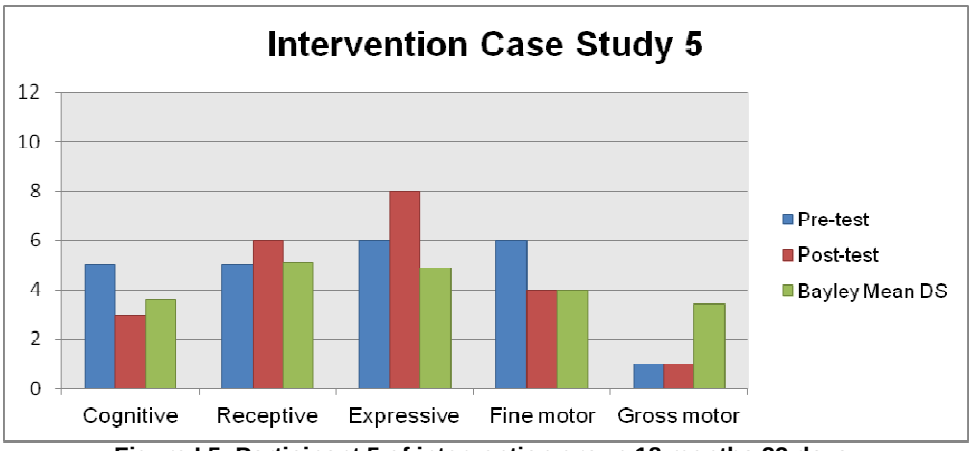

Figure I.5: Participant 5 of intervention group 18 months 22 days

I.6 Sesotho-speaking boy with DS aged 9 months 9 days after a six-month intervention period

This participant's cognitive abilities improved during the six-month period, as illustrated in Figure I.6. There was a decline in all the other domains' mean scores. This big-eyed boy was born at 34 weeks' gestation. His young, dedicated mother came very early in the mornings to attend the therapeutic sessions. This little boy never complained when any position was introduced at the beginning. As the sessions progressed, he cried occasionally. It was positive to observe his reactions and manipulation of objects.

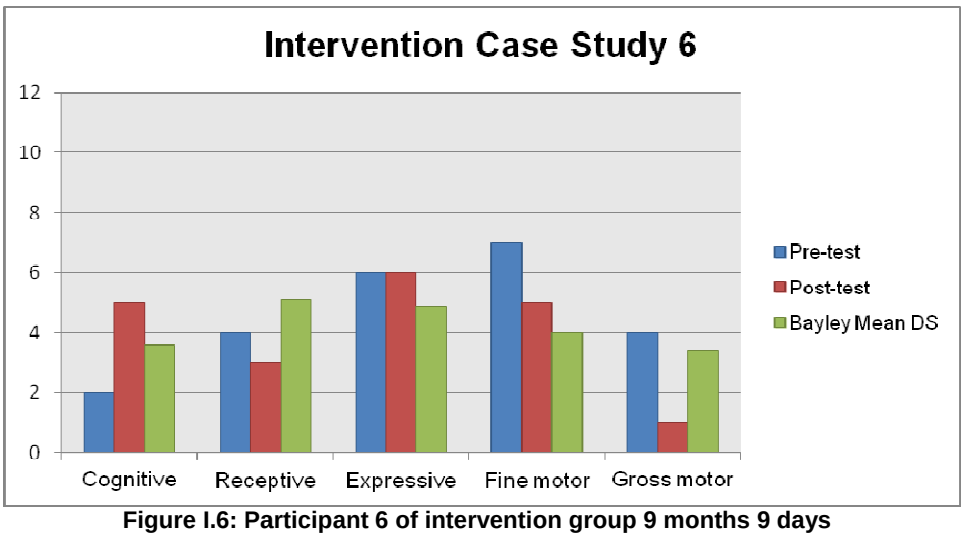

Figure I.6: Participant 6 of intervention group 9 months 9 days

I.7 Sesotho-speaking boy with DS aged 17 months 14 days after a six-month intervention period

The mean scores of this participant showed scores that would be expected off typically developed children (Case-Smith 2005:284; Melyn & White 1973:544). The standard deviation for the Bayley Scales III was seven. This boy's mean score for cognitive and gross-motor domain was 6.0. The mean score for receptive language was 7.0 and expressive and fine-motor 8.0 (cf. Figure I.7). This boy started walking at 17 months, which was during the six-month intervention period. His speech development improved and after six months he was sociable towards the other children in the intervention group. His dedicated and motivated mother followed all the instructions and after all the demonstrations she requested more help to enable her to master the activities independently.

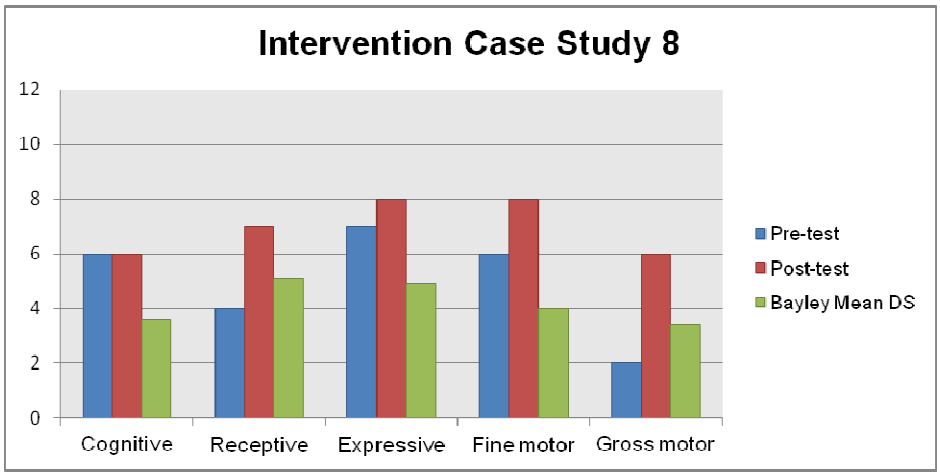

Figure I.7: Participant 7 of intervention group 17 months 14 days

I.8 Afrikaans-speaking girl with DS aged 15 months 15 days after a six-month intervention period

All the mean scores in the domains showed an increase. The cognitive-domain mean score of this participant was 6.0; receptive language 10.0; expressive language 9.0; fine motor 5.0 and gross motor 4.0 (cf. Figure I.8). She showed typical developmental trends after the six-month intervention period. She progressed from no movement to crawling and supported walking in the six-month intervention. She did not initially manipulate any objects and after the intervention period she participated in all fine-motor activities presented to her. She was quite "grumpy" at the beginning of the intervention and completed being communicative (babble) and a happier baby. These intervention sessions took place late, on Saturdays afternoon, as they were from the rural Free State.

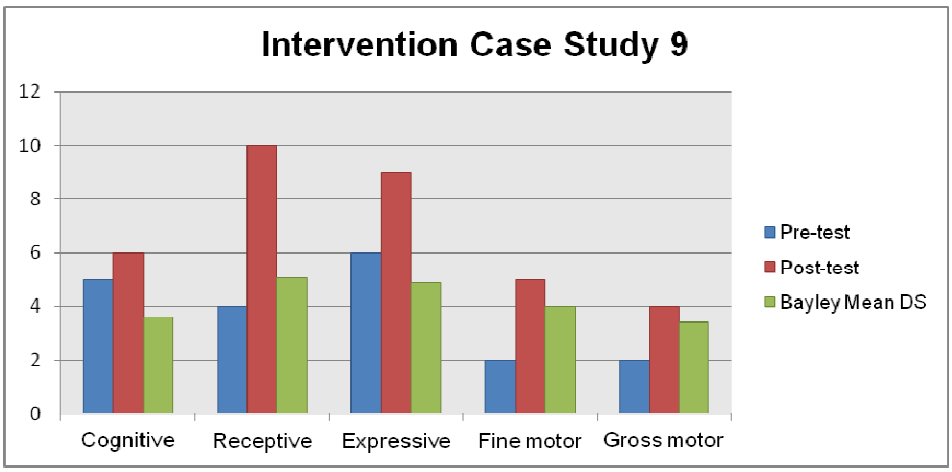

Figure I.8: Participant 8 of intervention group 15 months 15 days

I.9 Sesotho-speaking girl with DS aged 9 months 3 days after a six-month intervention period

According to Figure I.9, the cognitive-domain score of this participant increased. The fine-motor development showed the same scores and the gross-motor score declined after a six-month intervention period. This tiny baby girl was dressed in the biggest bright orange polo neck jersey. During the six-month intervention period she grew into the jersey. She was an unhappy baby who could produce tears at a second, rolling over her little cheeks. She was a low birth-weight 34-week gestation baby. Her arms looked like little sticks and weight bearing on her arms was not achieved easily. At the end of the intervention period more babbling was observed. The language mean scores showed an increase, as for typical development.

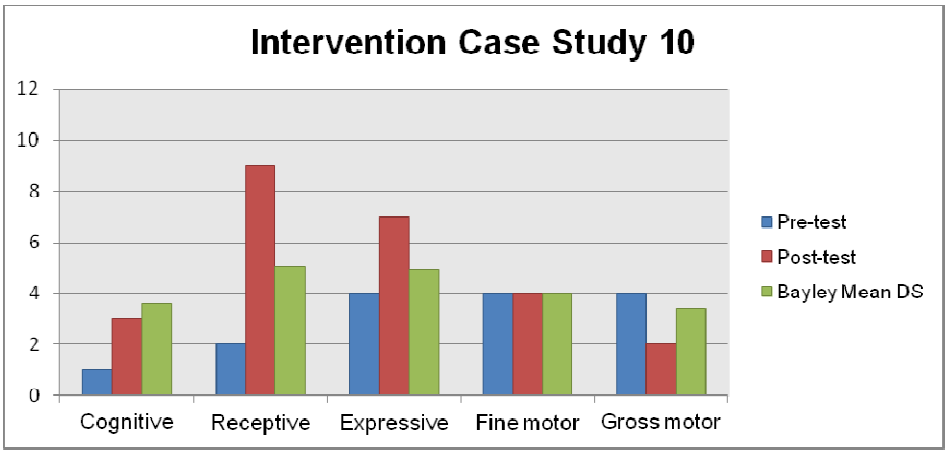

Figure I.9: Participant 9 of intervention group 9 months 3 days

I.10 Afrikaans-speaking boy with DS aged 8 months 22 days after a six-month intervention period

All the domain scores showed a decline for this participant, as illustrated in Figure I.10. He was one of twins. They were born at 32-weeks gestational. The other twin showed typical development and was not diagnosed with DS. The participant had Type 4 (very low) muscle tone. His intervention sessions were on a Saturday afternoon, as they lived north off Bloemfontein. He started at a two-month age, which could have inflated the scores, as discussed in Chapter 6. His dedicated parents were not discouraged by this slow process.

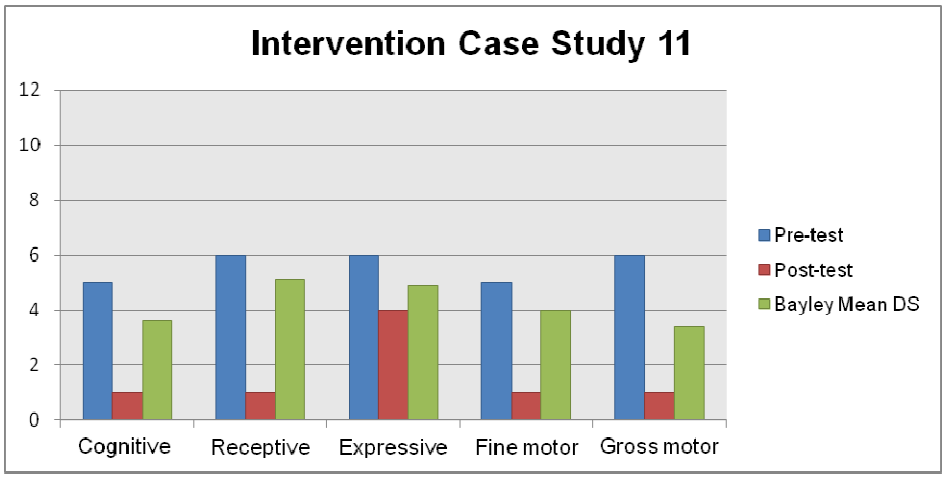

Figure I.9: Participant 10 of intervention group 8 months 22 days

I.11 Sesotho-speaking girl with DS aged 6 months 28 days after a six-month intervention period

This participant's mean scores showed an increase in all the domains, according to Figure I.11. This six-week-old baby girl was born into a family with immense social problems. She started off with low weight and a lethargic attitude, but it changed positively with support during the intervention. At the end of the six-month period, her development was what would be expected of a typical, developed seven-month baby. Her muscle tone was Type 1. This young mother participated with enthusiasm throughout the intervention period and exalted even through her position in her social environment was compromised.

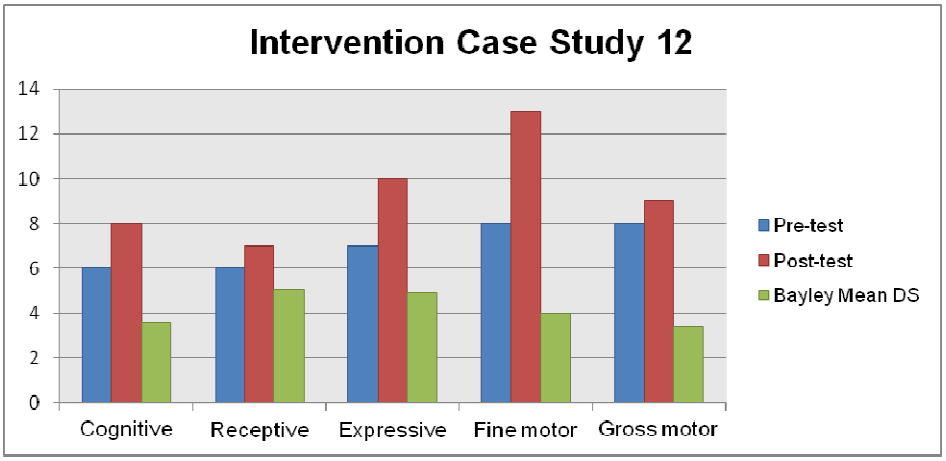

Figure I.11: Participant 11 of intervention group 6 months 28 days

I.12 Xhosa-speaking boy with DS aged 12 months after a six-month intervention period

According to Figure I.12, this participant's mean scores showed an increase in all the domains, but the gross-motor domain. This friendly boy did not enjoy the gross-motor activities. He would easily only extent his legs, so as not to participate in any activity that involves movement. His mother could master the gross-motor activities, but she was not active during the sessions. The six months were a challenge as the mother fell ill often and the sessions had to be re-scheduled five of the 12 times. This could be an explanation for the decrease in the mean score for the gross-motor domain.

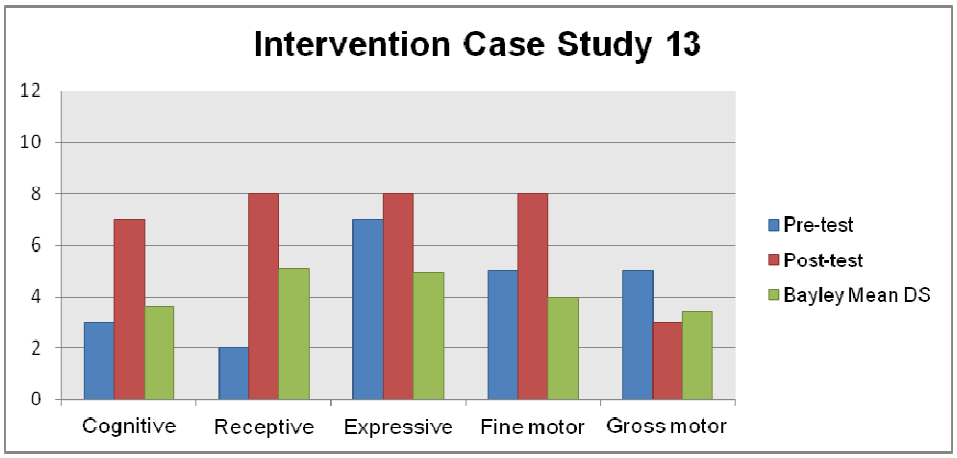

Figure I.12: Participant 12 of intervention group 12 months

I.13 Sesotho-speaking boy with DS aged 13 months 19 days after a six-month intervention period

The mean scores of this participant showed an increase in the language and fine-motor domains, according to Figure I.13. There was a marginal decline in the mean score for the cognitive domain and a greater decline in the gross-motor domain. This friendly participant engaged with enthusiasm throughout the six-month intervention period. His mother, however, was not actively involved in the gross-motor activities during the intervention sessions. She observed and at the end of the session she would only participate when requested by the researcher. The assumption could be made that the gross-motor activities were not performed at home, which the low score illustrates.

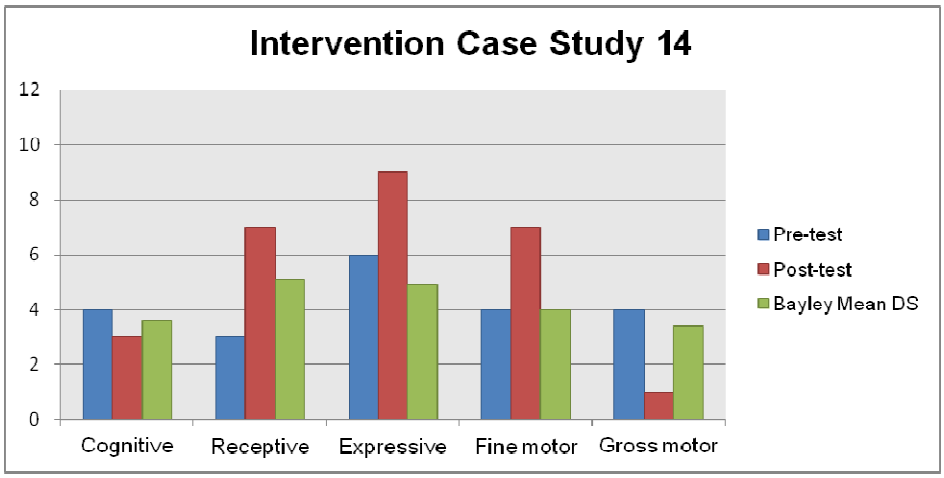

Figure I.13: Participant 13 of intervention group 13 months 19 days

I.14 Sesotho-speaking boy with DS aged 7 months 3 days after a six-month intervention period

According to Figure I.14, this tiny participant showed an increase in cognitive, expressive and fine-motor mean scores with receptive language remaining the same. The gross-motor mean scores declined from 10.0 to 2.0. This baby boy enrolled in the intervention programme at only 25 days old, which could be the rationale for the total inflated mean score for gross-motor domain. His muscle tone was Type 3. The mean score also influenced the total data for the intervention group. This young mother remained motivated and enthusiastic of her baby's development.

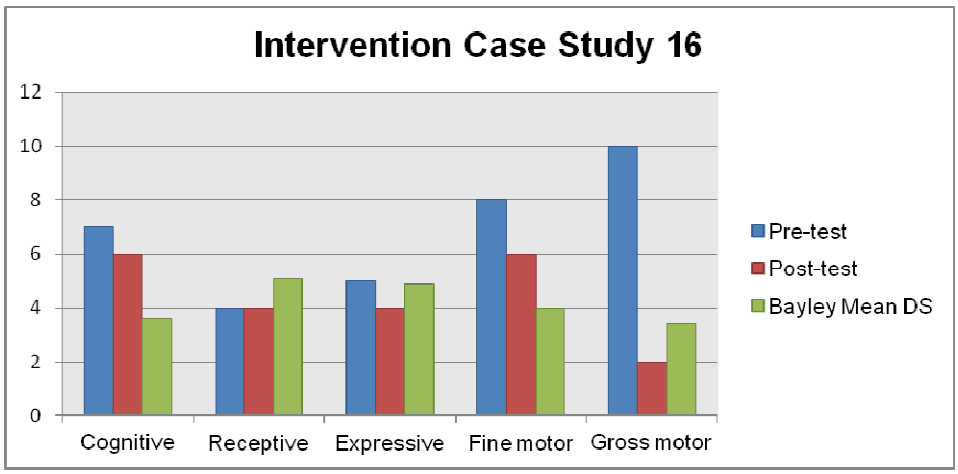

Figure I.14: Participant 14 of intervention group 7 months 3 days

I.15 English-speaking girl with DS aged 6 months 10 days after a six-month intervention period

According to Figure I.15, the participant's median score in the fine-motor domain showed an increase. The cognitive, expressive-language and gross-motor domain showed a marginal decline. The receptive-language domain showed a larger decline in the mean score. A discussion in the study explains that the baby younger than three months showed typically developmental trends and afterwards a developmental decline (cf. 6.2.2.3.2). This may be the reason for the inflated pre-test scores. Her muscle tone was Type 1. The development of this participant with the most beautiful long hair for such a young baby, still showed typical development with mean scores of 7.0 for cognitive, 7.0 for expressive, 11.0 for fine-motor and 8.0 for gross-motor domains after the six-month period.

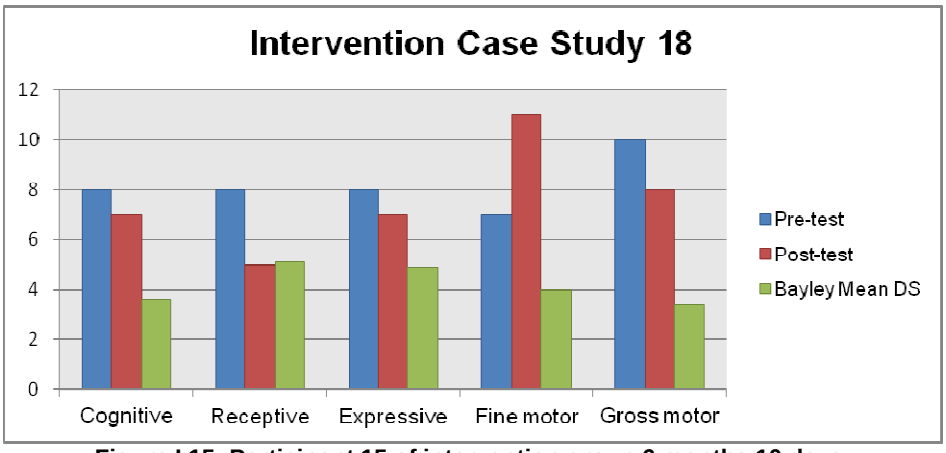

Figure I.15: Participant 15 of intervention group 6 months 10 days

I.16 Sesotho-speaking girl with DS aged 8 months 4 days after a six-month intervention period

The median scores of all the domains showed a decline, according to Figure I.16, with a major decline in the motor domain. Her muscle tone was type 4 (very low). Even though this baby girl did not respond positively towards the activities, her mother remained motivated and was pleased with any of the activity participation. This mother was the only mother not fluent in English or Afrikaans, which resulted in more demonstrations during the intervention sessions. The mother struggled with the execution of the motor activities and could not swiftly master the performance independently. This never discouraged her. The researcher believed the mother compensated for the developmental delay by dressing her baby as a princess in satin for most of the intervention sessions.

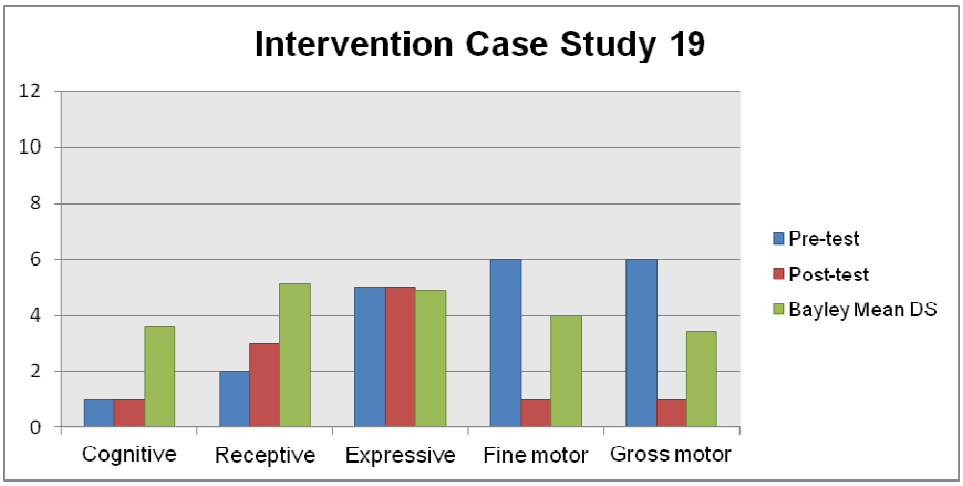

Figure I.16: Participant 16 of intervention group 8 months 4 days

Unfortunately, two participants passed away during the intervention period:

- *Participant seven was a four-month little-old Afrikaans baby girl who died of a bad heart condition on 2 March 2011, during the second month of her intervention. This condition had not been established at birth.*
- *Participant 15 was a 26-month-old Sesotho girl died of pneumonia on 5 May 2011*.

Appendix J

J.1 Afrikaans-speaking girl with DS aged 26 months 27 days after six months of pre-testing

The mean scores of this participant in the cognitive and gross-motor domain remained the same, according to Figure J.1. The language-domain mean scores increased and the fine-motor mean scores declined. Once a month during the six months she participated in an early-intervention programme at a centre, as well as weekly individualised private physiotherapy. This little girl was one of twins, and her sister was not diagnosed with DS.

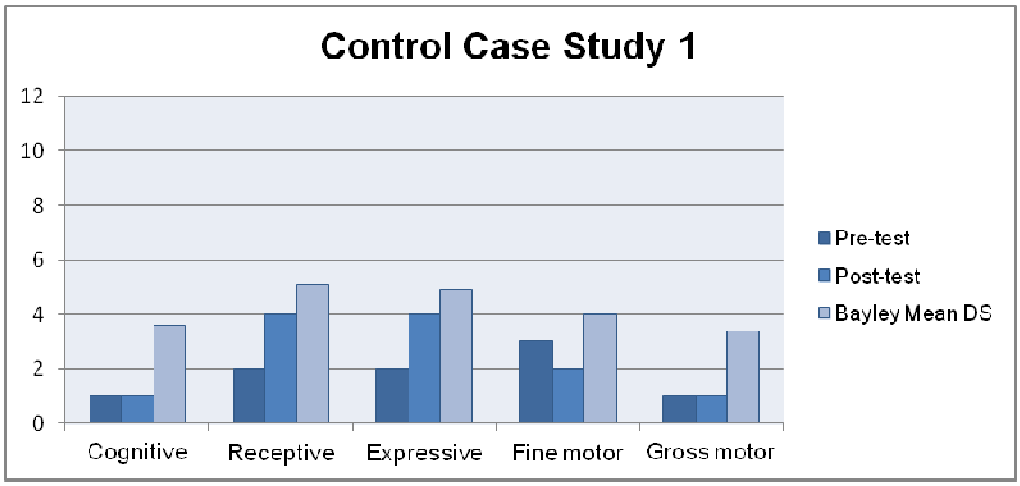

Figure J.1: Participant 1 of control group 26 months 27 days

J.2 English-speaking girl with DS aged 19 months 25 days after six months of pre-testing

This participant's mean scores for cognitive, receptive and gross-motor domain remained the same, as shown in Figure J.2. The mean score in the expressive-language domain declined and there was an increase in the fine-motor domain. This participant received weekly individualised private physiotherapy and speech therapy as well participated in an early-intervention programme at a centre once a month.

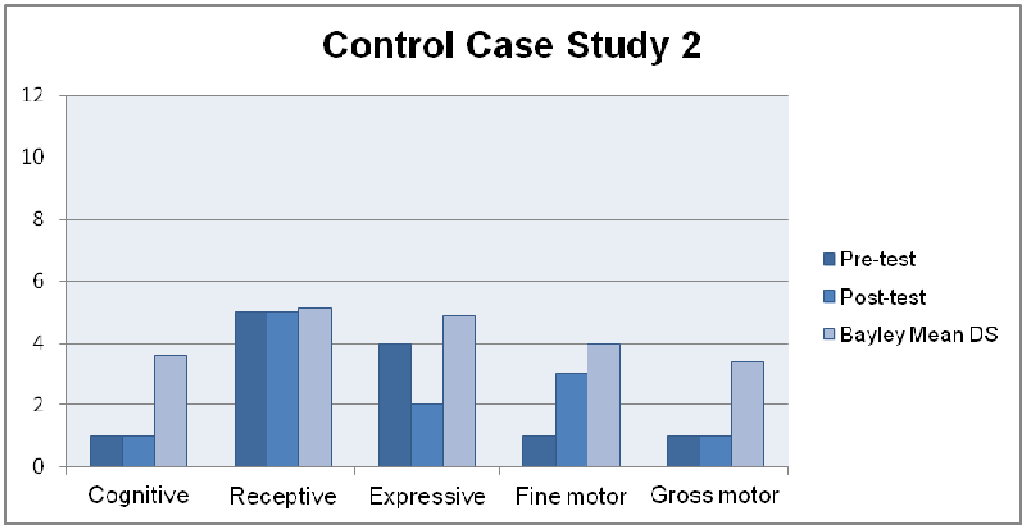

Figure J.2: Participant 2 of control group 19 months 25 days

J.3 English-speaking boy with DS aged 10 months 14 days after six months of pre-testing

This participant mean scores showed an increase in cognitive, expressive language and fine-motor domain according to Figure J.3. The mean scores for receptive and gross-motor domain declined. During the post-test period, the mother stated that she had expected more from her baby after the pre-test and did intervention every day at home. The participant was enrolled in weekly individualised private physiotherapy and once a month he attended an early-intervention programme at a centre.

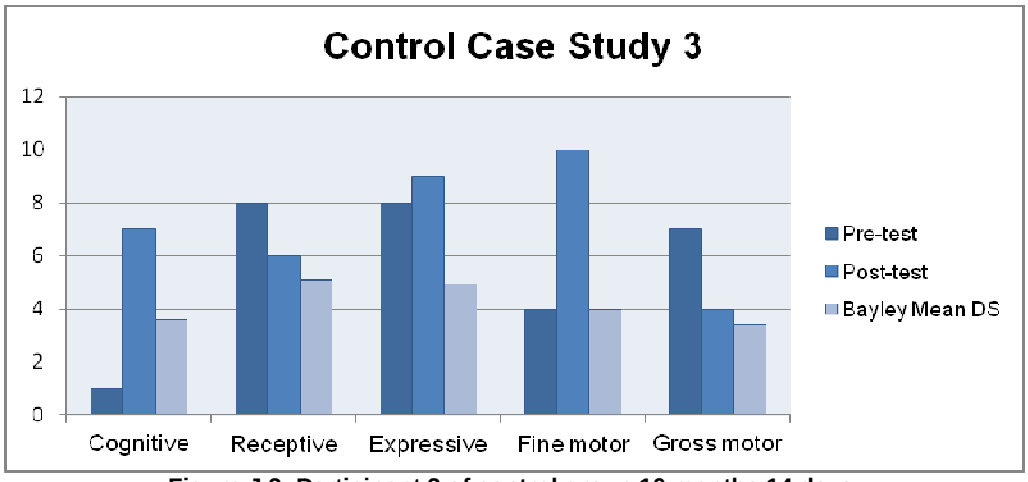

Figure J.3: Participant 3 of control group 10 months 14 days

J.4 Afrikaans-speaking girl with DS aged 15 months 16 days after six months of pre-testing

According to Figure J.4, the mean scores in the cognitive, expressive-language and gross-motor domains indicated a decline. The mean score in the receptive language and fine-motor domain showed an increase. The participant was enrolled in weekly individualised private physiotherapy and once a month she attended an early-intervention programme at a centre.

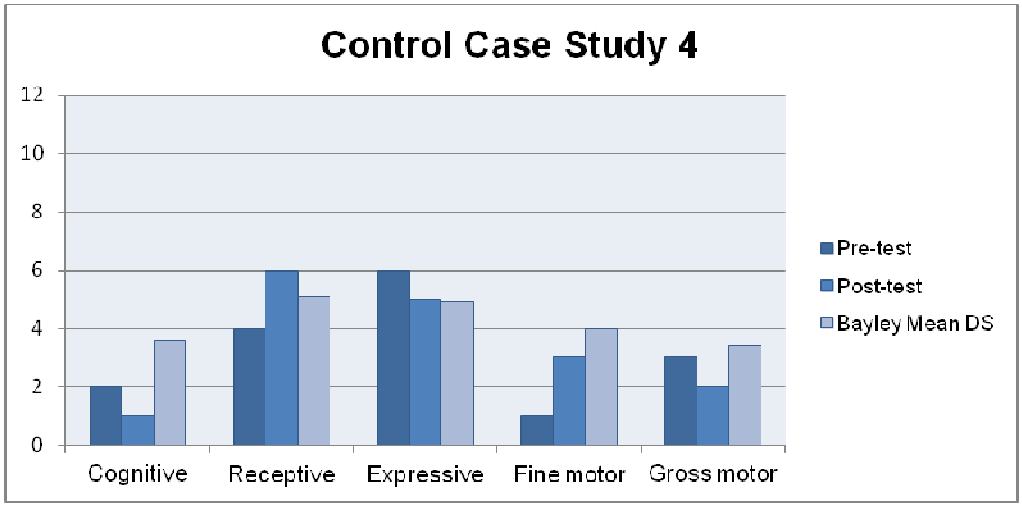

Figure J.4: Participant 4 of control group 15 months 16 days

J.5 English-speaking girl with DS aged 13 months 26 days after six months of pre-testing

This participant's mean scores indicated a decrease in the cognitive and gross-motor domain. The mean scores, according to Figure J.5, showed an increase in the language and fine-motor domains. No other therapy of early intervention took place.

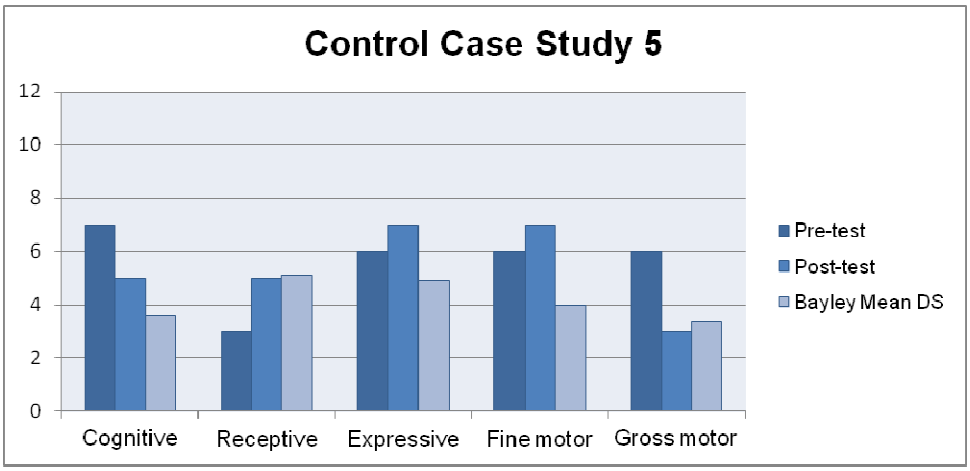

Figure J.5: Participant 5 of control group 13 months 26 days

J.6 Afrikaans-speaking boy with DS aged 15 months 11 days after six months of pre-testing

According to Figure J.6, the mean scores in the cognitive domain declined. The language domains showed an increase and the motor-domain mean scores remained the same. The participant was enrolled in weekly individualised private physiotherapy and once a month he attended an early-intervention programme at a centre.

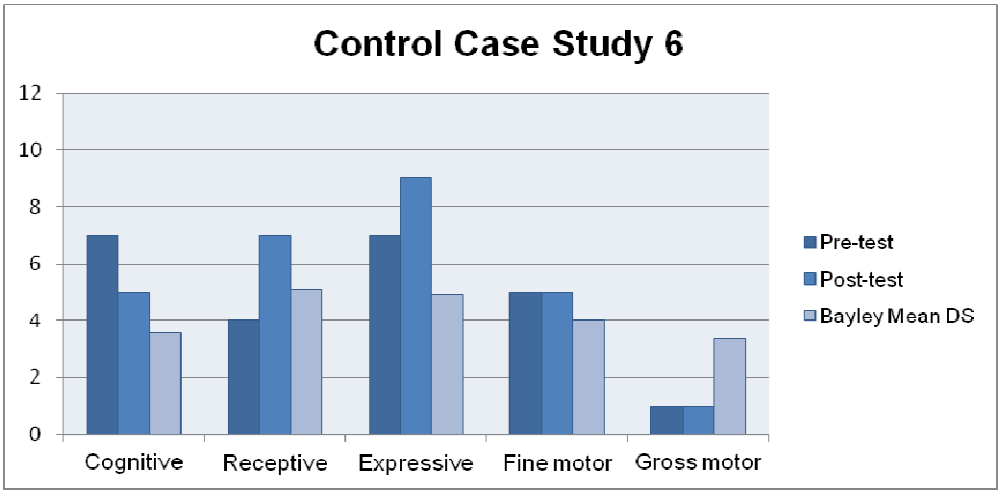

Figure J.6: Participant 6 of control group 15 months 11 days

J.7 English-speaking boy with DS aged 18 months 18 days after six months of pre-testing

The participant was enrolled in weekly individualised private occupational therapy, physiotherapy, speech therapy and an early-intervention home programme. According to Figure J.7, there was an increase in gross-motor mean scores. All the other domains, namely the cognitive, receptive-language and fine-motor domains showed a decline in mean scores. The expressive language remained the same and the mean score was what would be expected from typical development.

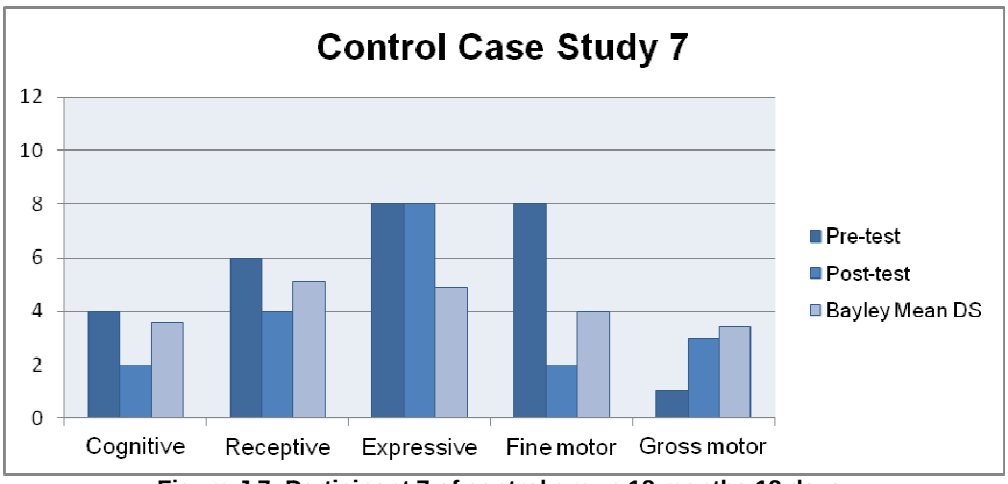

Figure J.7: Participant 7 of control group 18 months 18 days

J.8 Sesotho-speaking girl with DS aged 10 months 1 day after six months of pre-testing

This participant received speech therapy once every second week at a public-sector facility. According to Figure J.8, the participant's mean score in the expressive language showed an incline. The cognitive mean scores remained the same and the receptive-language and motor domains showed a decline in the mean scores.

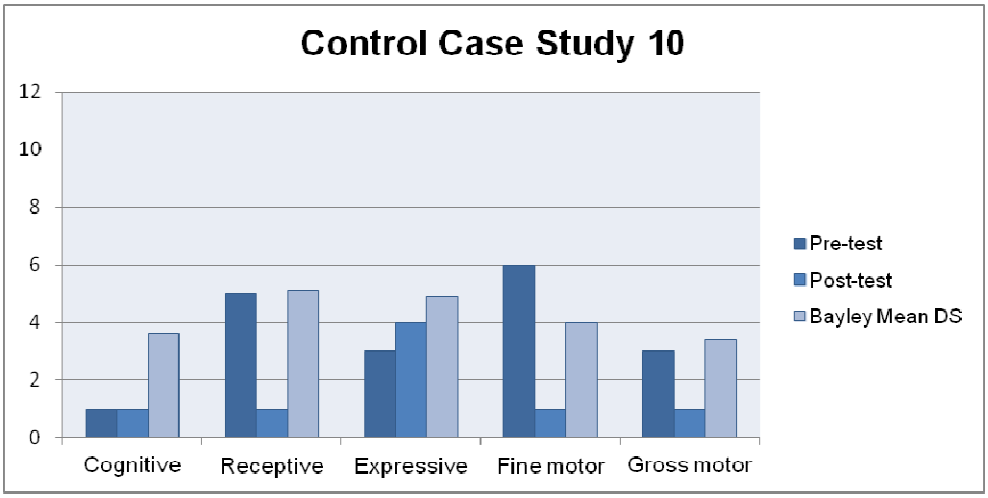

Figure J.8: Participant 8 of control group 10 months 1 day

J.9 English-speaking boy with DS aged 8 months 19 days after six months of pre-testing

According to Figure J.9, all the domains' mean scores showed a decline. This participant was not enrolled in any form of early intervention, by choice of the parents.

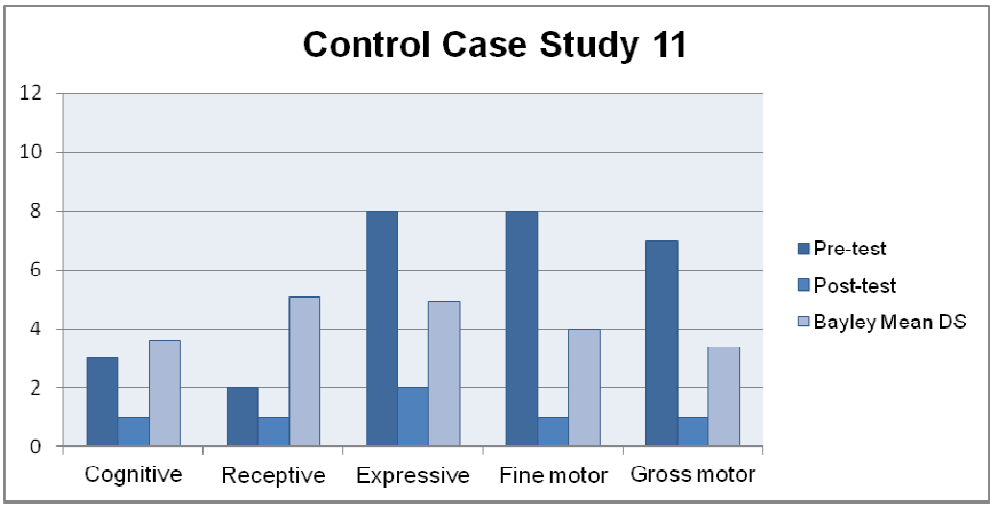

Figure J.9: Participant 9 of control group 8 months 19 days

J.10 English-speaking girl with DS aged 15 months 2 days after six months of pre-testing

This participant's mean scores in all the developmental domains increased during the six-month period, according to Figure J.10. The fine-motor domain mean score (8.0) indicated typical development. After the pre-test the mother enrolled her for public-sector occupational therapy and physiotherapy weekly.

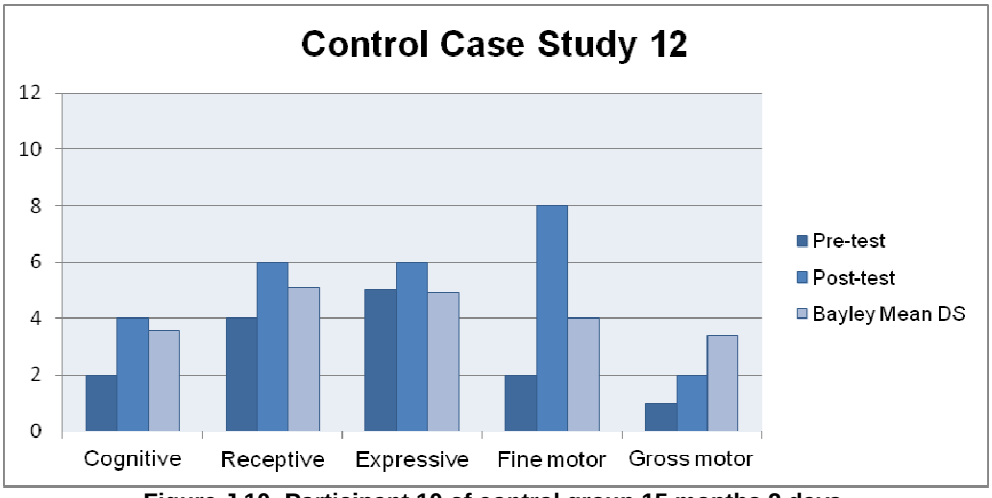

Figure J.10: Participant 10 of control group 15 months 2 days

J.11 Zulu-speaking boy with DS aged 20 months 21 days after six months of pre-testing

According to Figure J.11, the mean scores in the cognitive domain declined and remained the same in the expressive language. The receptive-language, fine- and gross-motor domains showed an increase in the mean scores. This participant received weekly occupational therapy, physiotherapy and speech therapy at a public-sector facility before the pre-test and continued with the intervention during the six-month period.

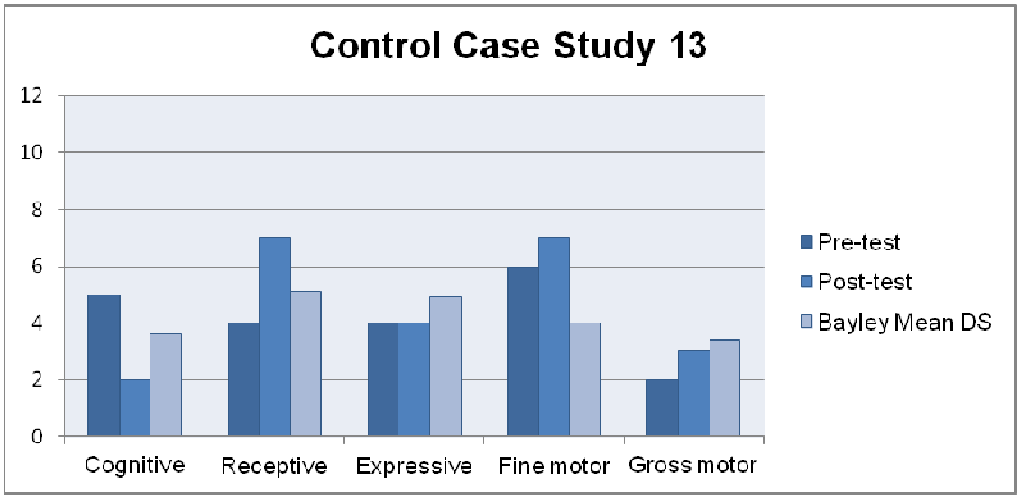

Figure J.11: Participant 11 of control group 20 months 21 days

J.12 English-speaking girl with DS aged 7 months 17 days after six months of pre-testing

According to Figure J.12, the mean scores in the cognitive, receptive-language and gross-motor domains showed a decline. In Chapter 6 an explanation for the inflated pre-test scores was discussed (cf. 6.2.2.3.2). The expressive-language and fine-motor domain mean scores remained the same. This participant used a home-programme stimulation manual during the six-month period.

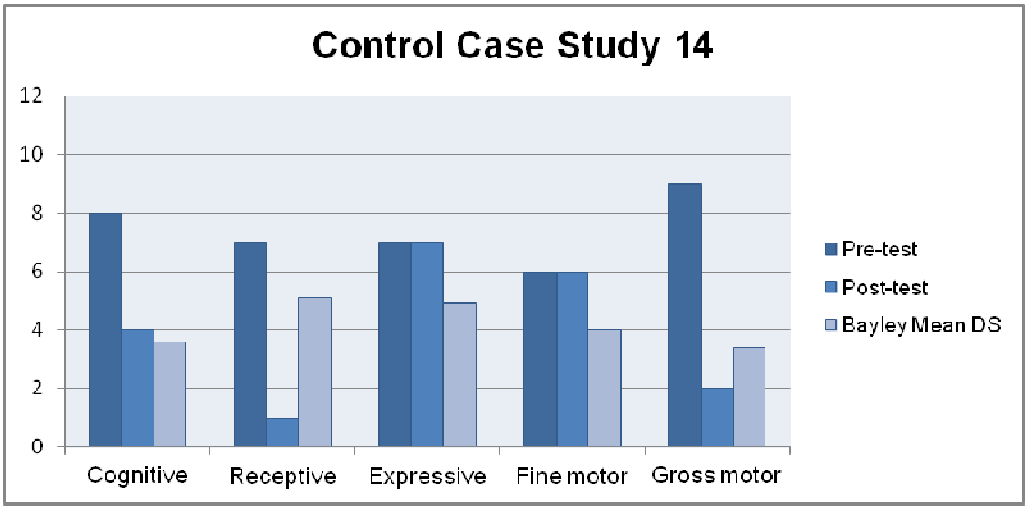

Figure J.12: Participant 12 of control group 7 months 17 days

J.13 English-speaking girl with DS aged 13 months 21 days after six months of pre-testing

According to Figure J.13, the mean scores in all the domains, except the gross-motor domain showed an increase. Her language domain showed typical development. The participant received individualised private physiotherapy.

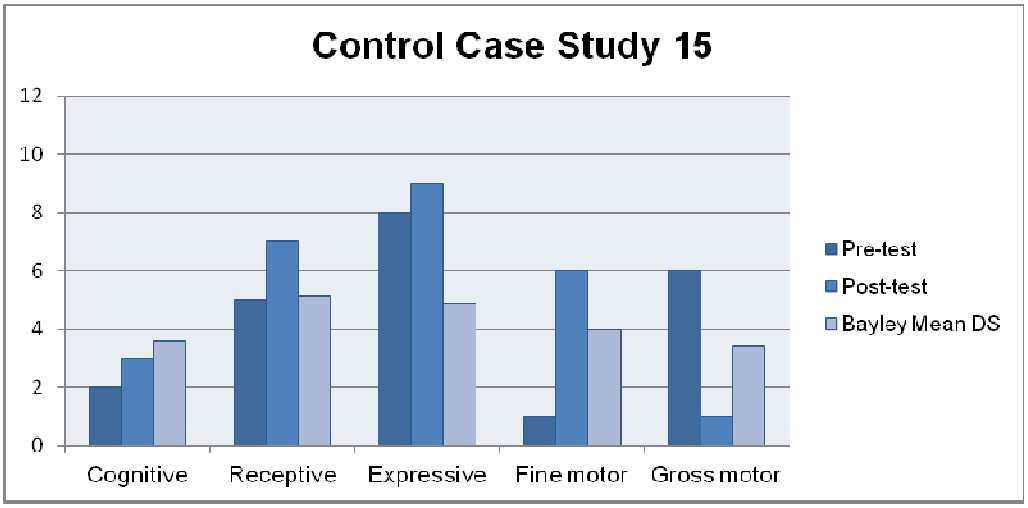

Figure J.13: Participant 13 of control group 13 months 21 days

J.14 English-speaking girl with DS aged 28 months 1 day after six months of pre-testing

According to Figure J.14, the participant's mean scores remained the same after the six-month period. She did not receive any form of intervention during the six months. She was one of twins also diagnosed with DS.

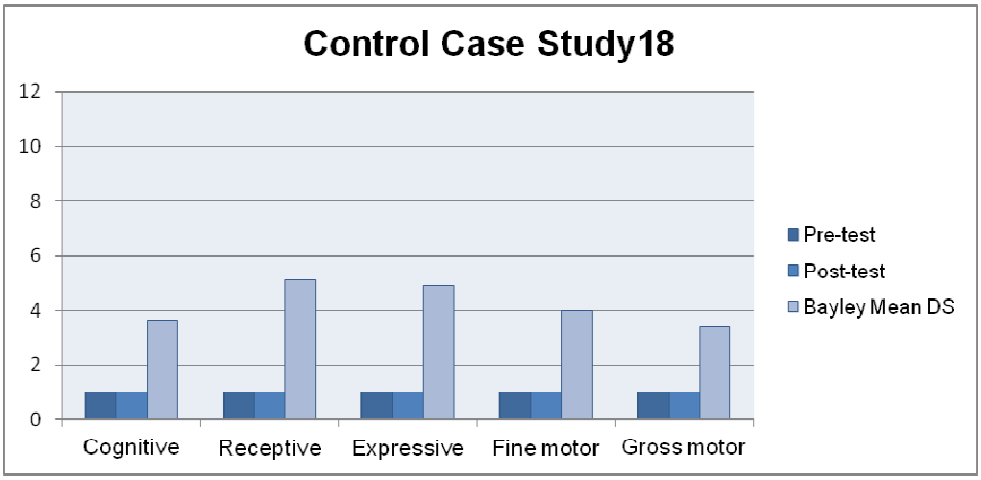

Figure J.14: Participant 14 of control group 28 months 1 day

Post-testing for four participants was withdrawn from the study for the following reasons, with the result that the post-tests were not carried out.

- *Participant 8 was a 16-month, 14-day English baby girl (pre-test age). Her parents withdrew on their own account from study and refused a post-test.*
- *Participant 9 was an 11-month, 26-day Sesotho girl (pre-test age). Unknown to the researcher and the mother, the participant had a heart condition. She had a heart operation before the post-test date (Artrialventricular septal defect repair).*
- *Participant 17 was a newborn Sesotho baby, who could not be traced after the pre-test. The researcher explored all the possibilities to trace this baby, but with no success.*
- *Participant 19 was a 22-month, 3-day English girl (pre-test age) who passed away with pneumonia.*

Appendix K

Appendix K: Calculation of medians

Intervention group: Cognitive development

id	pre	post	difference
1	6	7	1
2	6	7	1
3	3	3	0
4	2	2	0
5	5	3	-2
6	2	5	3
8	6	6	0
9	5	6	1
10	1	3	2
11	5	1	-4
12	6	8	2
13	3	7	4
14	4	3	-1
16	7	6	-1
18	8	7	-1
19	1	1	0

Pre-test values sorted from small to large:
1, 1, 2, 2, 3, 3, 4, 5, 5, 5, 6, 6, 6, 6, 7, 8
Median is **5**

Post-test values sorted from small to large
1, 1, 2, 3, 3, 3, 3, 5, 6, 6, 6, 7, 7, 7, 7, 8
Median is **5.5**

Changes (post-test - pre-test) sorted from small to large
-4, -2, -1, -1, -1, 0, 0, 0, 0, 1, 1, 1, 2, 2, 3, 4
Median is **0**

Calculation of medians

Control group: Cognitive development

id	pre	post	difference
1	1	1	0
2	1	1	0
3	1	7	6
4	2	1	-1
5	7	5	-2
6	7	5	-2
7	4	2	-2
10	1	1	0
11	3	1	-2
12	2	4	2
13	5	2	-3
14	8	4	-4
15	2	3	1
18	1	1	0

Pre values sorted from small to large:
1, 1, 1, 1, 1, 2, 2, 2, 3, 4, 5, 7, 7, 8
Median is **2**

Post-values sorted from small to large
1, 1, 1, 1, 1, 1, 2, 2. 3, 4, 4, 5, 5, 7
Median is **2**

Changes (pre-test - post-test) sorted from small to large
-4, -3, -2, -2, -2, -2, -1, 0, 0, 0, 0, 1, 2, 6
Median is **-0.5**

Appendix L

Comparisons of six matching participants Intervention and Control groups

According to the statistical data there was only a change in pre-test and post-test scores for cognitive, language development. Individual comparisons of participants, matching the intervention and control groups, there were changes in all the domains.

According to Figure L.1, the intervention group participant scored higher in all the domains than the control group participant and Bayley Scales III for DS.

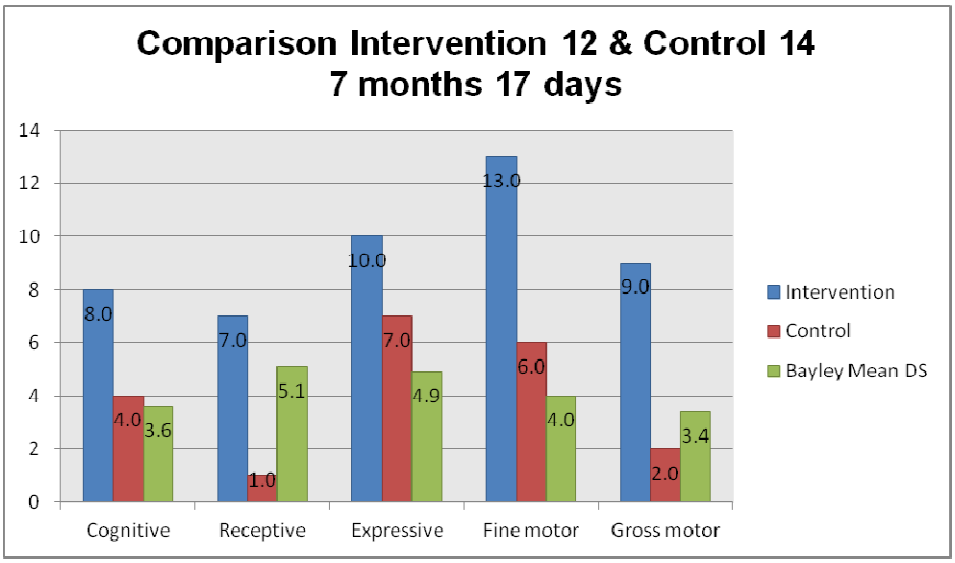

Figure L.1: Comparison Intervention 12 and Control 14

According to Figure L.2, the intervention group participant mean scores showed more increases that than the control and Bayley Scales III for DS.

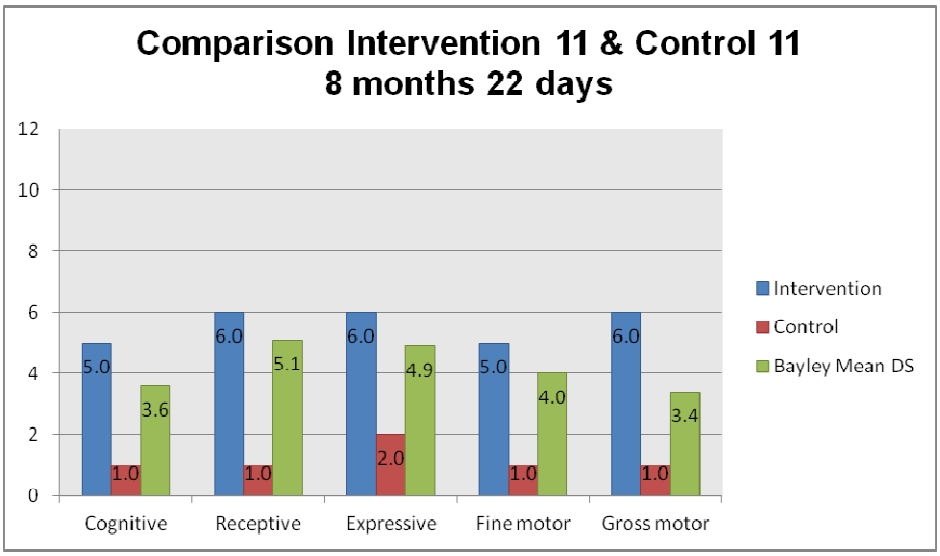

Figure L.2: Comparison Intervention 11 and Control 11

In Figure L.3, the intervention group participant scored remained the same in all the developmental domains, but increased scores in the fine-motor domain than the control group participant. The Bayley Scales III for DS were higher for cognitive and gross-motor domains.

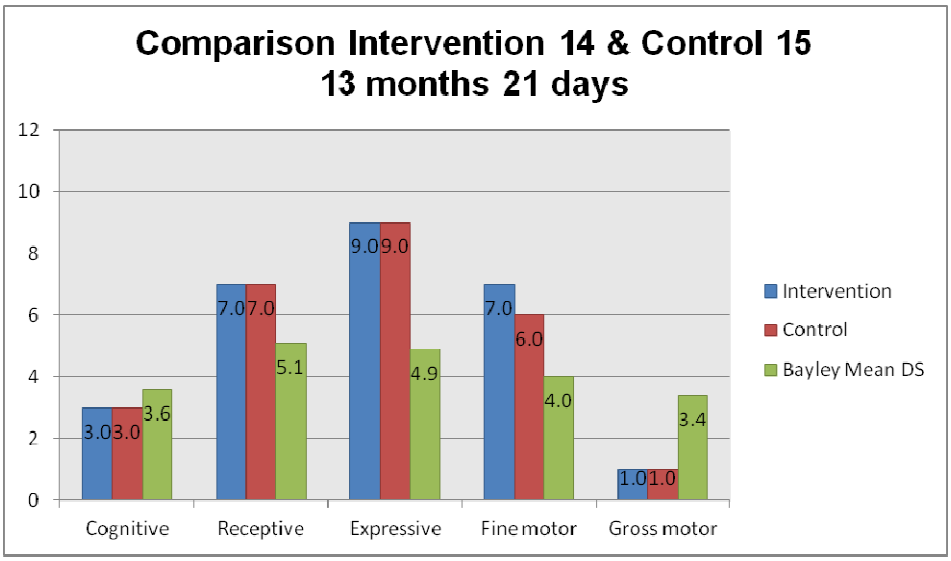

Figure L.3: Comparison Intervention 14 and Control 15

In Figure L.4 the intervention group participant had increased scores in all the domains, than the control group participant and Bayley Scales III for DS.

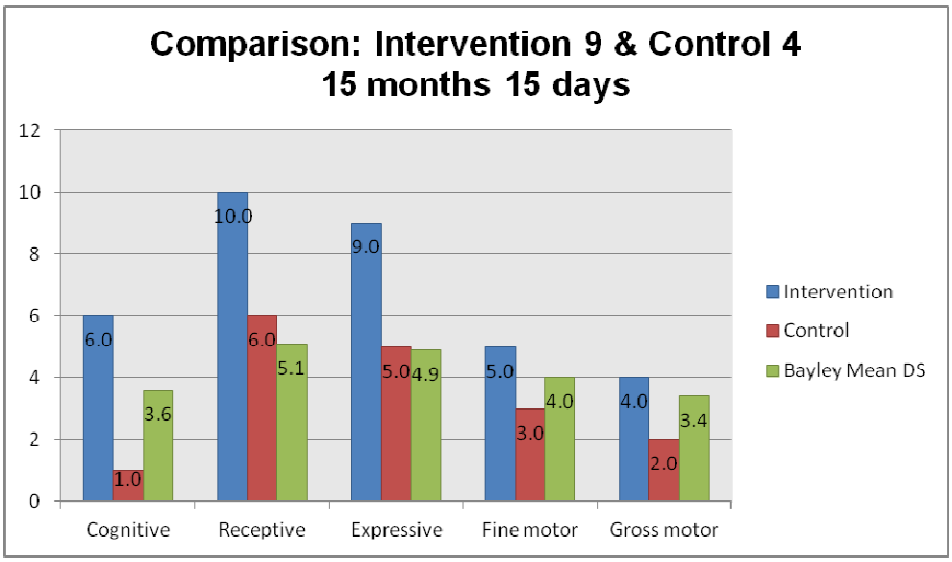

Figure L.4: Comparison Intervention 9 and Control 4

According to Figure L.5, the intervention group participant showed increased scores in all the domains than the control group participant and Bayley Scales III for DS, except the intervention participant scores remained the same for expressive language and fine-motor and poorly in gross-motor domain.

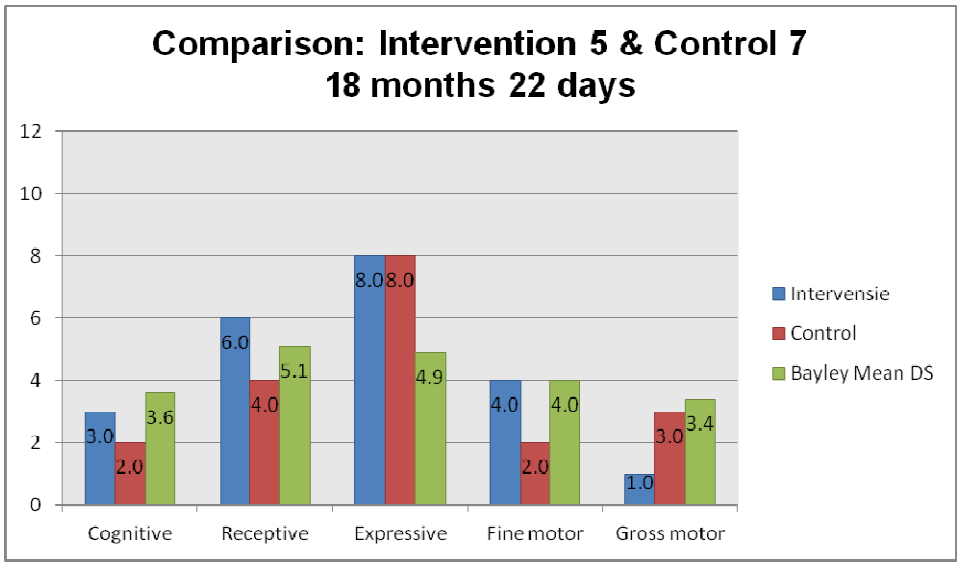

Figure L.5: Comparison Intervention 5 and Control 7

The same tendency as the previous comparison was shown in Figure L.6. The intervention group participant showed increased scores in all the domains than the control group participant and Bayley Scales III for DS, except slightly lower than Bayley Scales III for DS in the cognitive and gross-motor domain.

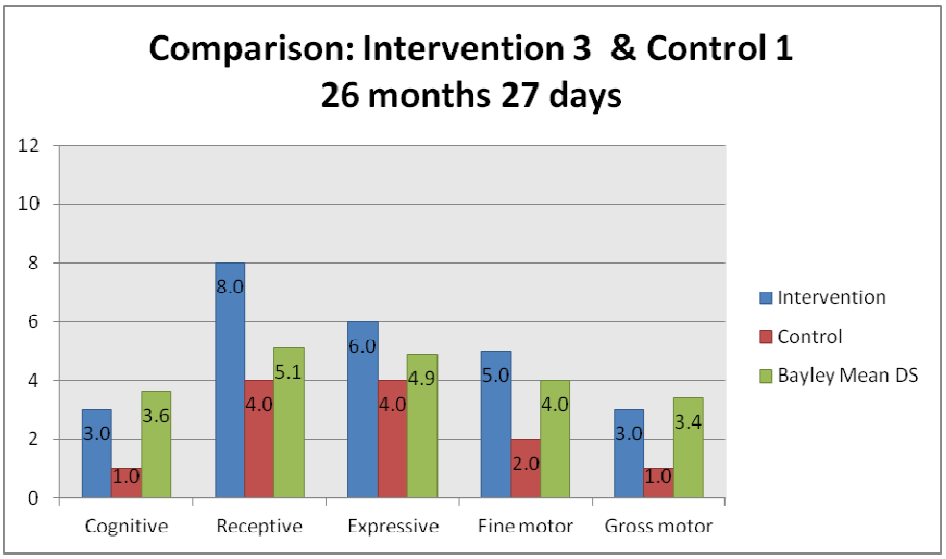

Figure L.6: Comparison Intervention 3 and Control 1

In all the comparisons the intervention group showed increased scores or the scores remained the same as the control group, however only one participant showed a decreased score in the gross-motor domain.