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DEPARTMENT OF OCCUPATIONAL THERAPY

THE CONTRIBUTION OF OCCUPATIONAL THERAPY IN THE HOLISTIC MANAGEMENT OF A CHILD WITH TETRA-AMELIA SYNDROME.

SUBMITTED IN FULFILMENT OF THE REQUIREMENTS FOR THE MASTERS DEGREE IN OCCUPATIONAL THERAPY

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“I can do everything through Christ who gives me strength”

- Philippians 4:13

DECLARATION

Student Number: 28000308

I, **Melissa Nicole Pretorius**, declare that **The contribution of Occupational Therapy in the holistic management of a child with Tetra-Amelia Syndrome** is my own work and that all the sources that have been used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted for any other degree at any other institution.

August 2018

Melissa Nicole Pretorius **Date**

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ABSTRACT

Introduction: Tetra-Amelia Syndrome (TAS) is a rare genetic disorder characterised by the WNT3 gene mutation and a clinical presentation of an absence of all four limbs. It creates a tremendous physical limitation for children and adults living with this condition. They require continuous support throughout their lives to function as optimally as they can. Occupational therapists often help children and adults with severe physical limitations to participate by adapting activities, enhancing occupational performance and participation and applying assistive technology.

Aims: The aims of this research study was to explore and describe the contribution of occupational therapy in the holistic management of TAS.

- Explore and describe how occupational therapy contributed to the development of occupational engagement in a young child with TAS.
- Explore and describe how assistive technology contributed to the development of occupational engagement in a young child with TAS.
- To reflect on future considerations for an individual with TAS.

Methodology: A single case study design was used to explore and describe the general nature of the case holistically from a variety of angles. Purposive sampling was used to select one unique individual case of a child with Tetra-Amelia Syndrome. Multiple sources of data included existing reports, videos/photographic evidence, semi-structured interviews with key role players and formalised testing with regards to participation in play, school and activities of daily living. The researcher used content analysis as described by Elo and Kyngäs (2008) to analyse the transcribed interviews. The themes identified included: Occupational engagement, Assistive technology (AT), therapeutic intervention, children's rights and future considerations.

Findings & Conclusion: Occupational therapy intervention has proved to provide a significant contribution in the occupational engagement of a child with TAS. Early intervention in her case has supported and paved her way to enhanced participation and performance in ADL, IADL, play, social and school occupations. Assistive technology including wheelchairs, tablets, laptops and low technology devices have further enabled her to overcome the physical barriers she encounters on a daily basis in aspects like mobility, self-care, play and academic pursuits. By encompassing the frameworks, models and principles of occupational therapy, the ongoing process of assessment, intervention and clinical reasoning has proved imperative to the success of this case. By looking at this case holistically and considering the person, environment and what occupations are important and meaningful, an occupational therapist can contribute greatly to the overall quality of life, wellness and satisfaction of a child with TAS.

Key words: Tetra-Amelia Syndrome, Occupational Therapy, case study, early intervention, assistive devices, assistive technology, occupational performance, occupational engagement, person-environment-occupational performance model, disability.

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LIST OF ABBREVIATIONS/ACRONYMS

Abbreviation/acronym	Meaning
ADL	Activities of Daily Living
AT	Assistive Technology
ATD	Assistive Technology Device
IADL	Instrumental Activities of Daily Living
MOHO	Model of Human Occupation
OT	Occupational Therapy
OTP	Occupational Therapy Process
OTPF	Occupational Therapy Practice Framework
PEOP	Person, Environment and Occupational Performance model
QUEST	Quebec User Evaluation of Satisfaction with Assistive Technology
TAS	Tetra-Amelia Syndrome
TVPS	Test of Visual Perceptual Skills
VMI	Visual Motor Integration

CHAPTER ONE

ORIENTATION TO THE STUDY

1.1. INTRODUCTION

Tetra-Amelia Syndrome (TAS) is a rare genetic disorder characterised by the WNT3 gene mutation and a presentation of an absence of all four limbs. Minimal data on the course of the disease or the prognosis are available because the condition is so rare. In nearly all reported cases, the pregnancy was terminated on diagnosis of TAS, or babies died shortly after birth because of other complications. Limb agenesis is generally compatible with life if adequate assistance is provided. The natural course of the disease is likely to be determined by extent and degree of associated manifestations (Kliegman & Nelson, 2007).

It creates a tremendous physical limitation for children and adults living with this condition. They require continuous support throughout their lives to function as optimally as they can. Occupational therapists (OTs) help children and adults with severe physical limitations to participate or engage more optimally in meaningful occupations by adapting activities and applying assistive technology (AT). The role of assistive technology with children is not simply to compensate for a missing or delayed function; but is also used to promote development in targeted performance areas (Case-Smith & O'Brien, 2014;18).

This study focused on exploring and describing the unique contribution of occupational therapy in the holistic management of a child with TAS.

1.2. RATIONALE/BACKGROUND

The researcher has had the privilege in working with children with severe physical, mental, emotional and social limitations and disabilities over the past few years. In this time, she came across one very rare and unique case of a girl, henceforth named

Emily (*not her real name), born with Tetra-Amelia Syndrome (TAS). Emily presents with no other conditions or limitations.

The researcher has been a part of a team of professionals that cared for Emily since 2013. As a young occupational therapist, it has taken much problem-solving, creativity and flexibility to look at her case holistically and provide her with appropriate intervention to enhance her quality of life. Even though Emily has no intellectual limitations, the physical nature of her condition has and stands the chance to affect her emotional, mental and social development in the future. It also poses the threat of limiting her mobility, participation in activities of daily living (ADL), instrumental activities of daily living (IADL), play participation, school inclusivity and quality of life.

Over the past few years, Emily has shown amazing resilience and adaptability to her own limitations. When the researcher first met her at a young age of 1 year old, she was learning to sit and roll herself on the floor in her home and was fully dependent on her caregivers for vital daily activities. Now at 6 years of age, she can now independently manoeuvre her own motorised wheelchair in her home, school and community. She is also a master in completing educational activities on her tablet using her left stump, feeding herself with an adapted utensil, and using a computer system for learning at school. It is evident that she needs access to assistive technology to adapt her play activities, aid in her independence with daily tasks and learning at school. Her development despite her limitations is amazing. She will however require life-long assistance and support to live her life as independently as possible.

It has come to the researcher's knowledge that the need for therapeutic intervention in such a case is vital for the long-term benefits of a person with TAS. The rights of such a person need to be advocated for in terms of acquisition of assistive devices to enhance their independence throughout their lifetime, school inclusivity as well as vocational pursuits, community and social participation. Due to the uniqueness of these cases, there is minimal research medically as well as in the occupational therapy field. Therefore, few guidelines for occupational therapists working with these children exist, especially in a South African context. There seems to be poor awareness of the long-term needs and rights of these children within the South African context.

There are currently no research studies/articles/book sections available for occupational therapy and the specific management of children with TAS. There is however some research and literature on the role of the occupational therapists in dealing with children and certain limb defects/deficiencies that one can apply. Per Case-Smith (2005), limb deficiencies in children are mostly due to congenital malformations. Common limb malformation conditions include polydactyly (excess of fingers and toes), syndactyly (webbing), bradydactyly (larger digits) and microdactyly (smaller digits). Congenital limb deficiencies include Amelia (absence), phocomelia (missing proximal segments of limbs), paraxial deficiency (medial or lateral aspect of limb missing) and transverse hemimelia (amputation of a limb segment across the central area). Research suggests that these children be fitted with prostheses or assistive devices as early as two months but usually by six months of age. Hybrid and myo-electric prosthesis have developed significantly over the past few years in 1st world countries, making the use of prosthesis more realistic and appropriate. This is not the case in South Africa due to lack of funding and resources.

It is said that if these devices (prosthesis, wheelchairs) are used early on in a child's life, the child develops a more intuitive use of the available muscle groups to power the device. As the child grows and matures, new devices are fabricated that suit the child's size and skills. This process is very complex for children with multiple amputations or limb deficiencies like in the case of TAS.

1.3. PROBLEM STATEMENT

As mentioned above, minimal data on the management of TAS exists. Persons without extremities depend on extensive, life-long assistance with most daily activities. They would require custom designed wheelchairs with assistive electronic technology and input control devices operated by available head, chin, or tongue movements. Should individuals with TAS survive, management depends on the presence and severity of associated malformations (organ abnormalities, neurological deficit etic) and may involve multiple interdisciplinary surgical interventions and the support of several medical and allied disciplines (Case-Smith & O'Brien, 2014).

A child born with TAS will present with barriers to meaningful occupations like activities of daily living, play, social and school participation. They need to be advocated for in

the context of South African to reduce marginalisation and to successfully include them in home, social and community environments. Quality of life and occupational competence should be pursued with support from their families, schools, medical team and community.

From the researcher's experience working as a therapist in a government setting in South Africa, even though orthotic, prosthetic and occupational therapy services are rendered at some government institutions, they do not fully cater for severe cases like Emily. The waiting lists are long for manual prostheses and powered wheelchairs or other high technology devices and they do not cater for children who would benefit from myo-electric prostheses or customised wheelchairs due to large import costs of parts. Therefore, therapists must adapt their strategies of intervention, use greater clinical reasoning skills to provide and facilitate more adaptive approaches as well as low cost assistive devices to enhance independence and occupational engagement of an individual like Emily.

There is a lack of knowledge and guidelines for occupational therapists working with severe cases such as Emily's. However, occupational therapists have a unique and significant role to play in the management and intervention of these children's lives; hence the need to conduct research.

1.4. RESEARCH QUESTION

How did the **occupational therapy process contribute to the holistic management of a child with Tetra-Amelia Syndrome**?

1.5. AIM AND OBJECTIVES

The **aim** of this research study was to explore and describe the contribution of occupational therapy in the holistic management of TAS.

The **objectives were to**:

- Explore and describe how occupational therapy contributed to the development of occupational engagement in a young child with TAS.

- Explore and describe how assistive technology contributed to the development of occupational engagement in a young child with TAS.
- To reflect on future considerations for an individual with TAS.

1.6. CONCEPT CLARIFICATION

Tetra-Amelia Syndrome (TAS): Tetra-Amelia Syndrome is a rare genetic disorder characterised by the WNT3 gene mutation and a clinical presentation of an absence of all 4 limbs (Kliegman & Nelson, 2007).

Occupational Therapy (OT): Occupational therapy is a client-centred health profession concerned with promoting health and wellbeing through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement (WFOT, 2012).

Occupational Therapy Process (OTP): The occupational therapy process is the client-centred delivery of occupational therapy services. The process includes evaluation and intervention to achieve targeted outcomes, occurs within the purview of the occupational therapy domain, and is facilitated by the distinct perspective of occupational therapy practitioners when engaging in clinical reasoning, analysing activities and occupations, and collaborating with clients. It includes the overview of the process as it is applied within the profession's domain, the evaluation process, the intervention process, and the process of targeting outcomes (AOTA, 2014).

Occupational Therapy Practice Framework (OTPF): The Occupational Therapy Practice Framework: Domain and Process describes the central concepts that ground occupational therapy practice and builds a common understanding of the basic tenets and vision of the profession (AOTA, 2014).

Occupational Science: Occupational Science is defined as having it's roots as a basic science aimed at building knowledge about the characteristics, form, function and meaning of what people do (Zemke & Clark , 1996). It also looks at the

occupational nature of being human (Wilcock, 2006). It involves building knowledge about the observable and phenomenological aspects.

Early Intervention: It refers to the program implementation or treatment designed to maintain or enhancce a child's development in natural environments. This usually refers to the first three years of a child's life, seen as the critical period. The goal of early intervention is 'to prevent or minimize the physical, cognitive, emotional and resource limitations of young children disadvantaged by biological or environmental risk factors" (Blackman, 2002).

Assistive Technology (AT): Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain or improve the functional capabilities of persons with disabilities (Assistive Technology Industry Association).

Occupation: Yerxa et al. (1989) defines occupation as "specific chunks" of activity within the ongoing stream of human behaviour. These daily pursuits are self-initiated, goal-directed (purposeful) and socially sanctioned. She further defines them as units of activity which are classified and named by the culture according to the purposes they serve in enabling people to meet environmental challenges successfully.

Participation: Participation can be described as the involvement in life situations (e.g. activities of daily living, play, leisure, education, social, work etc.) Participation or involvement in everyday occupations is vital for all humans. As described by the World Health Organization, participation has a positive influence on health and well-being. The presence of disability has been found to lead to participation that is less diverse, is located more in the home, involves fewer social relationships, and includes less active recreation. Occupational therapy is in a unique position to contribute to the development and fulfillment of participation for persons with and without disabilities (Law, 2002).

Independence: can be defined as the performance parameter found in occupational therapy treatment. It can be described as the measurable part of the goal laid out initially. Independence in activity or occupation can be divided into three phases namely; initiation of the activity, continuation of the activity and completion of the activity (Sames, 2010).

Occupational Justice: Occupational Justice is concerned with ethical, civic and moral issues such as fairness and equity for individuals specific to the engagement and participation of meaningful occupation. Occupational injustice can therefore be defined as the undermining of occupational rights of individuals to meet basic occupational needs and have equal opportunities to reach their potential (Boyt Schell, Gillen, & Scaffa, 2014, pp. 542-543).

1.7. SIGNIFICANCE OF STUDY

The study focused on the contributions of occupational therapy to a unique case of Tetra-Amelia syndrome. It stands the chance of assisting future cases of individuals born with TAS to enhance their performance and participation in all areas of their life; thus, providing quality of life. It will assist in raising awareness of occupational therapy profession and the vital role that occupational therapists can play in the management of children with severe physical disabilities; specifically, in a rare case such as TAS. It will provide a reference point for new or inexperienced therapists faced with such a case and can be used to advocate for funding from the government for better access to customised adaptive technology, school inclusion and participation and vocational pursuits for such cases.

1.8. CONTEXT OF THE STUDY

The study was conducted in the Gauteng province across various locations including a public special needs school, group foster home environment and university premises.

1.9. RESEARCH METHODOLOGY

A single, descriptive case study design was used to explore and describe the general nature of the case in a holistic manner. Purposive sampling was used to select one unique individual case of a child with Tetra-Amelia syndrome. Multiple sources of data were used. Case study research is used to explore real life experiences and situations,

when the researcher is interested in both the phenomenon and the context in which it occurs. Case study research seeks out rich, in-depth information. It aims to investigate a topic in its context from multiple viewpoints and it uses multiple methods and multiple data sources for its data collection (Salminen, Harra, & Lautamo, 2006).

The research methodology will be described in more detail in Chapter Three.

1.10. SUMMARY

This chapter provided the motivation for the study, the background information and problem statement that led to the development of the study. This was followed by a discussion of the aim, objectives, concept clarification, significance and context of the study and the research methodology and that guided the study. Thereafter a brief outline of how the study was organized was presented.

In Chapter Two, the Theoretical framework utilized in the study will be discussed.

CHAPTER TWO

PARADIGMATIC PERSPECTIVE, PHILISOPHICAL FRAMEWORK AND THEORETICAL FRAMEWORKS OF THE STUDY

2. INTRODUCTION

In this chapter the researcher discusses the paradigmatic perspective and the theoretical framework that underpins the study. The grounding principles (meta-paradigm) of the occupational therapy profession are also discussed in this chapter. These principles were applied to ensure that the study contributed to the knowledge base of the discipline.

2.1. PARADIGMATIC PERSPECTIVE

2.1.1. PHILOSOPHICAL ASSUMPTIONS

A paradigm refers to the patterns of shared understanding and assumptions that people have about reality and their world around them (Berman & Snyder, 2012). A paradigm is composed of specific philosophical assumptions that guide and direct people's actions and thinking (Mertens, 2010).

In this study, the researcher adopted constructivism as paradigm. Constructivism is a learning theory found in psychology which explains how people might acquire knowledge and learn. The theory suggests that humans construct knowledge and meaning from their experiences (The University of Sydney School of Education and Social Work, 2018). By taking on a constructivist approach, it allows the researcher to give meaning to the way things are, and to identify factors that otherwise could not easily be described through quantitative research, nor generalised across entire populations.

By using constructivism as paradigm, the researcher is able to accept that multiple social realities lead to the conclusions that knowledge is relatavistic. Relativism is the idea that views are relative to differences in perception and consideration. There is no

universal, objective truth according to relativism; rather each point of view has its own truth (Baghramian & Carter, 2017).

Constructivists believe that reality is socially constructed and only known from multiple subjective points of view. Qualitative methods and inductive logic are normally used to achieve the goal of understanding a particular phenomenon within its social context (Bliss & Rocco, 2013). This type of research highlights and focuses on the meanings of textual and verbal evidence. Analysis can be seen as more interpretive, rather than scientific. It aims to make sense of everyday life and experiences through rich and compelling interpretations (Highfield & Bisman, 2012).

Constructivism is an approach to social science that emphasises the importance of insiders' viewpoints to understanding social reality. The constructivist researcher relies upon the ''participants'' views of the situation being studied and recognises the impact on the research of their own background and experiences. Constructivists are most likely to rely on qualitative data collection methods, where quantitative data may be utilised in a way which support or expands upon qualitative data and effectively deepens the description (Brink, van der Walt, & van Rensburg, 2012).

Elements associated with a constructivist paradigm (Broom & Willis, 2007: 25-26) include the following:

- Naturalistic: data is collected in the context of everyday life.
- Interpretivistic: seeks an understanding with a focus on subjective meaning.
- Complexity: concerned with the depth of analysis.
- Validity: is high on validation that draws on the understandings of research participants, but is not necessarily generalizable as it relies on the interpretation of the researcher.

The constructivist paradigm assumes a relativist ontology, a subjectivist epistemology where the knower and the known co-create understandings, which implies an interaction between them, and a naturalistic set of methodological procedures (Denzin & Lincoln, 2005:24).

2.1.2. ONTOLOGICAL ASSUMPTIONS

Ontology is defined by Crotty (2003:10) as “the study of being”. It is concerned with “what kind of world we are investigating, with the nature of existence, with the structure of reality as such”. Guba and Lincoln (1989:83) state that the ontological assumptions are those that respond to the question ‘what is there that can be known?’ or ‘what is the nature of reality?’ Within constructivism there is a concentration on exploring and giving an account of how people make sense of a situation at a specific point in time (Baxter, Huges, & Tight, 2006). Constructivists believe that many constructed realities exist, rather than a single true reality. It is subjective and influenced by the context of the situation, namely the individual’s experience and perceptions, the social environment, and the dynamic between the individual and the researcher (Ponterotto, 2005: 130). They believe that reality is created in the mind, where different social experiences, cultures, organisations can therefore create a diverse range of social realities. What is real may be specific to an individual, but similarities may exist between individuals or groups (Highfield & Bisman, 2012:5)

The researcher assumed that there would be multiple perceptions regarding the unique phenomenon of Emily; a child born with Tetra-Amelia syndrome. Hence, the researcher interviewed a variety of key role players in Emily’s life including her genetic specialist and medical advisor, foster mother, teacher, school occupational therapist and seating specialist to obtain their views of their reality to better understand the phenomenon underlying the study as well as to understand what role the OT should play in this type of case. The researcher herself was also a vital part of the research process, acting as the consultant therapist for this unique case.

2.1.3. EPISTEMOLOGICAL ASSUMPTIONS

Epistemology is ‘a way of understanding and explaining how we know what we know’ (Crotty 2003:3). Epistemology is also ‘concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate.’

Constructivists believe in a transactional and subjectivist stance that maintains that reality is socially constructed and thus the dynamic interaction between researcher

and participant is pivotal to capturing and describing the 'lived experience' of the participant (Ponterotto, 2005:131). Research should be value-laden, not value-neutral and the researcher should aim to make value judgements (Highfield & Bisman, 2012:5)

In this study, the researcher's main objective was to develop an understanding of what should be known about the lived experience of Emily, the occupational therapy contribution to a specific case of TAS and how to gain such knowledge in order to understand the study process. The researcher communicated with the participants concerning Tetra-Amelia syndrome and the contributions of the occupational therapy process and focused on knowledge gathering in order to understand their views and perceptions. The researcher will use knowledge and clinical reasoning to explore and describe the relationship between the person, condition and context. Clinical reasoning involves more than a simple application of theory, particularly theory as understood in the natural sciences, because complex clinical tasks often require that the therapist improvise a treatment approach that addresses the unique meaning of disability as it relates to a particular patient (Mattingly, 1991).

2.1.4. METHODOLOGICAL ASSUMPTIONS

Methodology is "the strategy, plan of action, process or design lying behind the choice and use of particular methods and linking the choice and use of the methods to the desired outcomes." (Crotty 2003:3). The methodological assumption assists the researcher on how best to obtain evidence (Polit & Beck, 2012).

In this study, a single descriptive case study design (Yin, 2014:53: 215) was utilised to explore and describe the impact of occupational therapy on the holistic management of TAS. Multiple sources of data collection were utilised namely semi-structured interviews, reports, video and photographic evidence and formalised testing of body functions and occupations. Content analysis, document analysis and direct observation was used to analyse the data. In the following section the researcher focuses on the theoretical framework of the study.

2.2. FRAMEWORK OF OCCUPATIONAL THERAPY

A Metaparadigm is described as a set of concepts and propositions that sets forth the phenomena with which a discipline is concerned. A metaparadigm is the most general statement of a discipline and functions as a framework in which the more restricted structures of conceptual models develop (Saunders, 2003). The researcher aims to enhance the understanding of the occupational therapy profession, its principles and theory to the reader.

2.2.1. Understanding Occupational Therapy

Occupational Therapy (OT) is known to have a broad knowledge base, with its origins derived from medical and social sciences. It is also affiliated with the moral treatment and arts and crafts movements. Therapists can work wih all age groups and treat a diverse range of medical, social and environmental problems. Occupational Therapy practice focuses on understanding the factors that shape client's everyday activities; and thereafterr constructing interventions that will enable each client to achieve their goals (Duncan, 2011: 4-7).

Occupational Therapy looks at enhancing one's ability to be competent and confident in their daily activities and lives. Enhancing well-being and minimizing the effects of dysfunction or environmental barriers is key to the foundations of OT practice. OTs use everyday occupations and activities in a creative and therapeutic manner to achieve goals that are meaningful and relevant to the client. Clients/patients are encouraged to work together in the therapeutic process in order to partner in the design and direction of therapy to reach their goals of a quality-filled life (Duncan, 2011).

The World Federation of Occupational Therapists (WFOT) described occupational therapy as, *"A health discipline which is concerned with people who are physically and/or mentally impaired, disabled and/or handicapped, either temporarily or permanently. The professional qualified occupational therapist involves the patients in activities designed to promote the restoration and maximum use of function with the aim of helping such people meet the demands of their working, social, personal and domestic environment, and to participate in life in its fullest sense."* (WFOT, 2012)

2.2.2. Competence and dysfunction

Occupational competency in daily tasks depends on a complicated interplay between the individual, the activities they do, and their environment. Well-being is achieved when a person is able to meet the demands of a task, adapt to changing environments and use the skills and knowledge they have acquired to effectively take on all situations that they encounter. Therefore, the opposite of competency is *dysfunction*; which is a temporary or permanent inability to engage in roles, relationships and occupations expected of a person. The reasons for dysfunction can range from simple to very complex, and it is normally at this point when a referral is made to an occupational therapist (Duncan, 2011).

Typical examples of occupational dysfunction for a child could include the inability to feed oneself due to a physical limitation, the inability to partake in group play due to social difficulties or the inability to learn optimally in a classroom setting due to concentration impairments.

2.2.3. The occupational therapy perspective

OTs aim to understand the nature of a client's *occupational identity* (who they are and who they would like to be) and their *occupational performance* (what their physical, cognitive, sensory, emotional and social abilities are). OTs adopt a conceptual *model of practice* or *frame of reference* within the context, thereafter action is taken to reduce the impact of the client's condition and to maximize each clients abilitiy to engage in valued daily activities.

2.2.4. Skills needed as an OT

The occupational therapy profession requires qualified therapists to have a varied and diverse skill set. A vital skill of an OT is to bring an occupational perspective in terms of both the client's ability and identity, to the therapeutic context (Duncan, 2011: 34). The following core and specialist range of skills will be discussed in more detail in the Table titled '*Table 2.2.1: Skills needed as an Occupational Therapist'*, applicable to Emily's case below:

Table 2.2.1 Skills needed as an Occupational Therapist

Skill	Description
Analysis and adaptation of occupations	According to Hagedorn (2001), the analysis and prescription of occupations is purposeful in dealing with problems experienced by the client in all aspects of their everyday life as well as to use occupation as as specific therapeutic interventions to address occupational performance difficulties. Kielhofmeyer & Forsyth (2008) stated that OTs carry out activity analysis in order to consider: • The kind of performance needed to achieve the occupation e.g. motor, physical, cognitive, interpersonal, sensory etc. • the complexity of the activity • the social or cultural implications • analyzing the sequence of task performance • defining the tools, materials and environment required • Taking into account safety precautions or risk factors.
Environment-al analysis and adaptation	OT's believe that the physical and social environments may have a vital beneficial or detrimental effect on a person. The process of environmental analysis can provide important information on the causes of problems for the client, explanations for behaviour or suggestions for therapeutic adaptation.
Therapeutic use of self	Mosey (1986) defines an OTs use of self as a conscious therapeutic tool. He believes there is a difference between a spontaneous, unplanned interaction and a planned, guided and informed interaction. Four components that relate to the development of a therapeutic relationship include: (Yarwood & Johnstone, 2002) • The therapist needs to establish a rapport with the client. • The therapist should respect the wishes of the client. • The therapist should use honesty and strive to work alongside the client. • The therapist should show effective adaptation skills in her communication methods with clients.

2.2.5. Best practices for children

Occupational therapists support inclusion by focusing on goals that enable a child to be successful in inclusive environments, providing services in the child's natural environment and using consultation and education as primary methods of service delivery. They look at assistive technologies and the accessibility to the child in need. They also consider the effectiveness and appropriateness of treatment models and approaches to provide the best fit for a child's intervention programme. There are several models / frameworks such as the Person-Environment-Occupation (PEO) model, the Model of Human Occupation (MOHO) amongst others (Case-Smith, 2005;65-77) as well as the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2014). These will be discussed in more detail below.

2.2.6. The Occupational Therapy Practice framework: Domain and Process *(AOTA, 2014)*

The Occupational Therapy Practice Framework: Domain and Process describes the central concepts that ground occupational therapy practice and builds a common understanding of the basic tenets and vision of the profession.

The Domain of Occupational Therapy is illustrated in Table 2.2.2. All aspects of the domain, including occupations, client factors, performance skills, performance patterns and context and environment are of equal value, and together they interact to affect the client's occupational identity, health, well-being, and participation in life. Occupational therapists are skilled in evaluating all aspects of the domain, their interrelationships, and the client within his or her contexts and environments. In addition, occupational therapists recognize the importance and impact of the mind–body–spirit connection as the client participates in daily life. Knowledge of the transactional relationship and the significance of meaningful and productive occupations form the basis for the use of occupations as both the means and the ends of interventions (Trombly, 1995). This knowledge sets occupational therapy apart as a distinct and valuable service (Hildenbrand & Lamb, 2013) for which a focus on the whole is considered stronger than a focus on isolated aspects of human function.

Table 2.2.2: Aspects of the domain of Occupational Therapy. (AOTA, 2014)

OCCUPATIONS	CLIENT FACTORS	PERFORMANCE SKILLS	PERFORMANCE PATTERNS	CONTEXTS AND ENVIRONMENTS
Activities of daily living (ADL) **Instrumental Activities of daily living (IADL)** **Rest and sleep** **Education** **Work** **Play** **Leisure** **Social Participation**	Body Functions Body Structures	Motor Skills Process Skills Social Interaction Skills	Habits Routines Rituals Roles	Cultural Personal Physical Social Temporal Virtual

The Occupational Therapy Process (OTP) can be defined as a series of actions a therapist undertakes in order to provide services to their client. This linear relationship is illustrated in Figure 2.2.1: *The Occupational Therapy process viewed cyclically* and will be described in more detail below:

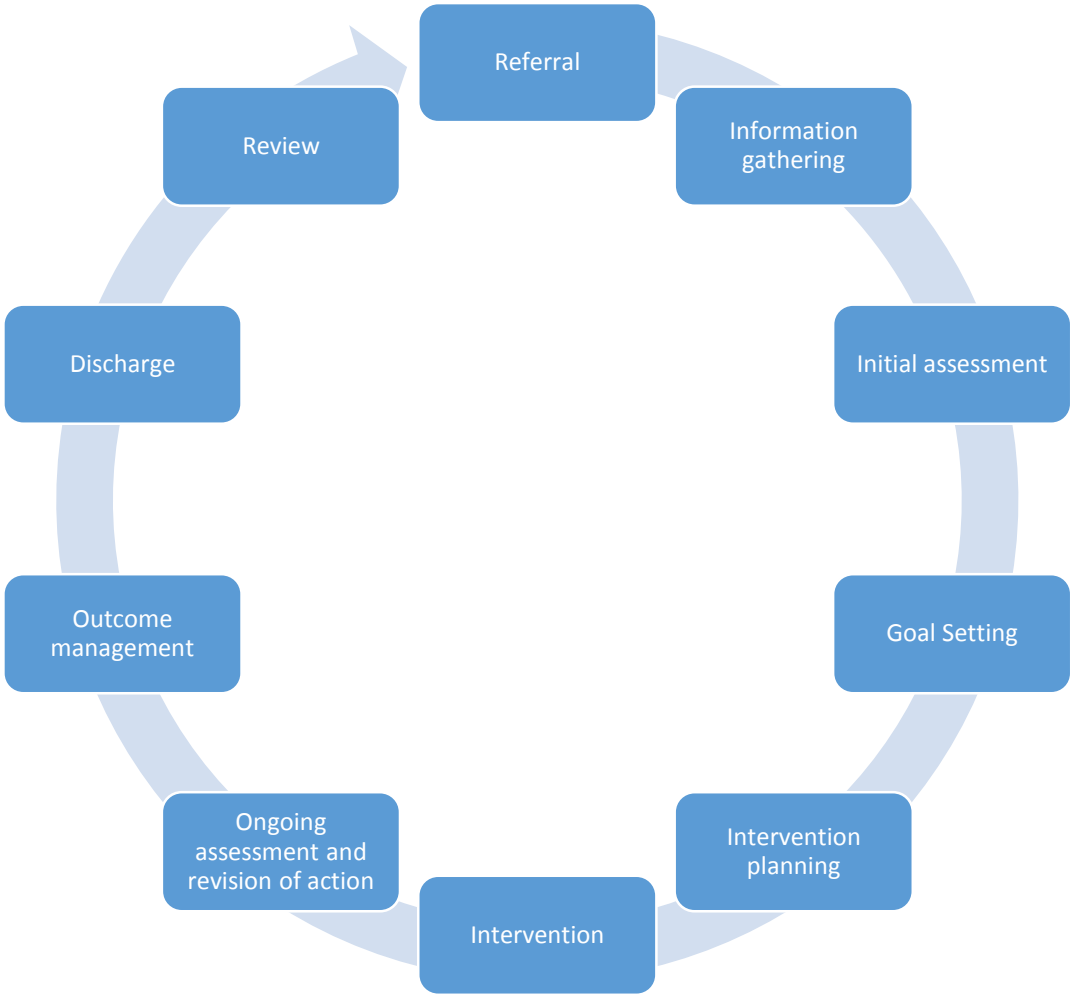
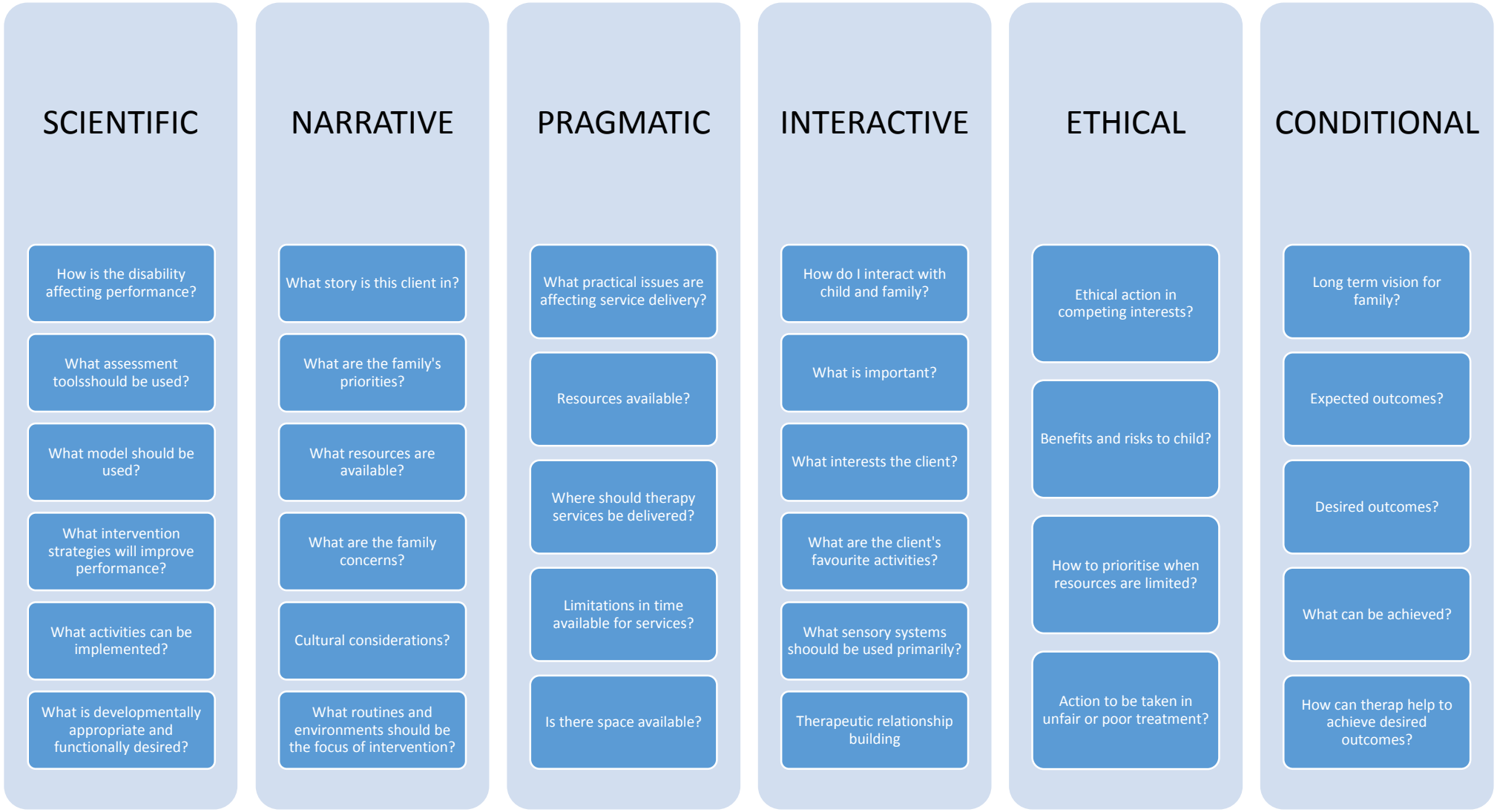


Figure 2.2.1: The Occupational Therapy process viewed cyclically. (AOTA, 2014)

2.2.7. Clinical Reasoning throughout the OTP

Occupational therapists use clinical reasoning to assess, plan and provide intervention for adults and children. It enables therapists to think broadly and deeply about their clients and to develop interventions that are holistic and effective. Multiple perspectives of a child and family must be considered including their values, interests, priorities and contexts. Types of clinical reasoning include scientific, narrative, pragmatic, interactive, ethical and conditional reasoning. (Case-Smith, 2005;5)

Table 2.2.3: Types of Clinical Reasoning. Modified from (Case-Smith, Occupational Therapy for Children, 2005)



2.2.8. Assessment (includes referral, information gathering and initial assessment)

Occupational therapy assessment involves systematic data collection and analysis to guide the development of an intervention plan. Standardised and non-standardised instruments are used to gain relevant information about a child's abilities, performance, contexts and the interaction between the child's abilities and the demands of the environment. It should also focus on the issues identified by parents, teachers, doctors or through observation but should be comprehensive enough for the therapist to gain a thorough understanding of the problems and its effects on the child's performance and participation (Case-Smith & O-Brien, 2014). It is vital to make use of ongoing assessment procedures throughout the process to revise action and implement positive changes where necessary.

2.2.9. Goal-setting

Once a professional perspective has been formed with regards to a child's priorities and needs, it is vital to set goals for treatment or intervention. Creek (2003) describes long-term goals as being the major goals, where both client and therapist view therapy as having been successful. Short-term goals are more immediate and seen as stepping stones used to achieve the longer term goal.

2.2.10. Interventions

Interpreting the information gained from the assessment to plan intervention requires that the therapist further analyse the child's occupational performance and participation. Some **guiding questions** that may help include: (Case-Smith & O'Brien, 2014)

- What are the priorities of the family and child?
- What skills does the child need to meet occupational roles?
- What developmental trajectory does the child demonstrate?
- What are influences of the performance contexts?
- Which theoretical models of practice or frames of reference guide the intervention?
- What is the nature of the disability?

- What adult support is needed to sustain improvements in the child's performance?

Occupational therapy **intervention strategies** are illustrated in the Table entitled *Table 2.2.4: Intervention purposes and strategies* below:

Table 2.2.4: Intervention purposes and strategies

Intervention Purpose	Strategies
Improving functional performance	• Using occupation as means • Graded activities: the 'just right' challenge • Preparation for activities • Augmented and individualized sensory cueing and feedback • Therapeutic use of self • Caregiver and teacher education and consultation
Adapting activities or providing assistive technology	• Compensatory strategies • Concurrent developmental and functional goals • Educating adults who support the use of compensatory strategies
Environment modifications	• Improving the fit between child and adult • Consultation and negotiation with adults in the child's environment
Promoting participation and preventing disability through education	• Educating other professionals and administrators • System change in the child's community

2.2.11. Outcome management

Outcomes are the end result of the occupational therapy process; they describe what clients can achieve through occupational therapy intervention. The benefits of

occupational therapy are multifaceted and may occur in all aspects of the domain of concern. Outcomes are directly related to the interventions provided and to the occupations, client factors, performance skills, performance patterns, and contexts and environments targeted. Outcomes may also be traced to the improved transactional relationship among the areas of the domain that result in the clients' ability to engage in desired occupations secondary to improved abilities at the client factor and performance skill level (AOTA, 2014). Discharge planning thus takes place when specific outcomes have been met.

2.3. THEORETICAL FRAMEWORK OF THE STUDY

The researcher looked at specific occupational therapy practice models and frames of references to understand the external reality of Tetra-Amelia Syndrome in the single case of Emily. This provided a good starting point for the study as well as for the development of the interviews and data collection choices. They also aided in interpreting the data collected and forming conclusions on the link between occupational therapy practice and its contributions in a single case of Tetra-Amelia syndrome.

Yin (2014:44) states that case study researchers should enter the field with prior theories as it assists in defining the appropriate research design and data to be collected. According to Merriam (2009:66-67) researchers would not know what to do in conducting their research without some theoretical framework to guide them. She referred to it as the 'structure, scaffolding or frame of your study.' The theoretical framework is derived from the orientation researchers bring to their studies. Merriam (2009) further states that theory affects every aspect of the study, from determining how to frame the problem to deciding how to make sense of the data collected. A theoretical framework also allows the researcher to perceive things in new and different ways.

The researcher will next discuss the selected theories, models and frameworks.

2.3.1. Conceptual models of Practice

Occupational Therapy conceptual frameworks originate from theories, other models and evidence-based practice. The occupation-focused / based conceptual frameworks put emphasis on the interconnectedness/ interaction between the person, environment and occupation. Conceptual models provide a way of thinking about, explaining phenomena or presenting how complex issues interact. Conceptual frameworks serve as guidelines for dealing with complexities. They provide a lens through which to view phenomena (Cole & Tufano, 2008).

A single phenomenon can be expressed using a number of frameworks and solutions for a single problem can be derived from using different frameworks. A number of frameworks can be merged or combined to illicit the best desirable solution for a problem or dysfunction. It is important to note that more than one occupation-based framework can be relevant to a given problem / situation.

The following models were studied by the researcher and used to guide the study:

- The Model of Human Occupation (MOHO)
- The Person-Environment-Occupational Performance Model (PEOP)

2.3.1.1. The Model of Human Occupation (MOHO)

The Model of Human Occupation (MOHO) (Kielhofner & Forsyth, 2008) is “an occupation-focused (Pedretti & Early, 2001), theory-driven (Elenko, Hinojosa, Blount, & Blount, 2000), client-centered (Law, Client-centrered occupational therapy, 1998), evidence-based (Law, et al., 1997) approach to occupational therapy practice.” The reason for the development of the MOHO was the realization that many factors beyond motor, cognitive and sensory impairments contribute to the difficulties in everyday occupation. The MOHO was then developed to address client’ motivation, routine patterning of occupations, and the nature of skilled performance and the influence of environment on occupation.

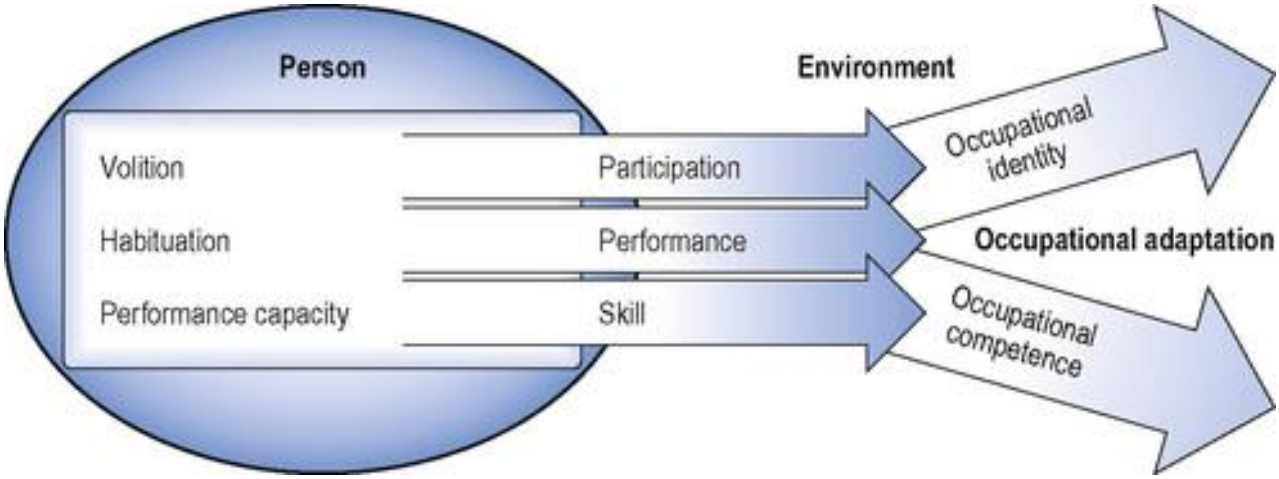


Figure 2.3.1: Model of Human Occupation concepts. Modified from (Kielhofner, Model Of Human Occupation, 2007).

The following concepts of MOHO illustrated in *Figure 2.3.1: Model of Human Occupation Concepts* will be described in more detail below:

- **MOHO related to the person:**

-Volition: can be described as the process by which individuals are motivated toward and choose what activities they do. All individuals have a need to participate in occupations and this need is influenced by previous experiences. These feelings are influenced by personal factors namely: personal causation (how capable and effective an individual feels), values (what the individual holds as important) and interests (what the individual finds enjoyable and intriguing).

-Habituation: can be defined as the individual's organization of their actions into patterns and routines. Individuals establish habituated patterns through repetition of actions in different contexts. Habits and roles govern these actions, which influence the manner in which individuals go about the routine aspects of their lives.

-Performance Capacity: this can be defined as an individual's mental and physical abilities, and how these abilities are used and experienced in occupational performance. The quality or ability for performance is affected by the individual's bodily system functioning. Approaches including the biomechanical, motor control, cognitive and sensory integrative approaches look at these aspects of performance capacity that can be observed, measured and modified (Ayres, 1979).

- **MOHO related to the Environment:**

Occupation results from the effective interaction of the person with the physical and social environment. The environment is described as the particular social, physical, cultural, economic and political features within an individual's context that may stand to influence the motivation, organization and performance of occupations.

- **Dimensions of Doing:**

MOHO lists three levels at which we can study an individual's engagement in occupations:

-Occupational participation: refers to participation in work, play, ADL and IADL that are necessary to an individual's well-being and quality of life.

-Occupational performance: refers to completing a task linked to a major life area.

-Occupational skill: refers to the actions and steps that make up occupational performance.

- **Occupational Identity, competence and adaptation:**

What people do, contributes to the creation of their identity. This identity is formed over time and with experience and can further be defined as the sense of who people are and who they wish to be. Occupational competence is how well an individual can sustain this pattern of doing. Occupational adaptation is the ability to enact this identity in various situations and contexts.

2.3.1.2. The Person-Environment-Occupational Performance (PEOP) Model

The PEOP model considers occupational performance as the primary outcome of interest to occupational therapists (Christiansen & Baum, 1997). The model describes how occupational performance is determined by the person, environment and occupation. The following constructs of the model are defined below:

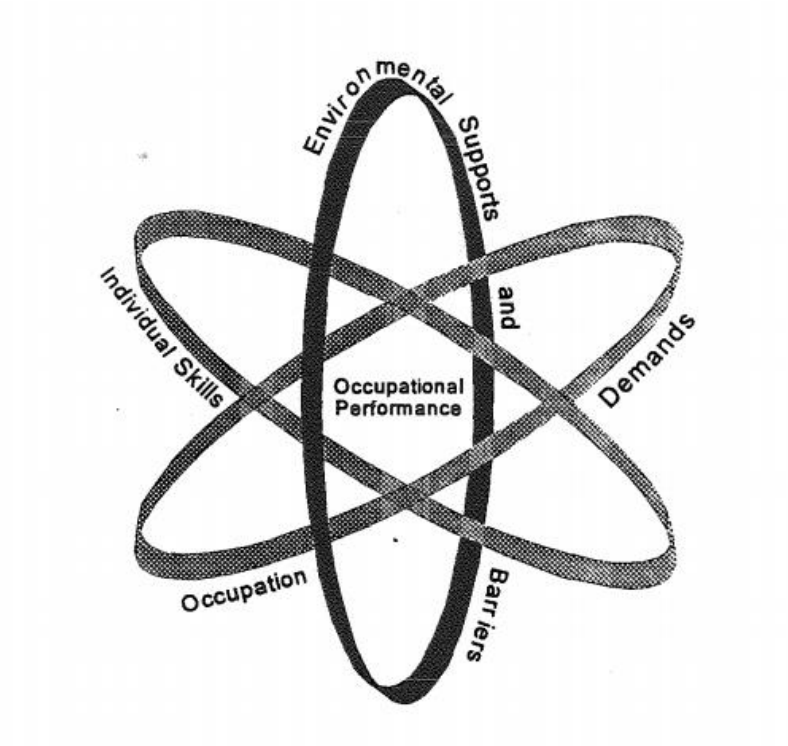


Figure 2.3.2: Person-Environment-Occupation-Performance Model (Law M. , et al., 1996).

- **Person:** in the holistic view of the person, one must acknowledge the mind, body and spirit. Values, interests, skills and life experiences help to determine what is important, meaningful and enjoyable to the person.
- **Environment:** the environment is where occupational performance takes place and consists of physical, social and cultural elements.
- **Occupation:** the PEOP model consists of actions (observable), tasks (actions with a common purpose) and occupations (goal-directed pursuits).
- **Occupational Performance:** can be referred to as the amalgamation of person, environment and occupational factors dependent on the 'goodness of

fit' of these factors. See *Figure 2.3.2: Person-Environment-Occupation-Performance Model.*

- **Person-Environment-Occupation Fit:** The model assumes that the three major components (person, environment, occupation) interact continuously across time and space in ways that increase and diminish their congruence. The closer their overlap or fit, the more harmoniously they are assumed to be interacting. *See Figure 2.3.3: Person-Environment-Occupation Fit.*

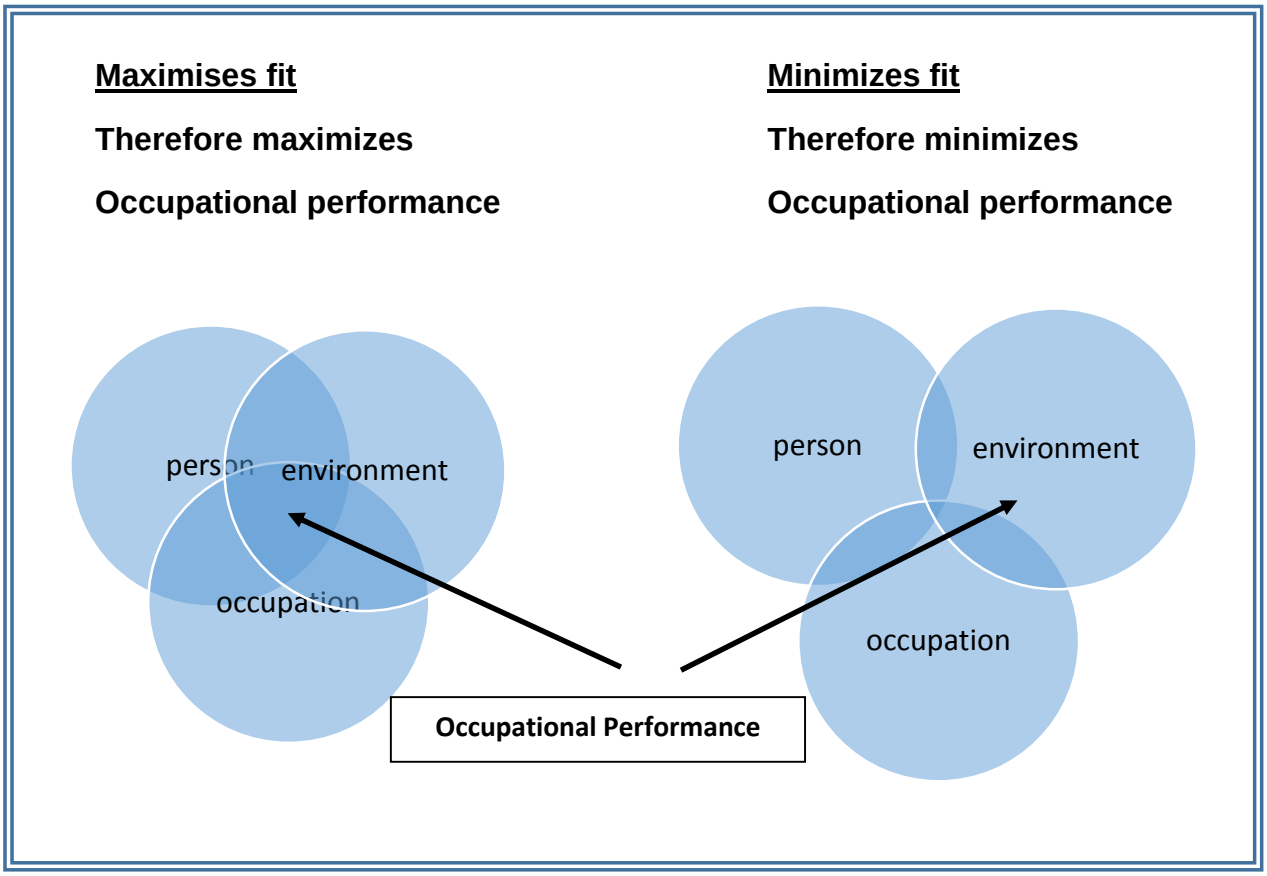


Figure 2.3.3: Person-Environment-Occupation Fit

OT practice identifies what occupations the individual desires or needs to perform. Barriers and facilitators within the person, environment and occupation are highlighted. OT practice comprises the promotion of inclusion of people with disabilities in all environments. OT's should serve as advocates for their clients with disabilities. See *Figure 2.3.4: Occupational Therapy: The Person-Environment-Occupation Model of Occupational Performance* for how this model is applied to Occupational Therapy practice.

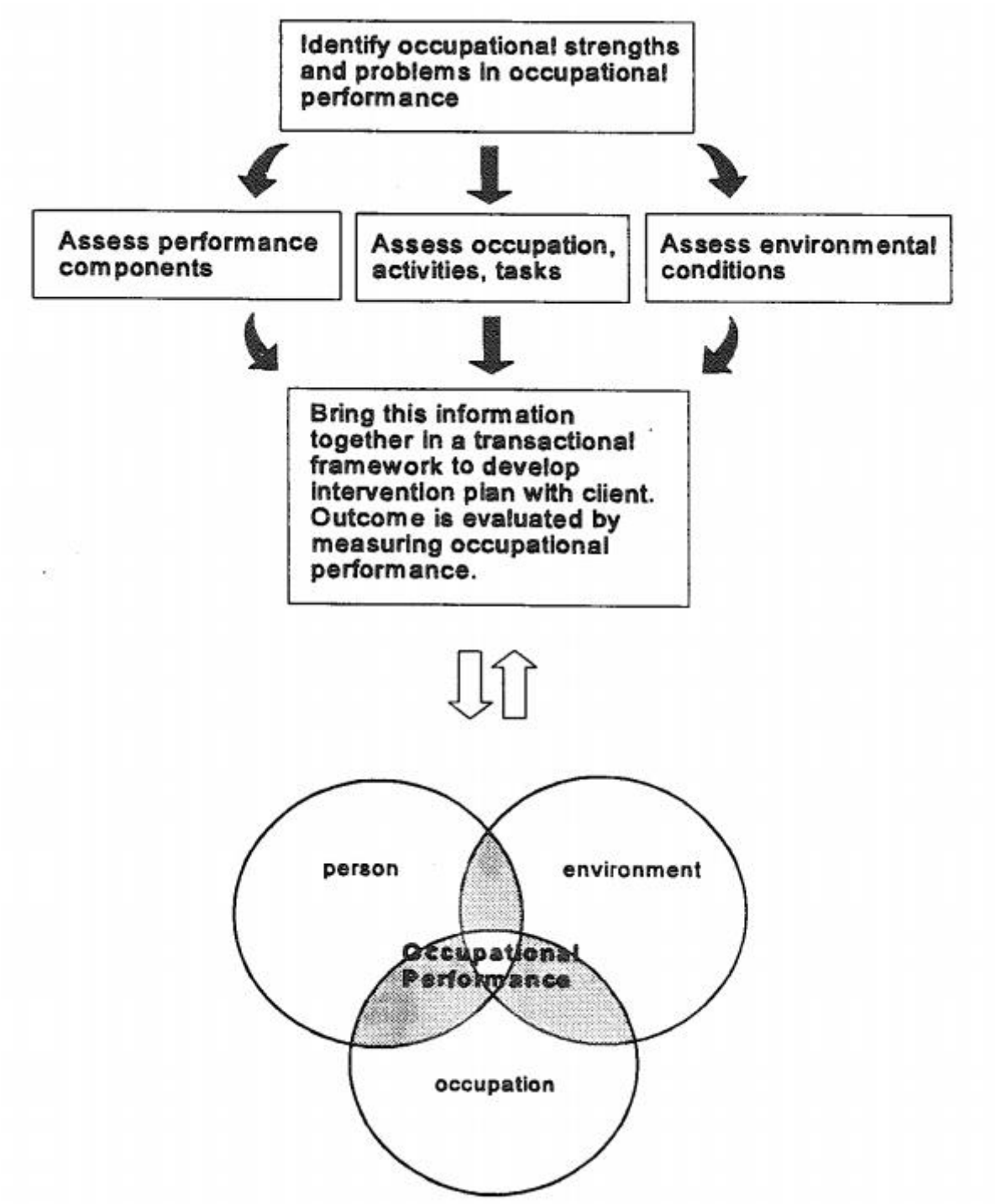


Figure 2.3.4: Occupational Therapy: The Person-Environment-Occupation Model of Occupational Performance (Law M. , et al., 1996)

2.3.2. Frames of references (approaches) that guide intervention:

In the Occupational Therapy, a frame of reference is used as a baseline for practical application. A frame of reference uses theories to guide evaluation and assessment and application to the practice. The frame of reference provides a structure for identifying relevant theories and then based on this information, outlines guidelines that occupational therapists use when assessing and providing intervention (Berry & Ryan, 2002).

A variety of approaches are used in occupational therapy practice. Often approaches are combined and used in conjunction with one another. An occupational therapist may switch from one to another based on the individual's response. The researcher chose the following approaches to discuss as they underlie the OT intervention in the case of Emily.

2.3.2.1. Client-centered approach:

Guiding principles for a client-centered approach include demonstrating respect for clients, involving clients in the intervention process and recognizing the client's experience and knowledge (Law, 1998: 3). Furthermore, it is to collaborate with clients to set goals. It is an approach focused on occupational performance which depicts a person's performance in self-care, productivity and play / leisure tasks and activities as influenced by a person's individual characteristics and the environment in which they live, play and work (CAOT, 1991). Advantages of using such an approach include; enhanced motivation, satisfaction, improved outcomes, client adherence and functional outcomes.

2.3.2.2. Rehabilitative (compensatory) approach:

This approach encompasses adaptation, compensation and environmental changes or alterations. It is appropriate for individuals with permanent impairments. It takes an individual's strengths into consideration as opposed to their limitations.

2.3.2.3. Cognitive functional models: Functional skill training and task or environmental adaptations:

Cognitive approaches are 'top down' or occupation-based approaches because the emphasis in therapy is in assisting the child to identify, develop and use cognitive strategies to perform daily occupations effectively. These approaches emphasize increasing a child's ability to select, monitor and evaluate his or her usage of these strategies during the performance of a task. It is then said that improved performance results from the dynamic interaction of the child's movement skills with the parameters of the task in the context in which it needs to be performed.

2.3.2.4. Ayres Sensory Integration ASI®:

ASI® proposes that neuroplasticity is evident in the developing brain. Interactions between higher order and lower order areas of the brain are fundamental to adequate sensory integration. The approach encompasses the goal of achieving adaptive responses (the ability to adjust ones action on environmental demand) which promotes higher levels of integration as a consequence of the feedback to the CNS (Ayres, 1972: 8). She also highlights the importance of an inner drive to meet and master a challenge, which leads to further development of sensory integration.

2.3.2.5. Developmental:

Developmental frames of references focus on physical, social and psychological aspects of life tasks and relationships. Llorens (1969) viewed the role of the occupational therapist to be one of facilitating development and assisting in the mastery of life tasks and the ability to cope with life expectations.

2.3.2.6. Functional:

A functional approach focuses on the child's functional abilities in interaction with environmental activities, contexts and conditions. To implement a functional approach, the therapist gathers information about the types of activities in which the child is to participate, methods of the child's participation, and expected goals for each activity. Using this information the therapist analyses competencies and barriers to the child's independent participation in relevant activities (Teti & Gibbs, 1990).

2.4. CONCEPTUAL FRAMEWORK

Yin (2014) refers to conceptual frameworks but fails to fully describe them or provide a model of a conceptual framework for reference.

Miles & Huberman (1994:18) describe the conceptual framework to have several purposes:

- Identifying who will and will not be included in the study.
- Describing what relationships may be present based on logic; theory and / or experience.
- Providing the researcher with the opportunity to gather general constructs into intellectual 'bins'

The conceptual framework serves as an anchor for the study and is referred to at the stage of data interpretation.

The researcher developed an initial conceptual framework in her exploration of the contribution of occupational therapy to the management of Tetra-Amelia syndrome. The framework was based on literature and the researcher's personal experiences. The major constructs that were proposed by the researcher are presented in *Figure 2.4.1: Initial Conceptual Framework of Occupational Therapy and TAS.*

A conceptual framework in case study research does not show the relationships between the constructs. It should be an ongoing process to develop and complete the framework as the study progresses. The relationships will emerge as the data is analysed and interpreted. A completed conceptual framework will include all the themes that emerged from the data analysis phase of the research (Baxter & Jack, 2008:553). *See Chapter 4 for completed conceptual framework.*

One of the pitfalls of a conceptual framework is that it may limit the inductive approach when exploring a phenomenon. To safeguard against becoming deductive, the researcher journalised her thoughts and decisions and discussed them with other researchers to determine whether her thinking had become too driven by the framework (Baxter & Jack, 2008:553).

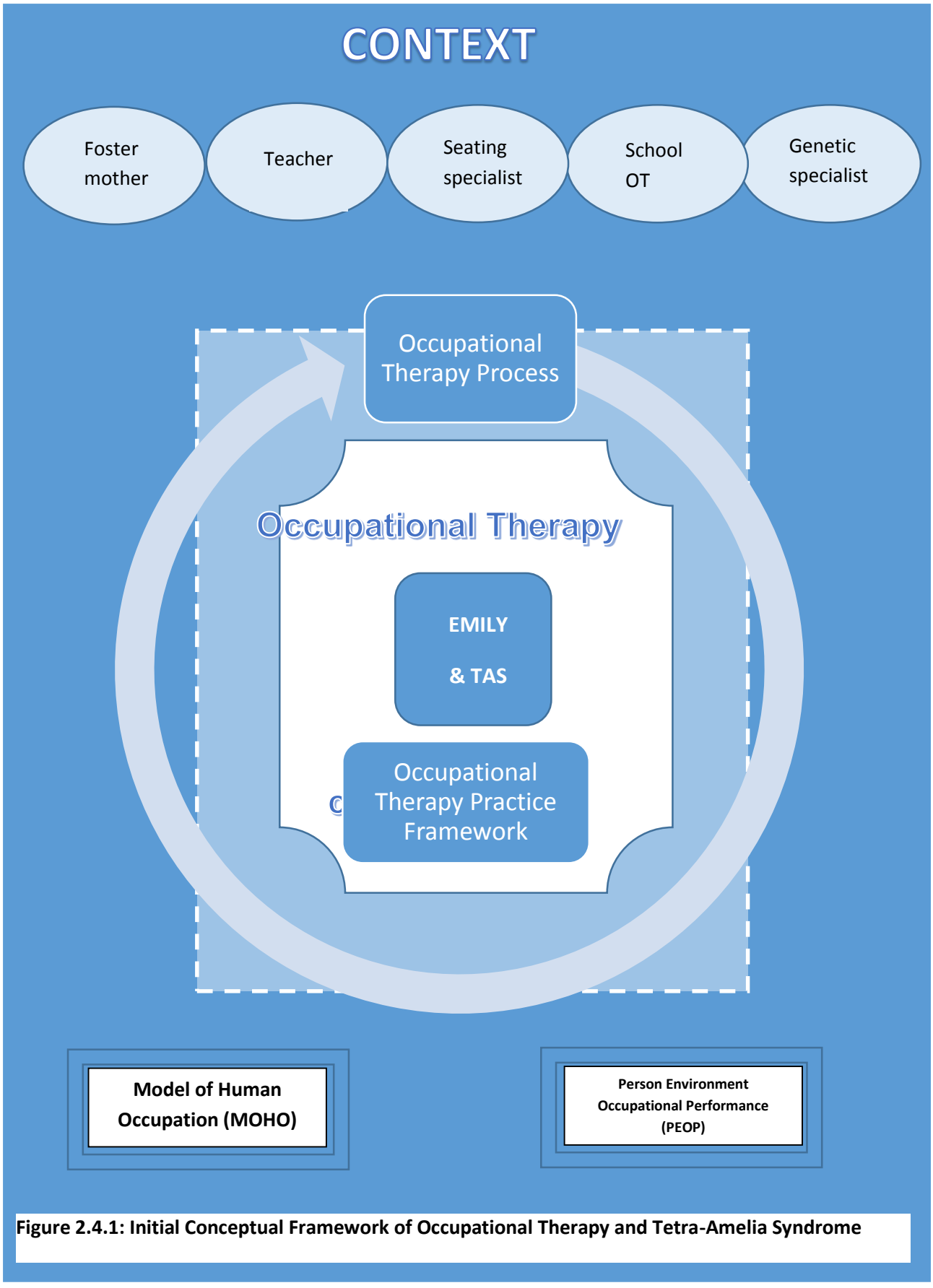


Figure 2.4.1: Initial Conceptual Framework of Occupational Therapy and Tetra-Amelia Syndrome

2.5. SUMMARY

In this chapter the researcher discussed the paradigm that underpins the study and the theoretical framework that was utilized for the study. The paradigm guided the methodology used to conduct the study and the theoretical framework is part of the research tradition in which the stud is embedded (Polit & Beck, 2012:129). The theoretical framework formed the framework for the development of the questions posed in the interview guide, selection of standardised testing procedures, selection of video / photographic evidence and assisted in interpreting the data obtained in the study. The theoretical framework also enhanced a better understanding of the occupational therapy profession and its unique contributions to a child with physical limitations.

The researcher will discuss the research methodology used to conduct the study in the next chapter.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1. INTRODUCTION

In this chapter research methodology used to address the aims and objectives of the study is discussed. The following research question was asked: *What is the contribution of occupational therapy to the holistic management of tetra-amelia syndrome?* In qualitative research studies, the aims indicate the phenomena, the participants and the setting under the study (Polit & Beck, 2012). The aim of this research study was to explore and describe the contribution of occupational therapy in the holistic management of TAS.

The objectives were to explore and describe the contribution of occupational therapy intervention thus far for this specific case of TAS with regards to:

- The importance of early intervention and support contributing to the occupational engagement of this particular individual.
- The importance of assistive technology to enable participation.
- Future considerations for an individual with TAS.

3.2. RESEARCH DESIGN

According to Yin (2014: 16-17) case studies have a two-fold definition that covers the scope and features thereof. Firstly, case studies can be defined as empirical enquiries that investigate the case in depth and within real life context. Secondly, a case study deals with a technically distinctive situation in which there are many more variables of interest than data points, using multiple sources of evidence to allow data triangulation to guide data collection and analysis.

Case study research is used to explore real life experiences and situations, when the researcher is interested in both the phenomenon and the context in which it occurs. Case study research seeks out rich, in-depth information. It aims to investigate a topic in its context from multiple viewpoints and it uses multiple methods and multiple data

sources for its data collection (Salminen, Harra, & Lautamo, 2006). According to Stake (2000:435) case study research has become a common way of performing qualitative enquiries. The focus is on the case, which can be studied holistically, analytically, organically or culturally using mixed methods. Yin (2014:4) states that a case study allows researchers to focus on a case and retain a holistic and real-world perspective.

Yin (2014:9) describes three conditions that are required when deciding when to use a case study as a research method. These include:

- The type of question asked,
- The extent of control a researcher has over actual behavioural events, and
- The degree of focus on contemporary as opposed to historical events.

The type of question asked:

Yin (2014: 10-11) states that defining the research question is the most important step that a researcher has to take when performing case study research. It is vital that research questions have both substance and form, thus the researcher needs to ask; *what is my study about*, and will I ask a *who, what, where, why* or *how* question. For this study the researcher posed the "*what"* and *"how"* questions as they are more explanatory and descriptive.

The extent of control a researcher has over actual behavioural events:

Yin (2014: 12) states that a case study is preferred when examining a contemporary event but the behaviour cannot be manipulated or changed. The phenomenon of the unique case of TAS in the study is a contemporary situation, which the researcher has little control over. Strengths of the study are the ability to deal with a multitude of evidence including documents, photographic / videographic artefacts, and interviews with persons involved in the study and direct observations of the phenomena studied.

3.2.1. SINGLE-CASE STUDY DESIGN

A case study is used for investigating a phenomenon in depth and within its real-life context (Yin, 2014; 27). Case studies are the analyses of people, events, decisions, periods, projects, and institutions which are studied holistically by one or more methods. According to Yin (2014; 27) one of the rationales for a single case study

design is that of an extreme or unique case. In these instances, a disorder can be so rare that any single case is worth documenting and analysing, as is the case with Emily's TAS. A holistic design is that in which the researcher explores and describes the general nature of a case from all angles and in a holistic manner. Therefore, for this study, a holistic, single **case study design** was used.

It is critical to identify the unit of analysis as it defines what the case is and it defines the initial research question. The unit of analysis defines what the case is and is thus a critical factor (Yin 2014: 31). The primary unit of analysis for this case will be one individual, Emily and the contribution of occupational therapy in the holistic management of this individual. The case will be bound to this one specific individual and the context within she exists.

Occupational therapy is interested in the person in their own living environment, and aims to achieve a good overall understanding of the person while also being interested in particulars, to take several viewpoints into account, and to value the subjectivity and experience of the client. Case study research offers a research methodology that respects the basic principles of occupational therapy. While an occupational therapist is interested in improving clinical practice, the therapist should consider it holistically, to understand its complexities, to analyse actions and underlying theories in her/his own work, and to evaluate them in the light of other perspectives. From this viewpoint, case study research offers occupational therapists a methodology that is well suited to the development of clinical practice (Salminen, Harra, & Lautamo, 2006).

3.2.2. CONCERNS ABOUT CASE STUDY RESEARCH

Case studies have their strengths and limitations that allow them to be viewed as less desirable as they could be confused with teaching cases as they have been used to demonstrate a specific point (Yin 2014:19-21). Some say that case studies are not vigorous enough and that adequate findings cannot be generalized from a single case. An additional limitation is the fact that case studies require tremendous effort and can result in lengthy, unreadable documents. The use of case study research does have advantages over quantitative research in that it allows for the *how, why* and *what* questions to be answered that cannot be answered through randomized control trials. They can be viewed as an adjunct to experiments rather than an alternative (Yin

2014:23). Simons (2009) states that “case study has the potential to engage participants in the research process.” According to Flyvberg (2006: 220) the case study is a necessary and sufficient method for certain important research tasks in the social sciences, and it is a method that holds up well when compared to other methods in social science research methodology.

3.2.3. COMPONENTS OF CASE STUDY RESEARCH

Yin (2014:29) describes five components of research design to consider when doing case study research. The researcher has adopted the five component of Yin’s approach and incorporated it in the study as follows:

The study’s questions: The research question is the heart of the study plan reflecting the line of enquiry. It reminds the researcher with regards to the information that needs to be collected and why (Yin 2014:14). The questions applicable to this study are discussed later in the chapter.

The study’s propositions: Due to the descriptive nature of the study, there are no propositions. According to Baxter and Jack (2008:551) not all studies need to have propositions e.g. an explorative study would rather have a stated purpose or criteria which the success will be judged.

The unit(s) of analysis: A child with Tetra-Amelia Syndrome in a South African context.

The logic linking of the data to the proposition: The data is linked to the purpose and aim of the study as no propositions were stated for this study.

The criteria for interpreting the findings: The interpretation of the findings will be discussed in chapter five.

3.2.4. BINDING OF CASE STUDIES

Even though the case study looked at the contribution of occupational therapy to the management of TAS, attention was also given to the key role players who have contributed in different way to this unique case. This included a medical doctor with a special interest in genetics, a seating specialist (a practitioner who assesses and prescribes optimal wheelchair and positioning devices), an educator, a school occupational therapist, a consultant occupational therapist (researcher) and a foster

mother with a special interest and extensive experience in caring for babies with medical needs. Invaluable data was collected from these role players to provide a broader view and more holistic approach to the case of Emily.

Additionally, the researcher's clinical knowledge and experience of working with this case from 2013 to present forms an integral thread in the write up of this report and binding of all the data collected. Once the general definition of the case has been determined, it is vital to then bind the case. If the unit of analysis is a small group, then it is necessary to distinguish them from those who are outside of the immediate topic of the case study (the context). Yin (2014:34) states that binding the case will determine the scope of data collection and how to distinguish data about the subject of the case (the phenomenon under study) and data external to the case (the context). According to Baxter and Jack (2008:547) the establishment of boundaries in a qualitative case study design is similar to the inclusion and exclusion criteria for sample selection in a quantitative study. Furthermore, the boundaries also indicate the depth and breadth of the study and not simply the sample to be included. See *Figure 3.1.4: The context of the case, the case and the unit of analysis* below.

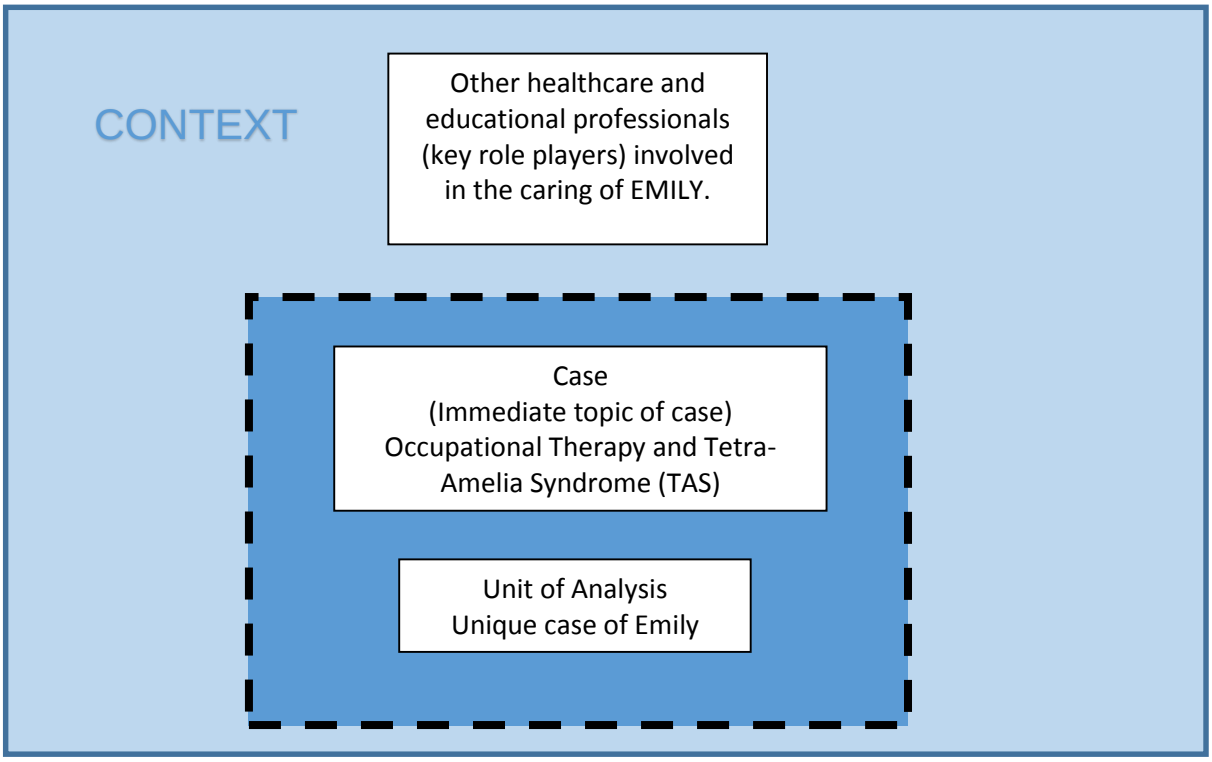


Figure 3.1.4: The context of the case, the case and the unit of analysis

3.3. RESEARCH METHODS

Research methods encompass techniques used by researchers to structure a study and collect data and analyse it in a systematic manner (Polit and Beck 2012:741). According to Speziale and Carpenter (2007:398) research methods are grounded in certain philosophical perspectives. This study was based on a constructivist paradigm, since the researcher believes that reality is multiple and subjective and can be constructed by individuals. The researcher interacted with the participants and the findings are the product of the interactive processes.

3.3.1. SITE AND PARTICIPANT SELECTION

In deciding which sampling strategy to use, the researcher was guided by the relativist paradigmatic perspective which acknowledges that multiple realities have multiple meanings that are observer dependant. Therefore, different participants will have different perspectives (Yin 2014:17).

Apart from Emily, additional participants from her context were invited to participate to assist with a comprehensive data collection. They were selected purposefully to obtain multiple perspectives on her case. Participants included Emily's foster mother (primary caregiver), one medical doctor with a special interest in genetics, one school teacher (Grade R), one seating specialist and one school occupational therapist. However, Emily was used as the primary unit of analysis for this research study. According to Speziale and Carpenter (2007:29) individuals are selected to participate in a study because they have first-hand experience of a phenomena, culture or social process and they are actively involved in the study.

When determining the site for the research study, the researcher made use of multiple venues to accommodate the participants. See *Table 3.2.1: Description of participants and site selection* for the characteristics of the participant and site selection.

Table 3.2.1: Description of participants and site selection

Participant number	Category	Employed by:	Site where research was conducted	Role in Emily's life:
01	Child with TAS (Emily)	N/A	School and Home	N/A
02	Occupational Therapist	Public Special Needs School	School	Providing occupational therapy intervention in a school environment. Implementation of AT and facilitating heightened independence and academic performance
03	Seating Specialist	Private company	Company premises, school, home	Providing specialised seating services (wheelchairs), and acquisition of appropriate mobility devices.
04	Grade R educator	Public Special Needs School	School	Providing education to Grade R learners at a public school.
05	Foster mother	NGO	Home	Providing for the daily needs of Emily.
06	Medical doctor	University of Pretoria & Government Hospital	University of Pretoria	Provided the medical diagnosis of TAS. Monitoring and check-ups of Emily.
07	Occupational Therapist	Private practice	Multiple sites	Provided occupational therapy intervention and consultation for Emily from 2 years of age.

3.3.2. PREPARATION FOR DATA COLLECTION

The researcher prepared for data collection by developing a study protocol that guided the research methodology. Having a case study protocol is desirable under all circumstances as it increases the reliability of the case study and guides the researcher in carrying out data collection (Yin 2014:84). The protocol assisted the researcher in remaining focused on the topic and forced the researcher to anticipate problems as well as ways on how the case study report will be completed (Yin 2014:73).

According to Yin (2014; 99), data collection for a single case study should be collected from multiple sources to provide a rich picture of the case being studied. These sources could include documents, archival records, interviews, direct observation, physical artefacts etc.

The researcher selected the following data collection sources and methods: interviews, direct observation and assessments. See *Table 3.2.2: Data Collection Sources* below:

Table 3.2.2: Data Collection Sources

Data collection source	Description
Interviews	Semi-structured interviews were held with purposefully selected participants i.e. foster mother / caregiver, school teacher and therapist, genetic specialist and seating specialist. The interview schedule was drawn up to cover the following topics; Emily's participation in areas of occupation, assistive technology and devices, therapeutic intervention, school, disability rights and future considerations. *Refer to Annexure A*.
Assessments	Relevant reports including Emily's birth certificate, medical and allied health care reports as well as school reports were used.

	Formalised occupational therapy assessment instruments to describe Emily's body functions and occupations were used. Selected assessments carried out during the research process included: • Winnie Dunn's Sensory Profile 2: focusing on sensory modulation. *Refer to annexure B*. • Beery Buktenica Developmental Test of Visual Motor Integration VMI (Visual motor integration subtest only). *Refer to annexure D.* • Gardner's Test of Visual Perceptual skills (TVPS3).*Refer to annexure E.* • Revised KNOX Pre-school Play scale; videos were taken of Emily in her natural school environment; playing alone AND with friends. This was then reflected upon by the therapist and an external rater per the scale. *Refer to annexure H.* • QUEST Version 2.0 (Quebec User Evaluation of Satisfaction with Assistive Technology). This was used to evaluate Emily's mobility using her powered wheelchair, ADLs using her manual prosthetic arms as well as Play/leisure/school using her tablet. *Refer to annexure I.*
Direct Observation	Existing videos/photographs showcasing Emily's supports and barriers in daily activities were analysed. An external rater (qualified occupational therapist) was also used to provide insights to the effectiveness of occupational therapy in the management of this specific case. Reflective analysis and direct observation of previous occupational therapy intervention/management. This was performed by the researcher and external rater (as above). The occupational therapy practice framework was used as a guideline (AOTA, 2014). Refer to Annexure P.

Appropriately designed field procedures are necessary for case study data collection. Data was collected from people in their natural settings, not in a controlled environment. Thus, real world events must be incorporated with the data collection plan because the researcher does not have control over the data collection environment. When conducting interviews, researchers need to cater for the interview schedule and availability of participants (Yin 2014: 88-89). For the purpose of this study the researcher developed a schedule for data collection based on appointments made with individual participants at a time that was convenient for them.

3.3.2.1. Development of the semi-structured interview guide:

Qualitative interviews are conversational and because the conversations are purposeful it requires preparation in advance (Polit and Beck 2012:541). At the heart of the case study protocol is the interview guide that consists of a set of semi-structured questions that reflect on the actual line of enquiry (Yin 2014:89). The researcher therefore developed a set of questions that guided the interviews and reflected issues to be explored. All questions were worded flexibly to allow for follow-up questions. The questions were simulated from the research questions and literature on TAS. The interview guide (Annexure A) consisted of 7 open-ended topics namely 1) General questions related to TAS, 2) Areas of Occupation, 3) Assistive/Adaptive technology, 4) Therapeutic intervention, 5) School inclusivity, 6) Child and disability rights and 7) Future considerations. The researcher used open-ended questions to allow participants to fully describe the case of Emily.

Yin (2014:96) states that a pilot case study will help to refine the data collection process. The researcher however did not do a pilot case study to test the questions as only a small number of research participants were chosen purposively due to their role that they have played in Emily's life. Instead, the researcher received assistance from her supervisor and co-supervisor to ensure the questions were not vague or misleading and that they were linked to the theoretical framework of the study.

3.3.2.2. Preparation of assessments

Relevant reports were assembled into an electronic documentation matrix in preparation for data retrieval (see Table 3.2.5 pg. 47). Selected formalized assessment instruments were chosen and prepared by the researcher. The

researcher made sure that she was apt in administering each assessment and made sure to go through each assessment beforehand to eliminate possibilities for errors.

3.3.2.3. Development of observational guide according to the OTPF

The researcher used selected sections from the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2014) to develop an observational guide for the external rater to make comments on while watching and reviewing archived photo and videographic evidence of Emily in natural environments of home, community and school as well as therapy sessions filmed by the researcher over the years. *See Annexure P.*

3.3.3. COLLECTING CASE STUDY EVIDENCE

According to Yin (2014:04) case study evidence may come from various sources namely, interviews, direct observations, participant-observation, archival records and document analysis to facilitate in-depth analysis and understanding of the data, which requires the researcher to master different data collection procedures. The data collection methods chosen for this study was determined by the purpose of the study, the research questions, and available resources (Yin 2014:10; Rule and John 2011:59; 61). A major strength of case study research is the fact that multiple sources of evidence can be used for data triangulation, causing the data to be more convincing and accurate. Strengthening the construct validity of the case was done by providing multiple measures of the same phenomenon (Yin 2014:119-121). According to Baxter and Jack (2008:544) using multiple sources of evidence ensures 'that the issue is not explored through one lens, but rather a variety of lenses which allows for multiple facets of the phenomenon to be revealed and understood.' This was applied in the case study by using data collected from a variety of role players in Emily's life through semi-structured interviews, document analysis and direct observation using photo and videographic evidence.

3.3.4. PRINCIPLES OF DATA COLLECTION

Yin (2014:105) outline four principles of case study data collection that are extremely important for doing high-quality case studies, namely:

- Using of multiple data collection sources of evidence;
- Creating a case study database;
- Maintaining a chain of evidence and
- Exercising care in using data from electronic sources of evidence.

The benefits of evidence collected can be maximised when using these four principles and these principles can be used for documents, artefacts, direct observations and interviews (Yin 2014:118).

Following is a discussion of the four principles of data collection and its application to the study (Yin 2014:118-130).

Principle 1: Use of multiple sources of evidence: The need of the use of multiple sources of evidence for case study research far exceed that of other research methods, such as experiments, surveys or histories. Using multiple sources of evidence increases construct validity and reliability of case study research. Multiple sources of evidence allow the researcher to address a broader range of historical and behavioural issues. The findings and conclusion are more convincing and accurate if it is based on different sources of information, following a similar convergence (Yin 2014:118; 120). However, the most important advantage of multiple sources of evidence is the development of converging lines of inquiry. The desired triangulation results from the principle of navigation, whereby the intersection of different points is used to calculate the precise location of an object (Yardley 2009 cited in Yin 2014:120). The use of multiple sources of evidence aims at corroborating research findings. Developing convergence data triangulation helps to strengthen the construct validity of case studies (Yin 2014:120121). For the purpose of this study the researcher used multiple sources of evidence, namely: interviews, assessments and direct observation (*See Annexures A, B, D, E, H, I, P*) to corroborate the findings, ensuring that through data triangulation the participants' perspective is rendered accurately. Construct validity and reliability of the case study findings will be increased.

Principle 2: Creating a study database: The way researchers organize and document the case study data that was collected become very important. The distinction between a separate database for evidence and case study report is necessary because the case study data, which is mainly in narrative form, were embedded in the text

presented in the case study report. The main purpose of a database is to allow for retrieval of documents at a later stage. The creation of a database increases the reliability of case studies because it allows critical readers to inspect the raw data that led to the study's conclusion. The case study database should be orderly (Yin 2014:123-124). For the purpose of this study the researcher stored electronic copies of transcribed interviews, documents and videographic/photographic evidence reviewed and field notes on a flash drive to be kept at the University.

According to Yin (2014:124-125) it is very challenging to develop a database for case study data in terms of four components, namely: field notes, documents, tabular materials and narratives. For the purpose of the present study the researcher used interviews, field notes, documents, and narratives to collect case study evidence to compile the database for the study.

Field notes: For case studies, field notes take a variety of forms and are the most common components of a database. Field notes for the present study were the result of interviews, observations or document analysis and were stored in electronic files on the researcher's computer.

Case study documents: Documents relevant to the case were collected during the course of the study and record was kept using a bibliography list. The researcher provided a compact overview of the documents used, with a bibliography section that can also serve as an index, that facilitate the document storage and retrieval at a later stage for inspection or perusal. Both hard copies and electronic copies of documents used in this study were kept by the researcher.

Principle 3: Maintain a chain of evidence: A third principle, to increase the reliability of case study information, is to maintain a chain of evidence. The researcher kept a chain of evidence to allow any external observer or a reader of the case study to follow the derivation of any evidence from the initial research questions to ultimate case study conclusions. The chain of evidence compiled by the researcher should allow the external observer to trace steps in both directions; from research questions to conclusions or from conclusions to research questions. The chain of evidence process furthermore indicates that the evidence was the same evidence collected during the data collection process. In addition, the researcher ensured that no original evidence was lost through carelessness or bias. By maintaining a chain of evidence the

researcher tried to increase the case study's construct validity with the aim of increasing the overall quality of the case study. The researcher ensured that the relevant sources, such as the documents, interviews and field notes used in collecting data were cited. The researcher also highlighted key phrases or specific words in the documents. In the method section it was also indicated under which circumstances the evidence were collected as well as the time and place where the interviews were conducted. The researcher also ensured that the circumstances were consistent with the specific procedures and questions contained in the case study protocol to show that the data collection followed the procedures as stipulated in the protocol.

Principle 4: Exercise care when using data from electronic sources: The researcher exercised care in searching for articles and documents from reputable websites such as the University of Pretoria's library's website for online journals and did not use any material from Wikipedia, Facebook, Twitter or YouTube.

3.3.5. DATA COLLECTION METHODS

Any findings or conclusions reached in case study research is more convincing when it is based on multiple sources of evidence (Yin 2014:119).

The researcher will next discuss the different data collection methods used for this study:

3.3.5.1. Interviews:

Interviews are one of the most important sources of collecting case study evidence (Yin 2014:110). Yin (2014:6; 112) points out that the following weaknesses may occur with interviews: researchers could be biased due to poorly articulated questions, response bias, information can be inaccurate due to poor recall and participants give answers that the researcher wants to hear.

For the purpose of this study the researcher used semi-structured interviews (Annexure A) with purposefully selected participants from Emily's context. The following is a description of the specific phases that the researcher followed for the interviews, namely the preparatory phase, the interview phase, and the post-interview phase (Polit and Beck 2012:541-544).

- The preparatory phase: Prior to data collection the researcher phoned or emailed each participant who had been selected for the research study. The researcher then made appointments with the participants who were willing to participate. On the day of the interviews, before the actual interview commenced, the researcher tried to make the participant feel comfortable to make it easier for them to express their innermost thoughts and feelings. The aims of the study were explained to all participants. Before commencing with the interviews the researcher conducted the process of consent. The participants were provided with an information document containing information such as: what the research is about, procedures to be followed, participants' rights, risks and benefits, and confidentiality. They were given time to read the participation information and consent document *(Annexure K)* and ask questions regarding the study should they have any. Participation was voluntarily and the researcher thanked the participants for their willingness to participate. The researcher further explained that all interviews would be conducted in English and sought permission from the participants to record the actual interview to which all the participants agreed. A video recorder was used to record the interviews to ensure a better rendition of the information provided by the participants than to just rely on making one's own notes (Yin 2014:110).

- Conducting the interviews: The interview phase consisted of the actual communication between the researcher and the participants. The researcher used the interview guide to ask the questions and gave participants the opportunity to respond to each question. Interviews were conducted in an honest, open and sincere manner and empathy was shown towards participants. Open-ended questions were asked during the interviews to provide participants with the opportunity to fully describe the phenomenon of Emily in her context. The interviews resembled guided conversations and a consistent line of inquiry was pursued, while the questions were fluid rather than rigid. Questions were posed in no specific order or wording and depended on participants' answers. In cases when clarity was sought the researcher used probing and the "why" question was posed and participants were given an opportunity to reflect before providing a response. The interviews were

conducted in a place that offered privacy, with the least interruptions and noise that allowed adequate tape recording of the interviews. The researcher collected data to the point that themes became recurrent and enough in-depth data were obtained that could illuminate the patterns, categories and dimensions of the phenomenon under study. Thus, data collection took place until the participants' descriptions became repetitive and no new ideas emerged. The duration of each of the interviews was approximately two hours each. The researcher closed the interviews by thanking each participant for their willingness to participate and they were reassured that the data would be kept confidential.

- Post-interview procedure: The researcher spent some additional time after each interview to write down her impressions and any other observations that may have stood out to her. After conducting the interviews the researcher listened attentively to the audio-taped data, checking for audibility and completeness before it was transcribed verbatim. The transcribed data was stored electronically and two hard copies of the transcribed interviews were made.

A total of five interviews were conducted over 5 weeks. The participants included a genetic specialist, seating specialist, foster mother, school occupational therapist and teacher. The researcher did not conduct any follow-up interviews as data saturation had been reached.

3.3.5.2. Assessment Analysis

Information obtained from documentation is likely to be relevant to every case study topic and should be part of the data collection plan. The use of documentation has a variety of advantages, it is stable and can be reviewed repeatedly, it is unobtrusive and not created for the case study, and it contains specific information and details of an event and is broad and can cover a long span of time, events and many settings. However, the use of documentation also has it weakness; it can be difficult to find, it might be incomplete, reporting bias or access to documents might be deliberately withheld (Yin 2014:106; 125). The researcher ensured that the documents used can be retrieved for perusal at a later stage.

Selected documents relevant to the case can be seen in *Table 3.2.5: Assessments used in the data collection phase of research.*

Table 3.2.5: Assessments used in the data collection phase of research

Assessments	Description
Birth certificate, medical and allied health care & school reports.	Relevant reports were used as collateral and background information of the case.
Winnie Dunn's Sensory Profile 2: focusing on sensory modulation. *Refer to annexure B*.	The profile was filled out by 1) foster mother and 2) school teacher with regards to Emily's sensory modulation in a home and school environment. The profiles were scored electronically and quantitative data was produced for analysis. **An external rater checked the scoring for correctness and to avoid bias*
Beery Buktenica Developmental Test of Visual Motor Integration VMI (Visual motor integration subtest only). *Refer to annexure D.*	The subtest was presented to Emily by the researcher at her school. A therapy office was used for correct testing conditions and confidentiality. The test was scored against standardized norms and quantitative data was reproduced for analysis. **An external rater checked the scoring for correctness and to avoid bias*
Gardner's Test of Visual Perceptual skills (TVPS3). *Refer to annexure E.*	The subtest was presented to Emily by the researcher at her school. A therapy office was used for correct testing conditions and confidentiality. The test was scored against standardized norms and quantitative data was reproduced for analysis. **An external rater checked the scoring for correctness and to avoid bias*

Revised KNOX Pre-school Play scale. *Refer to annexure H.*	Videos were taken of Emily in her natural school and home environments; playing alone AND with friends. This was then reflected upon by the therapist and an external rater as per the KNOX scale. Quantitative data was reproduced for analysis.
QUEST Version 2.0 (Quebec User Evaluation of Satisfaction with Assistive Technology). *Refer to annexure I.*	This survey was used to evaluate Emily's mobility using her powered wheelchair, ADLs using her manual prosthetic arms and universal cuff as well as Play/leisure/school using her tablet, head pointer, eye tracker. Surveys were completed by key role players in Emily's life. The surveys were scored and quantitative data was reproduced for analysis. **An external rater checked the scoring for correctness and to avoid bias*

3.3.5.3. <u>Direct observation:</u>

Because a case study should take place in the natural setting of the 'case', the researcher is creating the opportunity for direct observations. Due to the fact that the case in study is not a historical case, some relevant behaviours or environmental conditions were available for observation (Yin, 2014: 193). Yin describes that observational instruments can be developed as part of the case study protocol.

The researcher decided to use the OTPF Occupational Therapy Practice Framework (AOTA, 2014) as a guiding instrument in this regard *(see Annexure P).* The therapist documented her informal observations of interacting with Emily in her context as per selected domains of the framework. This will include reflective analysis of past therapy sessions, participation in different daily tasks, school visits, social and community outings and prospective analysis of her future path.

*An external rater was used to provide additional insight to the case in order to eliminate bias.

3.3.6. ANALYSING CASE STUDY EVIDENCE

A mixed method design? is a research paradigm that combines specific positivistic elements of quantitative research methods with specific constructivist elements of **qualitative** research methods. Generally, this approach can be sequential or parallel, with the **quantitative** and qualitative approaches used alternately or together to investigate the same phenomenon (Kitchenham, 2010).

Case study research often examines the descriptive questions of who, what, where, how many, and how much but can neglect the how and why questions often investigated in quantitative studies. Mixed methods research allows opportunities for the meaningful questions to be posed, measured, analyzed, and interpreted. Because both inductive and deductive reasoning are applied in mixed method research, the results are far more robust, especially in case study research that involves rich empirical data gathered through varied data collection techniques. In short, mixed method research is so powerful because it allows the “gaps” in qualitative research methodologies to be filled or overlapped by quantitative methodologies and techniques and vice versa (Kitchenham, 2010).

Yin (2014:133) indicates that the analysis of case study evidence is the least developed aspect. Therefore, the researcher used the process of content analysis as described by Elo and Kyngäs (2008) to analyse the content of interviews, assessments and field notes of the informal unstructured observations done during the interviews.

QUALITATIVE:

The interviews were transcribed by an external source. The following process were used to analyse the **interviews:**

(1) Transcripts of the interviewswere read to acquire an overall understanding of content related to the aim of the study;
(2) The interviews were read repeatedly and discussed with supervisors to achieve immersion and to gain a sense of the whole;
(3) The interviews were read again (word for word) while writing notes and headings in the margin of the transcripts;

(4) The process was repeated and subcategories with similar events and incidents were grouped together as categories (Dey 1993; Robson 1993; Kyngäs & Vanhanen 1999 cited in Elo & Kyngäs 2008).
(5) Each category was named using content characteristic words;
(6) The lists of categories were grouped together as main categories or themes to reduce the number of categories and to provide a means of describing the phenomenon and to increase understanding and to generate knowledge (Cavanagh 1997 cited in Elo & Kyngäs 2008);
(7) The abstraction process was repeated as far as possible (Elo and Kyngäs 2008; 107-115).

Direct observation as per the OTPF was checked by an external rater and information will be distributed into the matrix of categories laid out in the observational framework guide. See Annexure P.

QUANTITATIVE:

The **assessment analysis** used in the case is described in the *Table 3.2.6: Assessment Analysis* below:

Table 3.2.6: Assessment Analysis

Assessment	Analysis
Sensory Profile	The sensory profile will be filled out by Emily's foster mother and the school companion version will be filled out by her class teacher. It is a 1-5 scale rating looking at different sensory system's processing as well as links to emotional/behavioural outcomes (Dunn, 1999). The data collected will be analysed quantitatively (in a tabular format) to form a greater clinical picture for Emily's case. See Annexure C.
Beery VMI	The visual-motor integration subtest will be used to assess the extent to which Emily can integrate her visual and motor abilities (Beery & Beery, 2010). The results will provide the researcher with a raw score and scaled score. This numeric data will be used to support qualitative data. See Annexure D
TVPS	The Test of Visual Perceptual Skills assesses visual-perceptual strengths and weaknesses, using a response format suitable for all children, including those with disabilities. Scaled scores, percentile ranks, and age equivalents for each subtest and for overall performance can be obtained (Martin, 2006). This quantitative data collected will be analysed qualitatively to form a greater clinical picture for Emily's case. See Annexure E.
Revised Knox Pre-school play scale	The RKPPS is an assessment of play for 0 to 72 month old children. Children should be observed in both indoor and outdoor settings; as naturalistic or familiar environment as possible, with peers present. The child should be observed for a minimum of two 30 minute periods. In this specific research, the researcher will request Emily's teacher to take a 30 minute video recording both indoors and outside on the playground. A caregiver at her place of residence will also be requested to do the same. The researcher and an external rater will rate the play

	sessions according to the scale and results will be compared and discussed. Quality is further ensured due to the reliability and validity studies performed by Harrison and Kielhofmeyer (1986) and interrater reliability performed by Fallon & Jankovich and Associates (2006) as cited in (Parham & Fazio, 2008). See Annexure H.
Quest version 2.0	The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) is an outcome measurement instrument designed to evaluate a person's satisfaction with his or her assistive technology device. It is a self-response rating scale looking at ease, comfort, effectiveness etc. of each device. The scales will be completed by her primary caregiver (foster mother), school OT and school teacher. Reliability of this test will thus be ensured. (Demers, Weiss-Lambrou, & Ska, 2000). The qualitative data will be used to support qualitative data. See annexure I.

3.3.7. ENSURING HIGH QUALITY ANALYSIS

According to Yin (2014:133) qualitative data analysis consists of examining, categorising and verifying the data findings to draw empirically based conclusions. The study evidence constitutes of the transcripts of the individual interviews and the accompanying documentation.

According to Yin (2014:133) the analysis of case study evidence is the least developed aspect; therefore, the researcher used the process of content analysis as described by Elo and Kyngäs (2008). The researcher identified similar content in the transcribed interviews that was used to identify subcategories, categories and themes through a systematic process of coding. See *Table 3.2.7.1: Principles and Strategies used to ensure high quality analysis.*

Table 3.2.7.1: Principles and Strategies used to ensure high quality analysis

Principles	Strategies
Attend to all evidence	The researcher analysed the interviews in conjunction with the field notes and documentation ensuring that no evidence was ignored.
Analysis to address the most significant aspects of case study	The researcher paid attention to all aspects of the study during data analysis by providing step by step details of the analytic techniques used and how the researcher arrived at the findings.
Use of researcher's prior knowledge of the study	The researcher used her current knowledge and kept up to date through internet and journal searches, reading up on the latest information on occupational therapy and TAS.

According to Merriam (2009:52) 'the researcher is the primary instrument of data collection and analysis', and researchers must rely on their own instinct and abilities. The researcher believes in multiple realities and was committed to identify the approach that led to understanding the phenomenon of TAS. The researcher acknowledged that she is part of the research process and also valued the participants' viewpoints. The research findings are reported in a literacy style rich with participants' commentaries.

According to Yin (2014:72) 'a well-trained and experienced researcher is needed to conduct high quality case study research because of the continuous interaction between the theoretical issues being studied and the data being collected.' See *Table 3.2.7.2* for the attributes that researchers should have in order to conduct good quality case study research.

Table 3.2.7.2: Researcher's desired attributes for case study research

Desired attributes	How this has been addressed in the study?
Ability to ask good questions	The ability to ask good questions is a prerequisite for case study researchers bearing in mind that asking good questions is to understand that research is about questions and not necessarily about answers. Case study researchers should have an inquiring mind during data collection (Yin 2014:73-74). The researcher kept an open mind and created a rich dialogue with the evidence reviewing it and asking questions as to why events or perceptions appear as they do and based on judgement to search for additional evidence.
Be a good listener	The researcher had to listen carefully and make keen observations or sense what is going on and had to assimilate large amounts of new information without bias. During interviews the researcher had to listen carefully to hear the exact words of participants to understand the context from which the interviewees view the world and infer the meaning intended by the interviewee (Yin 2014:74).
Stay adaptive	The researcher had to remember what the original purpose of the study was and had to be able to adapt procedures and plans if unanticipated events occur. Therefore, the researcher has to be able to make minor changes when needed in order to pursue unexpected leads maintaining an unbiased perspective and recording such changes (Yin 2014:74-75).
Have a firm grip of issues being studied	The researcher stayed up to date with new research on the phenomenon under study and continued to search on internet for recent articles released on occupational therapy and TAS. The researcher had to interpret the information as data collection takes place to determine whether data saturation has taken place or whether additional evidence is needed.

Avoid biases	The researcher was open to contrary evidence and willing to report these contrary findings; she strived to maintain the highest ethical standards while conducting the study.

Credibility of the findings of a study depends on how well the categories cover the data (Graneheim and Lundman 2004:110) and in order to increase the reliability of a study the researcher needs to demonstrate that there is a link between the findings and the data (Elo and Kyngäs 2008:112). The researcher described the analysis process and findings in detail so that the readers may have a clear understanding of how the analysis was carried out. Therefore, the researcher kept all evidence in such a way that an external observer would be able to follow the derivation of any evidence. The researcher described the content of the categories through subcategories (Burnard 1996:279). The researcher analysed the raw data breaking it into smaller pieces and identified themes, categories and subcategories. The categories reflect the subject of the study in order to label the analysis process successful (Burnard 1991:462). After analysing the data independently, the researcher and supervisors met to discuss the themes, categories and subcategories in order to reach consensus on the coded data.

According to (Lincoln and Guba 1985; and Guba and Lincoln 1994 cited in de Vos, Strydom, Fouche and Deport 2011:584), qualitative researchers need to evaluate the quality of their data and their findings. They further suggested five criteria for establishing the trustworthiness of qualitative data and the ensuing analysis, namely: credibility, dependability, confirmability, transferability, and authenticity.

3.4. ENSURING THE QUALITY OF A CASE STUDY DESIGN

Ensuring validity and reliability in qualitative research indicate that the study is conducted in an ethical manner (Merriam 2009:209). Yin (2014:45) suggest four tests to determine the quality of case study research, namely: construct validity, internal validity, external validity and reliability. However, the researcher decided to rather use the framework by Lincoln and Guba (1985) due to the qualitative nature of data collection process. Yin (2014:45) also refer to these concepts; therefore, the researcher deemed it as acceptable to use with a case study. The quality of any given

study design can be judged according to certain logical tests. The researcher will next discuss measures used to ensure trustworthiness of the case study.

An approach to clarifying the notion of objectivity as it is manifested in qualitative research is found in the highly influential work of (Lincoln and Guba 1985 cited in Babbie and Mouton 2001:276-277). For them the key criterion or principle of good qualitative research is found in the notion of trustworthiness - the neutrality of findings or decisions. The basic issue of trustworthiness is simple: researchers need to persuade their audience that the findings of an inquiry are worth paying attention to or worth taking account of. According to Rule and John (2011:8) the concept of trustworthiness is an alternative to reliability and validity. Trustworthiness helps to gain trust and fidelity and promotes values such as rigour, transparency and professional ethics in qualitative research. The concept of trustworthiness is achieved when giving attention to transferability, credibility, dependability and confirmability as well as authenticity.

Credibility: According to Rule and John (2011:107) credibility is an alternative for internal validity and is a reflection on the extent to which a study measure in on what it is set out to study. Credibility ascertains whether there is compatibility between the constructed realities that exist in the minds of participants and those that are attributed to them? In order to achieve credibility of the research findings the researcher utilised her supervisor's knowledge and insight to verify that all the theme, categories and subcategories have been identified during analysis; the researcher that stayed in the research environment during data collection and multiple data collection sources was also used (Babbie and Mouton 2001:277).

Dependability: Dependability is seen as an alternative for reliability and focusses on methodological rigour and coherence towards generating research findings that can be accepted with confidence by the research community (Rule and John 2011:107). Dependability of qualitative data refers to stability over time and over conditions. An inquiry audit is a technique relating to dependability that involves a scrutiny of data and the relevant supporting documents by an external reviewer. The researcher gave a dense description of the methods of data collection, analysis and interpretation of the data that will provide information as to how repeatable the study might be. The researcher used her supervisors, who have extensive experience in qualitative

research, to check the research plan and the implementation of the plan. During the analysis stage the researcher utilised the help of her supervisors who are experienced in qualitative research. The researcher and the supervisors compared and discuss the themes, categories and subcategories. Consensus was reached amongst the researcher and supervisors (Polit and Beck 2012:593).

Transferability: Transferability is an alternative for generalisability and refers to the extent to which study findings can be applied in other contexts or to other participants. The qualitative researcher is not interested in generalisations. For the purpose of this study, the researcher provided detailed descriptive information that will allow readers to make inferences on whether the research findings can be applied to new situations, it is the reader who transfers the results (Polit and Beck 2012:525; Rule and John 2011:105).

Confirmability: Confirmability guarantees that the findings, conclusion and recommendations are supported by the data and that there is an internal agreement between the researcher's interpretation and the actual evidence (Lincoln and Guba cited in Babbie and Mouton 2001:278). According to Rule and John (2011:107) confirmability is a way that a researcher's influence and biases on the study can be addressed. The researcher kept an audit trail and raw data such as, interview guide, recorded interviews, written field notes, standardised test scores, photographs, videos, documentation, the analysed data and process notes. Instruments used in a master file will be kept under lock and key for 15 years for reviewing as an evidence that will enable auditors to trace the conclusion, interpretation and recommendations to their sources and to determine if they are supported by the inquiry.

Authenticity: According to Polit and Beck (2012:525) 'authenticity refers to the extent to which the researchers fairly and faithfully show a range of different realities. A text has authenticity if it invites readers into a vicarious experience of the lives being described and enables readers to develop a heightened sensitivity to the issues being depicted'. For the purpose of this study the researcher used an interview guide that indicated which questions should be probed; field notes was taken on all participants' emotions and body language expressed during the interview.

3.5. ETHICAL CONSIDERATIONS

A research proposal, number 289/2017, was submitted to the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria, for approval to conduct the study and approval was granted in July 2017 (Annexure O). Permission was also requested from and granted by the Department of Education, Gauteng Province to conduct research with a school learner (Annexure J). In addition, consent was obtained from the participants. The participant's rights were explained to them prior to their participation and an informed consent document was given to the participants as part of the consent process (Annexure K).

Ethical issues arise out of our interaction with other people, other beings (such as animals), and the environment, especially where there is potential for, or is, a conflict of interests. In many cases, ethical choices involve a trade-off or compromise between the interests and the rights of different parties (Polit and Beck 2012:152). According to Yin (2014:73; 76-77)

Case study researchers should avoid being biased and should conduct research ethically. The researcher strived to maintain the highest ethical standards while conducting the research.

The researcher will next describe the ethical principles that guided the study. (Brink, 2012; 30-36)

<u>The principle of respect for human dignity:</u>

Participants have the right to self-determination. This means that the individual has the right to decide whether or not to participate in the study, as well as to withdraw from the study at any time. The informed consent document made clear that the study is a research study, and not clinical therapy. The participant was informed as fully as possible of the nature and purpose of the research, the procedures to be used, and the expected benefits to the participant as well as the potential of risks, stresses, and discomforts. Polit and Beck (2012:162) state that confidentiality is the management of private data in research ensuring that subjects' identity is not linked to their responses. Therefore, the participants' names were not used in the research report. Furthermore, participants were assured that they will have the freedom to withdraw from the study

at any time without prejudice. Participants were advised should they have any queries to contact the researcher or her supervisors. The researcher eliminated coercion; which is the use of force or intimidation to obtain compliance for a research study by allowing the participants the freedom to decline participation in the study. At the time of the study, Emily was younger than 7 years of age, therefore her foster mother gave consent for her participation. Emily gave assent to her participation in the study.

Principle of beneficence:

The researcher made provision to secure the well-being of the participants, who have the right to protection from discomfort or harm, be it physical, emotional, spiritual, economical, social or legal. In any research, participants can be harmed in a physical and/or emotional manner. Emotional harm is often more difficult to predict and determine than physical discomfort, but often has more far reaching consequences for the participants (Polit and Beck 2012:163). However, the researcher did explain to participants prior to participation what the risks of participation might entail. The researcher strived to minimize the potential risks and maximize the potential benefits by ensuring that the researcher asked questions in a friendly and non-threatening manner and monitored the emotional discomfort of participants during interviews.

Ther researcher conducted the interviews and testing of her participants at sites that were private and confidential. Transcripts of interviews were completed by an exterrnal source who had no access to the names or details of the participants. The researcher made sure that all photo and videographic evidence was kept away from the public eye and those that were used for analysis, were kept as private as possbile by blacking out the faces of the subjects involved. Privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner (Polit and Beck 2012:162). Measures to ensure privacy and confidentiality include the protection of the identity of participants by keeping all data safe for 15 years and omitting their names in the research report. Practices of accountability are of the utmost importance in such a research setting and the researcher committed herself to respect participants' contributions by honouring the above stated measures to ensure responsible research. The researcher needed to be mindful as to not exploit her subject. Due to the fact that the participant is from a vulnerable population, her best interests should be keep at all times and the researcher should not only take gain from the research study.

Principal of justice:

The researcher should include the participants' right to fair treatment. The researcher must respect any agreements made, be punctual and stop the process at the agreed time. The researcher must also respect the subject's right to privacy. The researcher should not share private information without the subject's knowledge or against his/her will. The publication of photographic material must be restricted to protect the participant's privacy. The University should be prohibited to publish the thesis with the material in it on the internet. The researcher should make use of proper storage systems (locked drawers or password protected electronic documents) of documents that may divulge the participant's personal information. *Refer to Annexure M.*

Protection of human rights:

The researcher should carry out the research competently, honestly and accurately. The researcher should acknowledge fairly those who contribute guidance or assistance. The researcher should demonstrate respect for the scientific community by protecting the integrity of scientific knowledge i.e. avoidance of fabrication, forging, plagiarism, manipulation of data etc. *Refer to Annexure L.*

3.6. SUMMARY

In this chapter the researcher discussed the methodology used in the research study, the measures used to ensure trustworthiness and all ethical issues applicable. In the next chapter, the researcher will discuss the findings of the data.

CHAPTER FOUR

FINDINGS & DISCUSSION OF RESEARCH

4.1. INTRODUCTION

The research methodology used to address the research questions was described in the previous chapter. The data was collected using individual semi-structured interviews, assessments and direct observations. This chapter covers the research findings and discussion with related literature. Both the findings and discussion is included in one chapter due to the narrative ad descriptive style of the case.

4.2. DATA ANALYSIS

Data collection and analysis will occur simultaneously. Yin(2014) suggests techniques for analysis including lining data to aims and objectives, explanation building, developing a case description i.e. organising case study per some descriptive framework (OT Practice framework) and involving other research team members in the analysis phase. In this way, they can provide feedback on the researcher's ability to integrate data sources to answer the research questions. Data analysis means to organise, provide structure and elicit meaning to the raw data. Qualitative data analysis includes coding, categorising, concept mapping and theme generation (Simons 2009:117) which enabled the researcher to organise and make sense of the raw data obtained during the individual interviews. Data analysis was done using processes described by Elo and Kyngäs (2008). Quantitative data from documents and observation was also analysed.

4.2.1. THE RESEARCHERS ROLE IN DATA ANALYSIS

The researcher used the process of reflexivity to guard against preconception regarding the phenomenon under study in order to increase the credibility of the study (de Vos, Strydom, Fouche and Deport 2011:422). Researchers who conduct qualitative research rely on reflexivity to guard against bias in making judgements (Polit and Beck 2012:179). During data analysis the researcher reflected critically upon

her personal values; and kept it in mind, but did not write it down in order to guard against personal biases, preferences, special interest in, and fears about the research and theoretical inclinations that could affect data analysis and interpretations (Schwandt 2007 cited in Polit and Beck 2012:179). According to Merriam (2009:52) 'the researcher is the primary instrument of data collection and analysis'; hence, researchers have to rely on their own instinct and abilities. The researcher believes in multiple realities and was committed to identify the approach that led to understanding the phenomenon of TAS in the case of Emily. The researcher acknowledged that she is part of the research process and also valued the participants' viewpoints. The research findings were reported in a literary style rich with participants' commentaries (Speziale and Carpenter 2007:21). Thus, the researcher relied on her instincts and abilities, recognizing her own biases and assumptions of the phenomenon under study and acted as the voice of participants, ensuring that the research report is an accurate reflection of the findings.

4.3. FINDINGS AND DISCUSSION OF RESEARCH

Both qualitative and quantitative data collected from the three mentioned sources; 1) Semi-structured interviews, 2) Assessment Analysis and 3) Direct observation will be used to present the findings linked to the following themes and categories (see Figure 4.3.1. below). Data will be presented according the headings; "Interview data", "observational data" and "assessment data" for each theme and category. A discussion of each theme and category will follow.

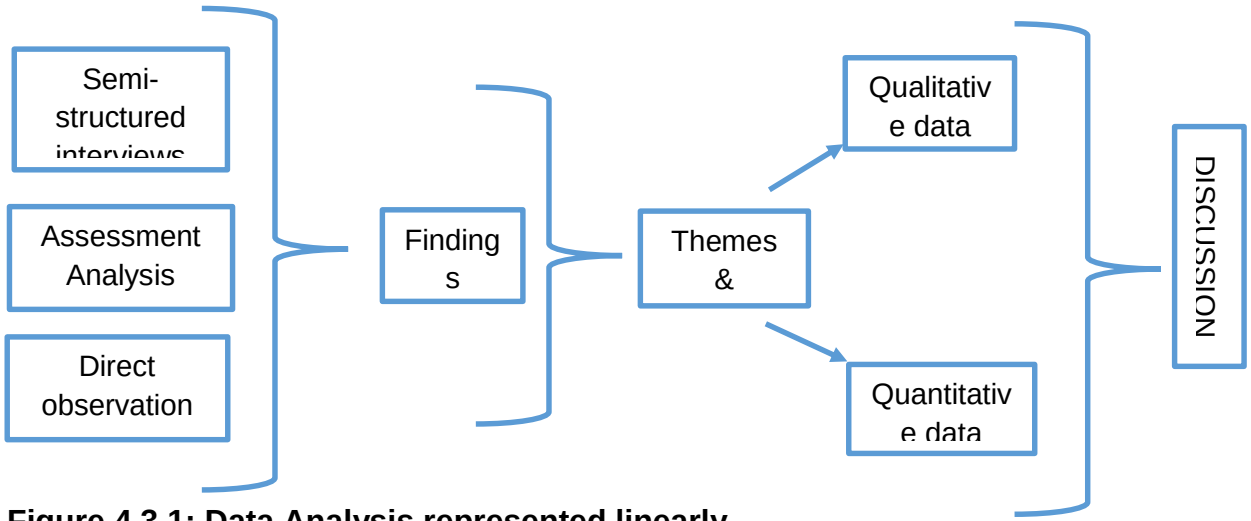


Figure 4.3.1: Data Analysis represented linearly.

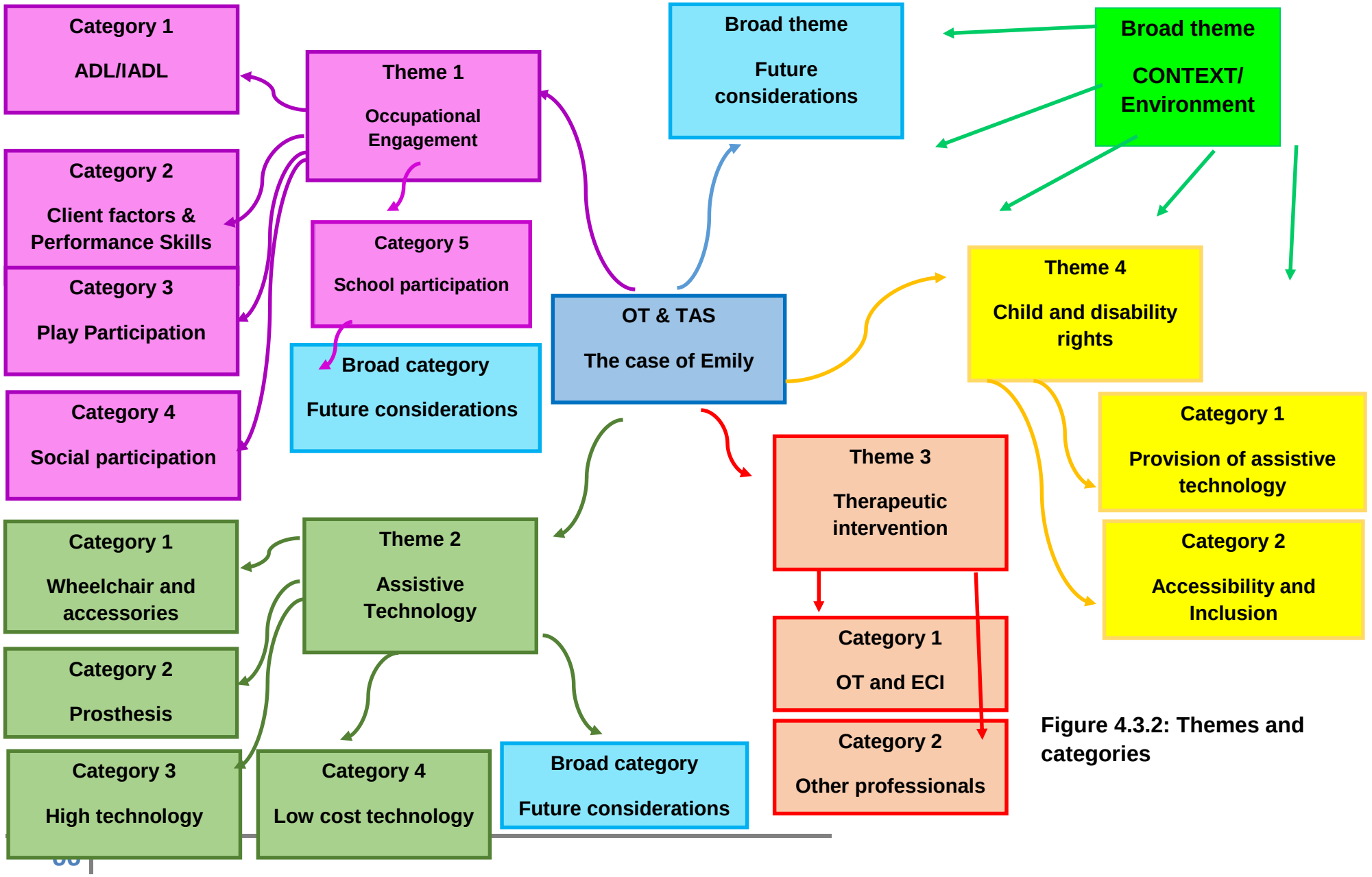


Figure 4.3.2: Themes and categories

When looking at this unique case of Emily, the researcher being an occupational therapist by profession, used the Occupational Therapy Process (OTP) in her continued work with Emily over the past few years. Standardized and non-standardised instruments were used to gain relevant information about Emily's abilities, performances and contexts and the interaction between her abilities and the demands of the environment. Issues brought to the fore by key role players in her life as well as observations made were used to form a comprehensive understanding of the problems and its effects of the child's performance and participation and assisted in guiding goal setting and intervention (Case-Smith, 2005).

The discussion of the results hopes to explore the research question: "How did **occupational therapy contribute to the holistic management of a child with Tetra-Amelia Syndrome**?"

The **aim** of this research study was to explore and describe the contribution of occupational therapy in the holistic management of TAS.

The **objectives were to**:

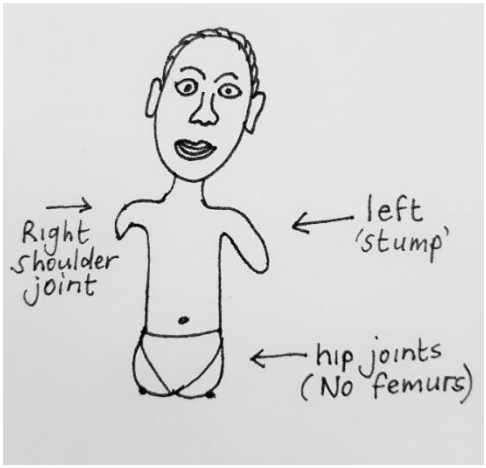
- Explore and describe how occupational therapy contributed to the development of occupational engagement in a young child with TAS.
- Explore and describe how assistive technology contributed to the development of occupational engagement in a young child with TAS.
- To reflect on future considerations for an individual with TAS.

With an understanding of Emily's participation within her context, an occupational therapist assists in defining specific abilities and limitations in the performance of activities. Quantitative or qualitative assessments are used as well as direct observation and collateral information from key role players to assess these abilities and limitation. In addition OT's note whether the performance becomes possible or moves to a higher level when the child is given assistance in the form of adapted equipment, assistive technology or environmental adaptations (Case-Smith, 2005). Further considerations include that Emily may perform differently in different environments i.e. mobility is more independent at home than at school.

Introduction to the case:

The researcher put together a profile for Emily using her birth certificate and early OT reports to paint a picture for the reader. *See Table 4.3: Emily's background profile.*

Table 4.3.1: Emily's background profile

Name:	Emily
Birth History	Emily was born on the 2nd August 2011 at 38 weeks via Caesarean section as she was in breech position. She weighed 2.20kg and measured at 27cm. Her APGAR scores were 7/10 and 9/10. After birth it was discovered that she did not have any limbs, and was subsequently diagnosed with Tetra-Amelia Syndrome by a genetic specialist. Her biological mother placed her in foster care at a place of safety, as she felt it would be unsafe for the child to return to home country with her due to superstitious beliefs surrounding this disability.
Medical History	A diagnosis of TAS was made 2 days after birth by a genetic specialist. No further complications were noted. She has received two separate operations at ages 4 and 5 to remove a Bursa on her left stump and to shave down the bone. It has been said that this may happen frequently due to the friction and excessive use of her left stump for mobility and manipulation of objects. Emily has also received stiches on two occasions on her forehead due to falling from an elevated position i.e. chair, wheelchair. 
School History	Emily started Grade RR in 2016 at a school catered for children with special needs. She struggled emotionally for the first 4 to 6 months but gradually showed more confidence and trust with the other children and teachers. She is now in Grade 1 and coping well with a facilitator to help her with her basic needs.
Family History	Emily was given up for adoption at birth. She resides with her foster mother and foster siblings at a place of safety.
Interests	Emily loves to chase her siblings around in her wheelchair. She loves swimming and going to the movies. She is a girly girl who loves handbags, shopping and dress-up.

THEME 1: OCCUPATIONAL ENGAGEMENT

For this theme, five categories were identified and the theme will be presented in conjunction with representative quotes from participants, documents and direct observation. The broad categories of 'Future considerations' and 'Context/Environment' will be discussed where relevant.

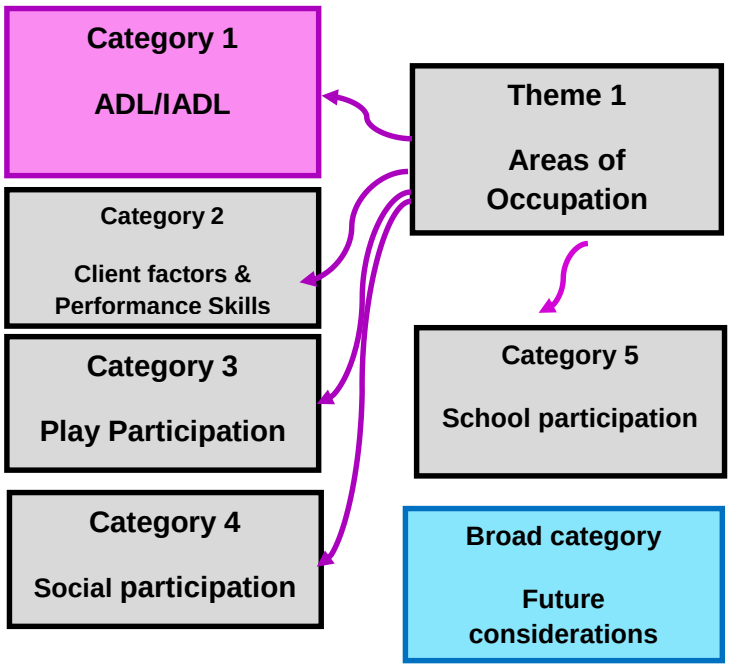


Figure 4.3.2.1: Theme 1 with categories

An analysis of the data and in conjunction with the interview questions, assessments and direct observation, this theme entails the various areas of occupation relevant in Emily's case, the opinions and perceptions of how her condition impact these areas, and how it is being managed or overcome by her caregivers and other role players in her life.

For this section, the following sub-categories will be discussed:

Category	Sub-category
ADL	Sleeping Feeding Dressing Bathing Grooming Toileting Mobility
IADL	Communication managements Community mobility Meal preparation and household management tasks

4.3.1.1. Category 1: Activities of Daily Living (ADL)

Activities of daily living (ADL) are activities oriented towards taking care of one's own body. These activities are "fundamental in living in a social world; they enable basic survival and well-being" (AOTA, 2014 pg. 518). A rating of self-care skill independence during task analysis, modified from Trombly will be used as follows under the direct observation quantitative data (*See Table 4.3.2. below):*

Table 4.3.2: Rating of Self-Care Skill Independence during task analysis (Trombly & Quintana, Activities of daily living, 1989)

Level of independence	Definition
Independent	Child does 100% of the task, including setup.
Independent with set-up	After another person sets up the task, child does 100% of the task.

Supervision	Child performs task by himself or herself but cannot be safely left alone, he or she may need verbal cueing or physical prompts for 1% to 24% of the task.
Minimal assistance or skilful	Child does 51% to 75% of the task independently but needs physical assistance or cueing for at least 25% of the task.
Moderate assistance (26% to 50% partial participation)	Child does 26% to 50% of task independently but needs physical assistance or other cueing for at least 50% of the task.
Maximal assistance (1% to 25% partial participation)	Child does 1% to 25% of task independently but needs physical assistance or other cueing for 75% of task.
Dependent	Child is unable to do any of the task.

When it comes to the analysis of data of her performance and engagement in Activities of Daily living (ADL), the following activities will be discussed with illustrative quotes from the transcribed interviews as well as direct observation: 1) Sleeping, 2) Feeding, 3) Dressing, 4) Bathing, 5) Grooming, 6)Toileting and 7) Mobility.

4.3.1.1.1. Sleeping:

Sleep participation encompasses ceasing activities to ensure onset of sleep, sustaining a sleep state without disruption, performing night time care of toileting needs, interacting with others within the social environment, ensuring warmth or coolness and protection and engaging in routines to prepare for restful sleep such as grooming, dressing, reading or listening to music (AOTA, 2014).

INTERVIEW DATA:

- *"She goes to bed at half past eight, she climbs onto her chair, gets into bed and climbs under her duvet, and normally goes to sleep immediately…She does need help with getting bathed and dressed before bed. She is able to page through books and say goodnight to her siblings"*
- *"When she had the eczema with the itching, it may have affected her sleep but at present I think she sleeps like a baby."*
- *"I must admit I have on occasion noted that she looks tired. And she went through a phase where she really did have dark marks under her eyes, and I don't know if that's related to the fact that her mom takes regular leave at a certain time of year, and I don't know if then she has sleepless nights because she does seem to worry about her mom a lot. And I think that going forward her sleeping patterns might have to be monitored just from a rest point of view."*
- *"If she gets too hot she climbs out the blanket. And she is able to do that herself."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Rest	Emily is independent with restful activities if the set-up is performed for her by someone else. She able to engage in quiet and effortless actions that interrupt physical and mental activity i.e. watching TV, sitting quietly outside, and listening to a story.
Sleep preparation and participation	Emily needs maximal assistance in sleep preparation i.e. putting her pyjamas on. She is able to get into bed independently and say goodnight to others. She sleeps well, unless the room is too warm. She struggles at times with temperature regulation. She is dependent on her caregivers to make her bed

DISCUSSION: Emily shows independence in sleep and engagement in restful activities. It should be highlighted however that set-up and preparation (night time bathing and dressing) by a caregiver or adult is vital for this occupation to be functional and flow smoothly. As a therapist, it was imperative to encourage some form of active participation in this occupation to provide meaning to Emily, thus adaptations were made to provide her a bed that was low to the ground that she could climb in and out of independently. She is also encouraged to partake in bedtime activities like reading stories and saying goodnight to her foster siblings. It was important to consider the environment in terms of adequate temperature and lighting to provide for the most optimal rest and sleep participation.

A further point to be considered for her future is how her emotional state affects her sleep. It has been recommended that she will need the ongoing assistance and management from a psychologist through all phases of her life to monitor her mental health including anxiety, stress and emotional wellbeing (*see Theme 3: Category 2: Other Professionals).*

4.3.1.1.2. Feeding**:**

The act of self- feeding comprises of setting up, arranging and bringing food (or fluid) from the plate or cup to the mouth (AOTA, 2014).

INTERVIEW DATA:

- *"She eats with a fork, she eats with a spoon, if we go out and you put a plate on her table, she will eat like you and I. I have seen how she manipulates utensils and food with her mouth and arm (left stump). We try and keep her on a Sippy cup (or a cup with a straw), because obviously sometimes she just tips a glass or cup too much. And obviously stuff like cutting meat we do for her. Otherwise she will pick it up with her left stump and nibble on it. At one point we were using that cuff (universal cuff) that we put the spoon in, but now she is a lot more mobile in terms of manipulating food or utensils without that. It assisted her in the correct movements she needed."*
- *"For snacks she can manage but eating a bowl of porridge, she needs help to keep the bowl stable. But she can feed small things by herself and the motivation is there, that's one thing from her: she is very determined. I have seen her try to feed herself yogurt and sometimes she would hold the spoon between the chin and her shoulder and I have sometimes seen her hold the spoon under her armpit. But the amount of manipulation that needs to happen there, it's very difficult."*
- *"Another thing I would say is difficult for her is small things like opening her lunch box, she is able to feed herself and drinks independently as well but sometimes even eating yoghurt…we have to feed her, because of the tool component it has. But she really doesn't like gadgets and so on to help her, she prefers working with her little stump."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Swallowing/ eating	Emily is able to manipulate food and swallow independently. She has no food allergies or intolerances.
Feeding	For this daily activity, Emily requires minimal assistance or supervision to perform it. She has become more dexterous and her control and manipulation of objects has improved – she now doesn't use the universal cuff or sponge handle for feeding anymore. She is also able to eat sandwiches and buns by placing them on her left stump and bringing it towards her mouth. She needs assistance with cutting food items into smaller pieces if need be i.e. meat, apples etc. Structuring of bowls and plates on her lap tray of her wheelchair is also necessary to provide structure to her mealtimes. She is able to drink independently by using a sip bottle or straw.

DISCUSSION: The occupation of eating was important for the researcher as it is an activity that occurs several times a day, providing children with nutritional intake, learning and interactional experiences. It provides a child opportunities to practice object manipulation, experience new sensations and learn how to communicate needs and desires. As with other developing occupations, a child's eating and self-feeding skills emerge from physical maturation. New challenging tasks that are presented and feedback about success enhances performance.

When helping Emily develop self-feeding skills, the therapist had to consider her underlying skills and limitations. With a holistic look at Emily's case, she fortunately did not present with swallow, suck or chewing difficulties. She did not present with oral sensitivities to different textures and tastes. Her limitations presented in the lack of range of motion in her limbs as well as the fine motor dexterity and co-ordination to manipulate utensils and food items. Her prominent strengths was her motivation to try and persevere through challenges as well as her intact cognition to learn new tasks *(see Theme 1: Category 2: Client Factors and Performance skills).*

Emily showed this eagerness to self-feed from an early age. She was able to hold her own bottle between her left stump and right shoulder from as early as 6 months old if she was in an inclined position (i.e. lying against a pillow). She was encouraged to explore with 'finger foods' like soft cookies, small pieces of bread, cheese etc. and had mastered this by 15 months of age. The important factor was her positioning that assisted performance and success. She used a Bumbo *(see Theme 2: Assistive Technology)* or feeding chair to assist her to maintain an upright position while food items were placed on the tray. She was encouraged to use her left stump and mouth to pick up items to eat. Thereafter, self-feeding was upgraded to exploration with utensils. A universal cuff *(see Theme 2: Assistive Technology)* or sponge handle was used initially at 2 years of age to provide her with stability of the utensil (spoon) and slightly more length. She was soon thereafter able to eat food items like yoghurt, mash and porridge independently as long as the set-up was done by a caregiver.

Over the years, she has become more dexterous and her control and manipulation of objects has improved – she now doesn't use the universal cuff or sponge handle for feeding anymore. She is also able to eat sandwiches and buns by placing them on her left stump and bringing it towards her mouth. She can also manipulate a spoon or a fork between her left shoulder and cheek. She still required assistance with cutting food items into smaller pieces if need be i.e. meat, apples etc. Structuring of bowls and plates on her lap tray of her wheelchair is also necessary to provide structure to her mealtimes. She is able to drink independently by using a sip bottle or straw.

Self-feeding intervention in Emily's case needed to consider the following aspects:

- *Context and environment:* it is important to consider her home, school and community setting for enhanced participation in meal time activities.
- *Positioning:* A bumbo or feeding chair works well at home, but using her wheelchair with lap tray at school is more effective at school. Both options provide her with an upright posture, adequate balance and ability to manipulate objects with her left stump, shoulder and mouth.
- *Adaptive equipment:* Equipment can provide simple adaptations to the feeding experience that enable a child to be independent in self-feeding. Assistive devices that have assisted and continue to assist Emily with feeding include: 1) non-slip mats and plate guards/elevated plates to avoid messing food or

crockery moving too much, 2) universal cuff or sponge handles, 3) halo or Sippy cups to avoid mess during tipping or placing on a surface and a future consideration; 4) a built-in cup holder on her wheelchair tray so that she can be mobile and stay hydrated.

- *Task modifications:* In Emily's case, it is vital for her self-feeding success for food items to be pre-cut into smaller pieces. Thus, school lunches need to be well prepared to minimise the need for a facilitator to help her. Finger foods and food items like bread and buns are easier for her to manipulate.

Intervention to promote a child's feeding and eating skills is an important role of the occupational therapist (Case-Smith, 2005 pg 515). Feeding interventions require a holistic approach in which multiple aspects of the child and environment are considered.

4.3.1.1.3. Dressing:

The act of dressing encompasses selecting clothing and accessories, obtaining clothing from a storage area, dressing and undressing in a sequential fashion and fastening and adjusting clothing (AOTA, 2014)

INTERVIEW DATA:

- *"When it comes to undressing, she can take out her arms, and sometimes she gets far enough that she can pull with her mouth. But obviously she can't get it all the way off. It's easier for her to wiggle out of her pants. With dressing, you can put on the top then she will wiggle her arms in. But basically she needs a lot of help. I'd like to think that as technology develops that's she'd get arms, remember we went and we saw the one with myoelectric arms, I'm hoping she would get that one day. So that at least she can dress herself and get to the toilet on her own. I think the dressing is not maybe always the hassle, but going to the toilet for her is difficult. Here it is not so bad, because we all help, but when you get older you want that privacy."*
- *"I think somebody will need to dress her completely…she can't dress or undress herself. I think that is one of the biggest struggles. I have seen her wearing tops, like little waistcoats, and she is able to take them off but little pants and so on is very hard."*
- *"One thing I have noticed is she often loses her pants when you pick her up due to the shape of her body. My further concern is that she is often sitting on the floor, and with her enhanced mobility on the floor, she may be prone to infections.*
- *"From what I've seen of her, she can definitely do the top, not a zip, she is able to take off a top, but she really struggles with the little pants that she wears. Getting that over her little bum, there is just nothing that she can hook onto. And it's the balance as well, because when you try to put something on you have to try to keep upright."*
- *"She'll tell us if she needs to use the bathroom, and one has to now lay her down and then help to undress her, then she uses the potty and then we dress her again."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Dressing	Emily requires moderate assistance in dressing. Emily is able to manoeuvre the top part of her body to assist in dressing with regards to shirts, jackets etc. Undressing is easier for her than dressing as she is able to wiggle out of her shorts and tops. She also takes an active role in selecting her clothing. She is reliant on her caregiver to assist with elements of dressing, do buttons, tie laces, zips etc. Due to her lack of limbs she has also needed clothing made for her especially in the winter months. Her shorts are often sewed closed to protect her buttocks when sitting and moving around. She benefits from vest type jackets in the winter or small jumpsuits.  

DISCUSSION: The act of dressing requires children to use a variety of performance skills to meet the unique demand of the activity. Emily presents with physical limitations of dynamic balance, range of motion of limbs, co-ordination and dexterity and requires moderate assistance from her caregivers. She takes an active role in choosing her clothing every day, assists in putting her left stump through a sleeve and tries to wriggle out of her pants. It is currently impossible for her to dress herself fully due to her physical limitations. Currently for time and hygiene purposes, her caregivers at home and facilitator at school perform most of the dressing process. As an occupational therapist, it is still vital that she does perform some steps of the activity actively.

Due to her unique body structure, it was imperative that clothing adaptations were made for her to accommodate for changing environments. An external seamstress was approached to assist in this regard. Examples of clothing adaptations include:

- Shorts; which are often sewed closed to protect her buttocks when sitting and moving around.
- Vest type jackets or small jumpsuits to provide warmth in the winter months.
- Clothing also needs to be comfortable and free from buttons or strings as she often uses rolling for mobility at home and during floor time in the classroom.

It is the researcher's hope that with advancing assistive technology, that in the future Emily will be more independent in the area of dressing. *Refer to Broad category: Future considerations.*

4.3.1.1.4. Bathing**:**

Bathing comprises of the following; obtaining and using supplies, soaping, rinsing and drying body parts, maintaining bathing position, transferring to and from bath (AOTA, 2014).

INTERVIEW DATA:

- "She's okay to bath, it's just obviously getting her in the bath that is challenging as well as the dressing and drying part. She will put soap on a sponge and rub as far as she can, she puts her head under the water to wash it and things like that, so she does basic bathing. She showers…I think just her arm is too short to get everywhere…

No other participants commented on this daily activity as they haven't witnessed it first-hand.

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Bathing/ showering	Emily currently requires maximal assistance in the activity of bathing. She needs her caregiver to run the water, control the temperature, transfer her in and out of the bath, wash her with soap and water as well as dry her. She is able to maintain her bathing position and is able to assist with cleaning her body with a long handled brush. The brush was implemented to provide her with a more active role in bathing. She is also able to sit in the shower.

DISCUSSION: It is important for an occupational therapist to consider the priority of which areas of daily living the child shows more eagerness to learn and master as well as to keep in mind the routines and contexts of the home environment. Emily lives in a place of safety with numerous children, thus bath times are quick and efficient. Independence in bathing in Emily's case is not as important for her and her caregivers as self-feeding or mobility is. An additional role of the OT in such a case would be to teach her caregivers bath time safety as well as to use proper body mechanics during bathing to prevent back injuries (Case-Smith, 2005 pg 552).

It is the researcher's hope that with advancing assistive technology, that in the future Emily will be more independent in the area of bathing. *Refer to Broad category: Future considerations.*

4.3.1.1.5. Grooming:

Grooming comprises of obtaining and using supplies, applying cosmetics, washing, combing and styling hair, caring for eyes, ears and nose, brushing and flossing teeth (AOTA, 2014).

INTERVIEW DATA:

- *"She brushes her teeth. She just needs help putting the toothpaste on and then someone needs to pick her up to rinse her mouth out at the basin. Flossing is too difficult… Things like hair brushing is difficult…she tries, but she can't get everywhere because of the shortness of the arms…She can blow her nose if someone holds the tissue, but she can wipe it, she can wipe her mouth and she can wipe her nose."*
- *"I think her hair is a bit of a problem for her. And the other thing that is a concern is the dog hair she picks up while rolling on the floor."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Personal hygiene and grooming	For this daily activity, Emily requires moderate assistance to complete the tasks. Tasks like tooth brushing, hair styling and nose/ear/eye care are more challenging due to the fine motor elements involved in these activities. She is able to brush her teeth, but requires assistance in putting toothpaste on her brush. The set up for tooth brushing also needs to be on the ground to be accessible to her. She is further dependent on her caregivers for hair brushing and styling, applying cream, caring for eyes, ears and skin. She is however able to blow and wipe her nose but needs someone to reach for and hold a tissue in place. Concerns were raised as to the hygiene of her hair as it was often messy and dirty due to the fact that she uses rolling for one form of mobility. Adaptations were made to style

	her hair in braids on a regular basis to eliminate the need for daily styling.

DISCUSSION: By 2 years of age, typically developing children imitate their parents when brushing their teeth. Supervision of tooth brushing continues until about 6 years of age (Case-Smith, 2005 pg 552). Emily showed eagerness to attempt this activity from an early age. With assistance initially with her universal cuff (see Table 4.3.8) and sponge handle, she was able to perform the back and forth brushing motions independently. She is now efficient in brushing her teeth but requires her caregiver to set-up the task (put toothpaste on toothbrush and position her close to the basin).

Face washing, hand washing and hair care are typical grooming activities taught to preschoolers. Even though Emily shows eagerness in these activities, her physical limitations are just too severe to fully partake in the finer elements of the tasks. An area of grooming where adaptations have been made is her hair care. A concern was brought to the fore at a stage that her hair was often dirty due to her rolling mobility on the floor. Taking cultural values and preferences into consideration, it was decided that it would be a priority to keep her hair braided and in an upstyle at all times to maintain hygiene.

It is the researcher's hope that with advancing assistive technology, that in the future Emily will be more independent in the area of grooming. *Refer to Broad category: Future considerations.*

4.3.1.1.6. Toileting:

Toileting comprises of the following; obtaining and using toileting supplies, managing clothing, maintaining toileting position, transferring to and from toilet, cleaning body and caring for menstrual needs (AOTA, 2014).

INTERVIEW DATA:

- *"Going to the toilet for her is difficult. Here (at home) it is not so bad, cause we all help, but when you get older you want that privacy. With things like menstruation, I hope that there would be something that can help her, and as she gets older and her growing, I think she will devise plans of how to do things."*
- *"She is often in a nappy, but I think it is just because of the setup at home. She is very much able to tell someone I need to go to the toilet. She feels the sensation for both weeing and bowel movements, even if she has got her nappy on she will ask me, I want to go to the toilet, so then we go, we take the nappy off and obviously there is a lot of assistance needed there, so at home they have got a little bit of a seat that makes it smaller, so she is able to sit, but getting her there she needs assistance, and on a normal toilet seat she is way too small for that so you actually have to hold her for that. So we are busy talking to the school to maybe get her one, just that she can use there. At the end of the day toileting is a huge issue, and if she's got the sensation and she can tell you that she needs to go then she is already toilet trained. I think they just leave the nappy on for in case there is a delay in someone getting to her, and I've seen it at home, there are delays, there is not always someone there for her every beck and call. They just leave it on for in case, even at night she doesn't wear it to bed, she will wake up and call someone or she sleep through, so she is actually toilet trained in that sense, mentally. And I feel for her for when she gets older with menstruation and just basic human decency and privacy.*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Toileting and toilet hygiene	Emily currently requires maximal assistance in toileting and toilet hygiene. Emily wore nappies for slightly longer than the able bodied child as her caregivers were worried that she wouldn't get to the toilet on time. She is now able to ask to be taken to the toilet and thus doesn't wear a nappy anymore. She has full sensation of knowing when she needs to urinate or defecate. She is dependent on her caregiver or facilitator to place her on the toilet and assist with cleaning, as well as the undressing and re-dressing elements of toileting. At home she has an adapted toilet seat which is smaller than the actual toilet seat so that she can sit independently. At school, she is also fully dependant on her facilitator and needs to be held at her trunk as the seat is too big. The school is in the process of getting her a smaller seat.

DISCUSSION: Toileting independence may be delayed in children with physical limitations (i.e. strength, range of motion, body structures and manipulation and dexterity) (Case-Smith, 2005 pg 544). These limitations lead to the inability to transfer from the floor to a toilet, difficulty in dressing elements, difficulty in cleansing after bowel or bladder movement.

Even though Emily has the cognitive skills to learn toileting skills, her severe physical limitations mean that she requires maximal assistance in toileting and toilet hygiene. The following elements are of importance in enhancing toileting independence as well as providing respect and privacy to the growing child:

- *Social environment:* Of all ADL tasks, toileting requires the most sensitive approach on the part of those who work with a child. In Emily's case, her requests to toilet should be honoured timeously and utmost privacy must be ensured as far as possible. In her classroom setting, she has her own facilitator

who she can discreetly ask to take her to the toilet, so as to eliminate possible teasing or bullying from peers.

- *Toileting adaptations:* Adaptive equipment can be used to enhance toileting including long handled reachers, toilets with self-contained mechanism sprays or clothing adaptations can assist in the preparation before toileting.
- *Adaptations for unstable posture:* When children sit on the toilet, they need to feel posturally secure. Reducer rings or toilet seat inners aid in decreasing the size of the toilet seat and improve sitting support. This allows Emily a small element of privacy and her caregiver can leave her on the seat for a moment and close the door or leave the room.

It is the researcher's hope that with advancing assistive technology, that in the future Emily will be more independent in the area of toileting. *Refer to Broad category: Future considerations.*

Another area of concern is when she starts to menstruate. The process of toileting and toilet hygiene is so personal, it would almost be necessary that a solution be made for Emily to be more independent in some aspects of the process so that she doesn't have to rely on someone throughout. To avoid the physical handling of sanitary pads or tampons, an IUD like Mirena or Implanon contraceptive could be considered to eliminate monthly bleeding. It would be vital to prepare Emily for this when the time is right and also to discuss all the possible alternatives she has in the management of menstruation.

4.3.1.1.7. Mobility:

Mobility comprises of moving from one position to another (during performance of everyday activities) such as in-bed mobility, wheelchair mobility and transfers (wheelchair, bed, bath, car, toilet and floor). It includes functional ambulation and transportation of objects (AOTA, 2014).

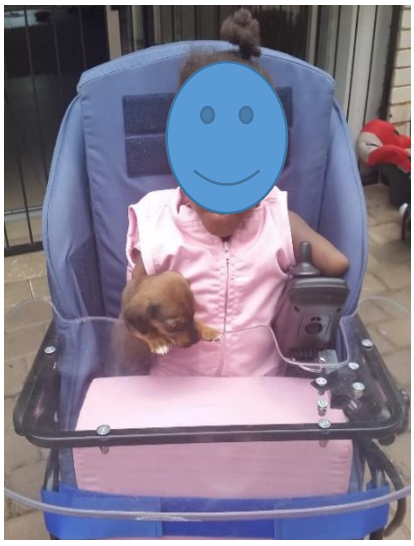
INTERVIEW DATA:

- *"It's awesome, she doesn't need help at all. She'll ask if she wants to be put on a couch, she does her homework with the other kids, but we put her in a baby chair because it is safer. Other than that she is fine, even outside, now when it was hot, the kids were running around and shooting water pistols at each other, and she was 'running' away (*she hops forwards on her buttocks) *from her brother without her wheelchair. I think the wheelchair just gives a little bit more speed and more freedom. With the wheelchair, she is able to ride bikes along with her siblings, they play hide and seek, she goes to the movies, and she goes to the shops just in her wheelchair, that's what her wheelchair is for. So her wheelchair definitely gives her independence and she loves it."*
- *"Although she seems to have gotten over that (she was initially very nervous being in areas with lots of people) quite a bit, we went somewhere and her wheelchair battery was flat, we went to the barn, and there were lots of people, and I put her down and I said come walk, and she said okay…And sometimes if we go to the shops and things like that and I don't take the wheelchair with then sometimes I put her in a trolley, but sometimes I do put her down and say okay we leaving the trolley here and we going to sit at that table and you must 'walk' there. I think it is also good for her that people look at her, they don't stare, but they do look, I'm trying to build up that kind of confidence in her…and if we go to people that she knows, like at the Christmas party as well, we don't take her wheelchair cause it is so high and there are 300 kids, so there she waltzes up and down between everybody."*
- *"Well she hops around the house and I think her abdominal muscles are very strong as she lifts herself from a lying position. Then she obviously rolls around but in climbing stairs or climbing into a car or lifting herself up to a chair is difficult, so her mobility is restricted. On a flat surface she can move fine, obviously slower than us but mobility is challenged.*"

- *"Well I was just amazed right from the start at how mobile she is without a chair, how mobile she is rolling, sitting…getting about, I mean she really is fast. And I remember when she first started school, she didn't want to move because I think she was fearful that someone was going to run over her in a wheelchair, so I think she then just decided not to be mobile. And the chair gave her then the confidence and the safety, because it think being on the floor at home with the little babies is not threatening, but being at school with adults and other children and other children with devices…there is a huge fear of being run over, stepped on or something like that. So I think that any chair that is well adapted…my biggest concern was…and that's why I made the chair for her…we made the little jacket for her so that she could be zipped up in and so that she could be straight. She does have the tendency to lean to one side, and that is the side where her stump is, because obviously she has got more flexibility, more mobility and more control. And I just wanted her to be more central so that we are not dealing with scoliosis or anything in the pelvic region going forward."*
- *"Another thing she needs help with is moving her from and to the chair where she sit is at the table, and from and to her wheelchair. Other things are small things like if she drops something on the floor, her friends are more than willing to help and pick it up for her.*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Functional mobility	For this area of daily life, Emily is mostly independent, but requires supervision for certain tasks. From a little baby, who learnt to roll, sit up, cruise on her buttocks, pivot and climb furniture and stairs, she is now fluent in manoeuvring her wheelchair and moving around in her different environments. Emily is able to move independently on the floor by means of rolling or hopping on her buttocks. She is able to climb stairs and low furniture by using her upper left limb (stump) and core strength. She needs assistance for the following transfers; in and out of the bath, toilet and car. She is able to get onto her wheelchair and bed independently. She shows great functional mobility in her motorised wheelchair (speed, turning corners, reversing, and parking) and it allows her to transport objects like toys, food, learning material, which she is unable to do without her   wheelchair.
Personal device care	Emily's caregivers and therapists make sure her wheelchair and adaptive equipment are kept clean and in working condition. She is currently fully dependant on them for this activity.

DISCUSSION: Mobility is vital to a child's overall development and functioning in occupations of self-care, play and school and is essential to quality of life (Case-Smith, 2005 pg 657). Mobility mastery poses the widest influence in all spheres of development as children gain a broad range of learning experiences as they move about. Piaget (1954) described active mobility as a crucial building block of knowledge. He believed that movement laid the basis for a child's unnderstanding of space, objects, cause and effect and self and the ability to influence their own environment is internally motivating. These movement experiences are said to foster curiosity, exploration, mastery and persistance and vital for later intellectual functioning.

According to Butler (1988) restricted experiences and mobility during early childhood can have diffuse and lasting influence on emotional and psychological development. Learned helplessness can result; which is a condition in which a child gives up trying to control his or her own world because of motor limitations and diminished expectations of caregivers (Everland, 1997). Emily was encouraged to move and explore her environment as much as possible from as early as 5 months when she could roll from side to side. Her context and caregivers have allowed her to be more independent as she wasn't kept in a chair or held for extended periods of time. She also presented with adequate muscle tone and strength in the existing muscles of her trunk and back which aided her in developing movement patterns that were appropriate to her unique condition. She showed curiosity to explore her environment and persistance and resilience in trying out new challneges.

Occupational therapy intervention focused strongly on using these strengths to enhance her mobility in ADL tasks, play activities and later for school participation. Perceptions from the interviews showed that her powered wheelchair (received at 2 years of age) has given her increased independence, confidence and the ability to participate in more meaningful occupations like play, social and community outings. It provides an element of safety for her when she is in larger groups or in a school or community environment. It allows for greater social inclusion and she is often assisted by her able bodied peers should she need it. Research shows that children as young as 18 months can achieve independent skills in powered mobility (Furumasu, Tefft, & Guerette, 1998). She has had 2 different wheelchairs in 4 years as the team is continually striving to improve her assistive technology. This will be discussed in more detail under *Theme 2: Assistive Technology*. Her functional mobility and devices will

need to be considered into the future due to changes in her body and specific needs as well as to keep up with new advances in technology.

With regards to her personal device care of her wheelchairs and batteries, it would be the hope that in the future, when she is old enough, she will be trained to maintain her devices i.e. charge batteries, manage her own follow up seating appointments, let her caregiver or OT know when a device is broken or showing signs of deterioration etc. The more responsibility and ownership she shows in the intervention process and her assistive technology, the less need she will have to receive assistance from caregivers. This would be an area for future intervention.

The foundations for ADLs begin in infancy and are refined throughout the various stages of development. As unique individuals living in certain contexts, children learn these activities at varying rates and have occasional regression and unpredictable behaviours. When a child is born with a disability, parental and child expectations for ADL are modified. An OT assists families to learn how to modify activity demands and routines so that child can be more participatory in ADL and IADLs. Active participation in occupations have several benefits, including maintaining and improving body functions and mastering tasks meaningful and purposeful to the child.

4.3.1.2. Category 1 (Continued): Instrumental Activities of Daily Living (IADL)

IADL include activities to support daily life within the home and the community that often require more complex interactions than those in ADL.

As a child learns new ADL and IADL tasks, he or she develops a sense of accomplishment and pride in his or her abilities. This increasing independence also gives parents, caregiver and teachers more time and energy for other tasks (Case-Smith, 2005). Only relevant IADL tasks were chosen to be discussed due to Emily's young age. Future tasks like shopping, financial management, health management and home maintenance will be areas for future consideration.

4.3.1.2.1. Communication management:

Emily can communicate her needs via speaking to her caregivers, teachers and friends. She has no speech impediments. She makes use of tablet/laptop for further learning opportunities at home and in the classroom setting. She uses her left stump to work the touch screen of the tablet/laptop and is quite proficient in many educational games, taking photographs etc. In the age of advancing and ever-emerging technology, she would need to become proficient in emails, social media (Facebook. Twitter, Instagram) and SMS/WhatsApp proficiency on a cell phone to assist her in greater independence in communication management for professional and personal purposes.

4.3.1.2.2. Community mobility:

Emily makes use of her motorised wheelchair for community mobility like going to the shops, a restaurant or the movies. Her foster mother has a larger car that can house her wheelchair. A wheelchair ramp was also installed to assist with transporting her wheelchair. Her 1st wheelchair was too heavy to be transported, thus Emily was often carried in her earlier years. Her 2nd wheelchair is much smaller, thus easing her access to community outings. She has arranged school transport where her driver collects her from home, carries her to the car and delivers her to her school wheelchair. Although she has been exposed, she is unable to access terrains like beaches or very rocky paths independently.

4.3.1.2.3. Meal preparation and household management tasks:

During childhood, most children learn home management tasks that help them contribute to family functioning. Performing these tasks gives children a feeling of self-worth and develops future abilities for independent living and work environments. The following Table 4.3. Adapted from (Case-Smith, 2005 pg 558) illustrates the developmental norms for household and management tasks.

Table 4.3.3: Developmental sequence for household management tasks

Age	Task	Emily's participation level
6 years	-Makes a sandwich -washes dishes with help -makes bed -dusts, cleans, gardens with help -puts toys away -crosses street safely -runs simple errands -puts dirty clothes in laundry -fixes snacks	Emily is able to make herself a simple sandwich if the ingredients are laid out for her. She tries her best to assist with chores like packing away toys, cleaning, laundry etc. but in her context, it is not seen as a priority for her to perform these tasks. She is furthermore dependent on her caregivers for meal preparation and household management tasks.

7- 9 years	-begins to cook simple meals -packs clothes away -manages small amounts of money	Through this process, it has come to the researcher's attention that participation in IADL, even if only partial participation, will be beneficial in the long run for enhanced independent living skills. This is an area that needs to be advocated for and educated upon in her home environment.
10 – 12 years	-sets table -begins doing laundry -washes dishes -cares for pets with reminders	
13 – 14 years	-laundry -cooks meals -cares for pets -money management	

4.3.1.3. Broad Category: Future Recommendations

When discussing Emily's future path in terms of daily living skills and future daily living skills she will need, it is important to think ahead, to appreciate the vital role her personality and temperament has to play in her motivation, how assistive technology has assisted her and will continuously need to provide her support throughout her life. Future activities include meal preparation and shopping, independent living skills, driving or community transport, care of pets or children, financial management, home maintenance, health maintenance and the like.

INTERVIEW DATA:

- *"I think it is very important that you are considering her future…as many people will just think of the here and now…I think her future is going to be a tough one and she will face many challenges."*
- *"She will always need someone to assist with the cleaning aspect of toileting and that is not something that she is going to get away from. It's just a pity that she can't manoeuvre her way up on to a toilet by herself. If there was like a little ramp, because she is quite mobile."*
- *"She is going to have to have a caregiver, even if it's Betty (*name changed for confidentiality), as a simple example, which she is at the moment, so that she can help her when she needs help. And then transport is one of the big things…but I mean I know of people that can drive their own car with no arms or no legs, there is such nice technology now with adapting cars. People can use their mouths…"*
- *"I really do hope she manages to live independently one day…but unfortunately I am realistic about situations, and I do think that it would be challenging for her, and if she does find a partner that she can depend on to help with certain things in the household… But on her very own I would say no."*
- *"There is no reason why she couldn't get married one day or have kids of her own…if she wanted to…the sky is the limit. Once again she would need help and a special kind of husband who could tend to certain needs…"*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Bathing and showering	Possible devices that Emily can use in the future include: 1) a mobile bath seat that can transfer her in and out of the bath, 2) a low to the ground bath with a side door for easy access, 3) a shower head with pre-set temperature, 4) a body blow-dryer to eliminate the need for a towel and 5) Non-slip mat for in the bath tub or shower.
Toileting	Possible devices that Emily can use in the future include: 1) an electronic toilet with flushing, cleaning and drying options, 2) a toilet step to get on and off the toilet independently and 3) an inner toilet seat to allow for independent seating. *Please see Dressing for dressing and undressing alternatives.* Another area of concern is when she starts to menstruate. The process of toileting and toilet hygiene is so personal, it would almost be necessary that a solution be made for Emily to be more independent in some aspects of the process so that she doesn't have to rely on someone throughout. To avoid the physical handling of sanitary pads or tampons, an IUD like Mirena or Implanon contraceptive could be considered to eliminate monthly bleeding. It would be vital to prepare Emily for this when the time is right and also to discuss all the possible alternatives she had in management of menstruation.
Dressing	Possible devices that Emily can use in the future include: 1) long handled zip hook or button eye, 2) clothing or underwear that open at the bottom to eliminate having to take the entire garment off for toileting purposes, 3) myo-electric prosthetic arms for more optimal reach and dexterity *(this will be discussed in more detail under Assistive technology)*

Feeding	Assistive devices that have assisted and continue to assist Emily with feeding include: 1) non-slip mats and plate guards/elevated plates to avoid messing food or crockery moving too much, 2) universal cuff or sponge handles, 3) halo or Sippy cups to avoid mess during tipping or placing on a surface and a future consideration; 4) a built-in cup holder on her wheelchair tray so that she can be mobile and stay hydrated.
Personal hygiene and grooming	Possible assistive devices that could assist Emily in the future include: 1) One handed toothbrush press and 2) a myo-electric or 3D printed prosthetic arm to allow her slightly more length in her stump and dexterity to perform finer grooming elements of self-care (this will be discussed in more detail under Assistive technology

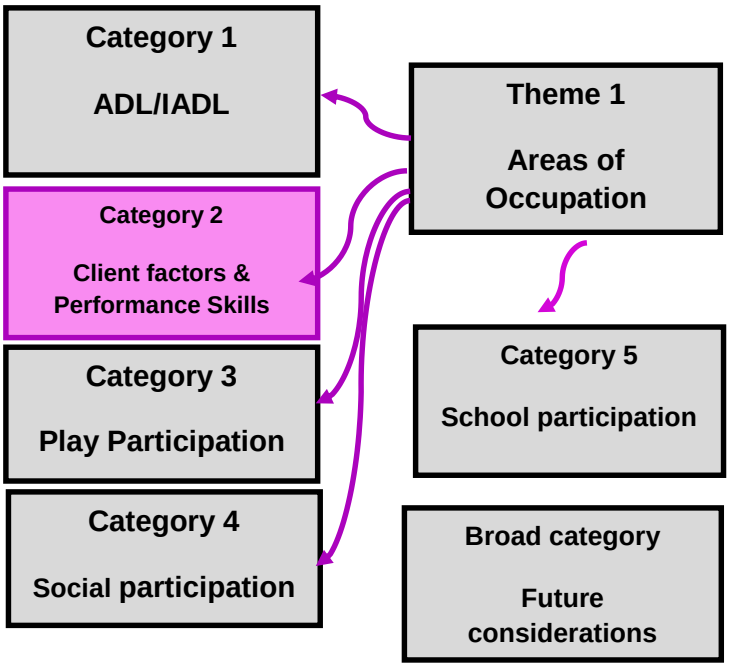
DISCUSSION: When looking at her future course, occupational therapy and assistive technology can help her in increasing her independence in daily activities. In discussions with her caregiver and foster mother, the one avenue of thought is that she will require a caregiver for all phases of her life. As an occupational therapist, we are trained to think of maximal independence and for Emily, the ultimate goal would be to have her living as independently as possible. Although more difficult in a third world country like South Africa, the acquisition of assistive devices is not impossible. These devices will require much problem solving and the financial implications will need to be planned for many years in advance. *(Please see the discussion on fundraising and starting an NGO for Emily under the Advocacy heading)*

During the course of intervention with Emily, the researcher has learnt a great deal about client-centred focus and holistically looking at a client in his / her unique contexts. In 2010, the council of WFOT published a 'Statement on Occupational Therapy' which affirmed for the member organisations, the scope, practice, education and focus of occupational therapy worldwide (WFOT 2010). The statement opens with; "Occupational Therapy is a client-centred health profession concerned with promoting health and well-being through occupation" (WFOT 2010 p4). As a therapist, I have learnt that my optimal or ideal plans are not always in the best interest of the client or may not be their priority. It is vital to have a broad knowledge set, but clinical reasoning

skills and client-centred practice will lead to greater well-being for the client. I have also been humbled by Emily as she often finds better ways of doing things in her life that what I could have thought out for her.

Occupational therapy has an integral role to play in enhancing participation and independence in activities of daily living in children with disabilities. One can note from this research, the importance of looking at a child holistically, taking their environmental context, preferences, skills and limitations and availability of adaptive and assistive devices and technology into account when planning intervention and choosing strategies.

4.3.2.1. Category 2: Client factors and Performance Skills



Client factors include body functions and body structures that reside **within** the client that influence the client's performance in occupations. An occupational therapist seeks to uncover the impairments associated with a child's limitations. The OT identifies client factors that are impaired or missing, therefore impacting performance and participation. Just as importantly, the OT identifies factors that are strengths and those on which the child relies to perform an activity (Case-Smith, 2005).

The Person-Environment-Occupation Model (PEOP) of Occupational Performance (see Chapter 2) guided the researcher to identify **supports and barriers** present when looking at Emily's case holistically. The following section describes relevant client factors, combining assessment tools and collateral information from key role players. The researcher used quotes from participant interviews, assessments and direct observation to portray this category.

The information in this category will be discussed according to the following structure:

Interview data	Temperament/Personality Emotional/Mental functioning
Assessment data/direct observation	Sensory profile Test of Visual Perceptual Skills (TVPS) Beery VMI Occupational Therapy Practice Framework

4.3.2.1.1. INTERVIEW DATA:

From the interview transcriptions, the interviewer drew out quotes to illustrate Emily's unique **temperament and personality** and how it assists her in achieving success in her daily life.

- *"My perceptions of her abilities have most definitely changed over time, obviously when she first started here, you feel like you want to help her with everything, and do everything for her, and then you realize that she is able to do many more things than I would expect her to do…And I feel like we can all learn from her…And she* ***perseveres****, and she is a go getter."*
- *"I feel that the fact that I don't treat her differently and focus on the disability has really helped her because she has to* ***figure out how to help herself****. How to do things herself…because if you coddle her, she is going to sit in a wheelchair her entire life and do nothing. Then she is never being challenged…"*
- "*Oh yes, totally and utterly amazed by the way she finds ways to do normal things. I can remember her coming to me one day and saying I must please pick her up, she wants to go to the kitchen, and I said no you are heavy, you must learn to 'walk'. And on Monday I went to work and when I came back she said look Mommy I can 'walk'. And off she went on her bum, and I mean her* ***tenacity*** *and her* ***strong will****…that is also what drew me to her when I went to see her for the first time. When I picked her up she was 5 days old, and these eyes where just full of life…She had that will to live."*
- *"She has a very* ***strong personality****, strong leadership skills, sometimes tend to be a little bit bossy. And another thing that's definitely counting in her favour is that she is willing to take any challenge head on."*
- *"…but what I know from her is that she is* ***resilient*** *and she has a* ***never give up*** *attitude."*
- *"She doesn't see herself as having limits, so she will go onto the swing and she will go flying into the air and she will go higher and higher, and she will go careering down the driveway. She is fearless…she just wants to go out and make it all happen, But I think regardless of her condition she was always going to be a wild child. It's her personality, and her personality really does over shadow her condition.*

DISCUSSION: Emily is known to all that meet her as a strong child despite her severe physical condition and limitations. As seen in the above quotes, she is described as tenacious, resilient, one with a never give up attitude and fearless in her endeavours. During the course of this research, the researcher has come to believe that her **personality and temperament** has been one of the biggest supporting factors that has aided her in her successful growth and development.

As occupational therapists, we know that humans have the capacity to change across the lifespan and that human development is believed to have relative plasticity (Lerner, Anderson, Balsano, Dowling, & Bobek, 2003). Gottlieb (1997) refers to plasticity as the fusion of the child and the environment (including cultural, physical and socioeconomic characteristics). Individual development involves the occurence of new structural and functional components over time and the 'goodness of fit' between the child and his / her context determines the quality of development. Positive goodness of fit can increase the child's developmental trajectory. A lack of this goodness of fit can create disruptions of psychologic development and may put the child at risk for behavioural or academic problems.

According to Chess and Thomas (1999) a child's **temperament** is an important determinant in how well a child matches the environment and social interaction. Temperament is believed to be innnate and learned. Nine areas of temperament include 1) activity level, 2) approach or withdrawal, 3) distractibility, 4) intensity of response, 5) persistence, 6) quality of mood, 7) rhythmicity, 8) threshold of responses and 9) adaptibility (Chess & Thomas, 1999). Emily can be described as a child with an easy temperament, who is able to adapt mostly to her changing situations.

Developmental outcomes have also been attributed to a child's **personality.** Resiliency refers to a child's internal characteristics that enable him or her to thrive and develop despite high-risk factors in the environment. A resilient child has protective factors that enable him or her to develop positive interpersonal skills and general competence despite stressful or traumatic experiences (Werner & Smith, 1992). Emily shows this resilience despite her condition (physical limitations) and context (foster home and special needs school). It has enabled her to accept challenges both in na therapeutic environment as well as her home, school and

community environments. It has assisted her in enhancing her independence and self-confidence in daily occupations.

Elements illustrating her **emotional and mental functioning** related to her context have been illustrated by the quotes below:

- *"I think there is a little bit of an **abandonment** issue, just from her personal background of being abandoned as a baby and every single time her foster mom leaves there are huge issues surrounding that, and I think that is when Emily becomes her most difficult and it's out of **pure fear**. I think that new **changes** in her life or disruptions at home would play on her mind a lot, because she **thinks** a lot. I don't think she is a frivolous child that doesn't think, she takes it all on board…"*
- *"So she does have a strong will but I think, always being looked after must have an effect on your personality and always getting stared at it must have an effect and because she's so intelligent she knows that she's different to others. And I saw it specifically when she started school, she was quite ok before school in terms of **emotional well-being** and in her first year of school she really struggled and she often said to me "don't you think I would work better in school with arms" or "be better if I had legs" and she started looking at the other children, and most of them have a disability (but most of them are mobile and might have a cognitive disability or so), so she is very much aware that she is different. So she did take a bit of a knock there…"*

As mentioned above, Emily does show **resilience** in her circumstances. An area that one must consider however is her emotional well-being. She is an intelligent little girl, who shows a perceptive nature to her environment and peers. She seems to adapt well to change but is reliant on a positive support system. Emily was taken in to a foster home for abandoned babies as early as 3 days old. She was given up by her biological mother who returned to Zimbabwe shortly after birth. Her foster mother accepted her with open arms and along with a 'village' of other role players, we try our best to provide what is necessary for Emily for each new emerging phase of her life. A perception from the interviews brought an element of **abandonment** to the fore. Emily has shown mild to moderate signs of distress when her foster mother takes

leave at certain times of the year, and particularly when she started school. She took a good part of a year to settle into school and often expressed feeling sad or wanting her foster mother. Even though she is strong willed and resilient, new environments do overwhelm her, thus it is vital that she receives support.

It is known that foster children sometimes struggle with healthy **attachment and bonding** with their primary caregiver (Sears & Sears, 2001). Attachment is a term that refers to a psychological and biological event. It is the affectional bond that develops between a primary caregiver, usually the mother, and her infant. The process of attachment often begins *in utero* when the mother feels affection for her developing baby and looks forward to the baby's birth. For other mothers it may begin after their baby's birth and is a process that takes time through a series of daily caring interactions. Developing a secure attachment to a primary caregiver is extremely important as the child's mental representations of intimate relationships and the foundation trust often carry over into adulthood, affecting future adult relationships. "Studies of attachment have revealed that the patterning or organization of attachment relationships during infancy is associated with characteristic processes of emotional regulation, social relatedness, access to autobiographical memory and the development of self-reflection and narrative" (Siegel, 1999). In Emily's context, she has 2 caregivers who look after her physical needs of food, bathing and other elements of self-care. Her foster mother provides as much emotional support as she can under the circumstances (there are at any given time 6 to 10 medically in-need babies and 5 older foster children in the house). Hence, Emily has to share her caregivers and this could be leading to insecurities in her attachment with new people or new environments. Emily also has to deal with death of an ill baby on occasion in the house as well as the reality of her own disability.

Chronic disability often produces feelings of helplessness, frustration, hopelessness or great sadness (AZ Direct Care, 2011). It is common for a child to experience grief at multiple losses and perceived losses i.e., sadness when not being able to play with an able bodied child on a swing on the playground, or not being able to draw as fast as a peer in class. Regardless of the condition, there is a powerful component which contributes to the need for physical and emotional support. There is a definite connection between mind and body and they affect one another transactionally. Occupational therapists have an interest in a **holistic view** of a client's emotional,

physical and spiritual needs in providing care. In Emily's case it has been vital to provide her with emotional support through each new phase of her life (i.e. school, transitioning from classes and new teachers, adapting to new assistive devices, loss of children in her home environment). It is however imperative that Emily receive the assistance of regular **psychological services** to assist in working through her emotions through each phase of her life. *See Theme 3: Category 2: Other Professionals.*

4.3.2.1.2. QUANTITATIVE DATA FROM ASSESSMENTS:

Quantitative data regarding her client factors and performance skills were collected using the following assessment instruments and direct clinical observations:

- Sensory Profile (Home and School Companion). *See Annexures B & C.*
- Beery Buktenica Test of Visual Motor Co-ordination. *See Annexure D & F.*
- Test of Visual Perceptual skills. *See Annexures E & F.*
- Direct observation using the OTPF (Occupational Therapy Practice Framework). *See Annexure P.*

4.3.2.1.2.1. SENSORY PROFILE

The sensory profile provides a standard method for professionals to measure a child's sensory processing abilities and to profile the effect of sensory processing on functional performance in the daily life of a child. Each item describes children's response to various sensory experiences. The caregiver who has daily contact with the child completes the questionnaire by reporting the frequency with which these behaviours occur. The therapist then scores the responses on the questionnaire (Dunn, 1999).

Sensory Processing is the way in which our nervous system manages incoming sensory information from our sensory systems: tactile, proprioceptive, vestibular, visual, auditory, olfactory, and gustatory.

- **Sensory modulation:**

Sensory Modulation refers to the ability to regulate and organize a response to sensory input in a graded and adapted manner.

-Over-Reactivity refers to sensory information being too much, disturbing, or overwhelming. It includes the tendency for avoidance behaviour or sensitivity to input.

-Under-Reactivity refers to sensory information not being readily perceived (registration) or requires a higher intensity of sensory input in order to process / recognize (seeking.

-Typical refers to being able to efficiently or readily modulate sensory information.

A Sensory Profile was filled in by Emily's foster mother and a School Companion to the Sensory Profile was filled out by her Grade R teacher to obtain holistic information with regards to Emily's sensory modulation in different settings. The results of the two profiles have been illustrated in table format in Annexure C.

According to the HOME profile, Emily shows **typical** processing for the majority of sections. Her vestibular processing shows an **over-reactivity** from the norm. This can be explained however from the angle that she avoids certain gravitational activities due to her innate knowledge and body awareness that she is unable to perform certain tasks independently i.e. jumping off a lady, merry-go-round. Even though she is adventurous and keen for most challenges, she does show mild gravitational insecurity for activities where she doesn't feel grounded in her body or where she doesn't have external security. This can also be linked to emotional responses linked to sensory input i.e. showing anxiety if the swing is moving too fast.

According to the factor summary, she **does not** show signs of sensory seeking, emotional reactivity, low endurance, oral sensitivity, inattention, poor registration, sensory sensitivity or sedentary behaviours. The only factor where she scored **atypically** according to her age was her **fine motor** factor summary. This can be explained due to her lack of upper limbs and dexterous movements.

Her SCHOOL companion showed an overall **typical** performance, showing that she is efficiently or readily able to modulate sensory information in a class and school setting and this is a support to her academic success.

One of the most distinctive contributions that Jean Ayres made to understanding child development was her focus on sensory processing, particularly with respect to the senses (vestibular, tactile and proprioceptive, auditory and visual). These senses

dominate a child's interactions with the world early on in life. Ayres believed that the sensory systems serve as a foundation on which complex occupations are built (Ayres, 1979). The researcher believes that it has been vital to provide Emily with sensory nourishment in her daily life. Taking her sever disability into mind, Emily's course may have looked very different to what it looks now. If she had gone back home with her birth mother to Zimbabwe, she may have not been afforded to same opportunities that she has been given in her foster home, surrounded by a team of professionals who have her best interests at heart.

Sensory input is necessary for optimal brain function (Case-Smith, 2005 pg 357). The brain requires to take in a modulated stream of sensory information, otherwise sensory deprivation may result. It is now well established that serious impairments in cognitive, social and emotional functioning often result when young children are institutionalized in environments that are impoverished with respect to availability of a wide range of sensory experiences, the presence of a nurturing caregiver and opportunities for sensory-motor exploration (Cermak, 2001).

A child does not passively absorb sensations that come along their way. The child actively selects those sensations that are most useful at the time and organise them in a fashion that facilitates accomplishing goals. This process is known as *Sensory Integration* (Case-Smith & O-Brien, 2014). When a child has good sensory integration, adaptive responses occur which are referred to goal-directed actions in his or her specific environments. These adaptive responses are powerful driving forces that assist developmental growth. In making adaptive responses, the child is an active doer, not a passive recipient. No one can force a child to responnd adaptively, although a situation may be set up that is likely too elicit adaptive responses from the child. Occupational therapy with a Sensory Integrative approach encompases therapeutic activities and environments to engage the child's inner drive, elicit adaptive responses and in doing so advance sensory integrative development and the child's occupational competence (Case-Smith, 2005).

Ayres reasoned that the refinement of sensory integration provides a sensorimotor foundation for higher-order functions, such as academic ability, behavioural self-regulation and complex motor skills. By enhancing lower-level functions related to senses, one might have a positive influence on higher-level functions. Even though Emily didn't' show definite signs of sensory integrative dysfunction, her sever disability stood the chance of complicating her natural sensory development. The researcher used this approach greatly in the intervention plan for Emily. *See Theme 3: Therapeutic Intervention.*



4.3.2.1.2.2. TEST OF VISUAL PERCEPTUAL SKILLS

The TVPS-3 is a standardised assessment tool (Gardner & Morrison, 2012), intended to give occupational therapists, school psychologists, education specialists, optometrists, and other professionals a reliable and valid measure of a child's visual perceptual abilities. Since visual perceptual abilities are used in a number of academic pursuits, including learning to read, it is important to know which processes the child may be having difficulty with. The entire test was presented to her at her school in a private room as per the normal instructions for an able bodied child. She pointed to the correct items by using her left stump. She was positioned in her wheelchair for support and used her tray table to press on. The following table illustrates the raw and scaled scores for her age group.

A scaled score of between 8 and 12 is expected per age norm.

Testing age: 6 years 1 month

TVPS (Test of Visual Perceptual Skills)

Table 4.3.4: Test of Visual Perceptual skills scores

Subtests – TVPS	Raw score	Scaled score
Visual Discrimination	5	8
Visual Memory	5	**7**
Figure ground	6	11
Visual Closure	6	11
Form constancy	5	9
Spatial Relations	7	10
Sequential Memory	8	12

Overall, Emily's visual perceptual subtests fall into the **average norm** for her age and can be viewed as a **strength or support** to her learning potential. Visual perception is defined as the total process responsible for the reception (sensory functions) and cognition (specific mental functions) of visual stimuli (Zaba, 1984). The sensory function is the process of extracting and organizing information from the environment, and the specific mental functions provide the ability to interpret and use what is seen. Together, this allows a child to understand what he or she sees and are necessary for functional vision. Adequate visual perception allows a child to make accurate judgements on the size, configuration and spatial relationships of objects (Solan & Ciner, 1986).

The only visual-cognitive subtests that fell just below the norm with a scaled score of 7 was her *Visual Memory subtest.* This subtest looked at short term visual memory, which is the ability to hold a limited number of unrelated bits of information for approximately 30 seconds. A child with visual memory difficulties may fail to attend, allow for storage of visual information or may show a prolonged response time. The child may demonstrate inconsistent recall abilities and poor ability to use mnemonic strategies (Todd, 1999). This should be monitored in her classroom setting to assess whether it is having a functional effect on her learning and progress. Intervention

strategies to enhance visual memory include consistent experiences, chunking (introducing information in smaller units), repetition of concepts, mnemonic devices (rhymes, songs, poems) and memory games such as remembering what was removed from a tray of items (Gibson, 1971).

It is important to assess and treat these skills as an occupational therapist as they have a direct effect on performance skills and occupations. Childhood **play occupations** such as cutting, colouring, block construction, puzzle building and **school occupations** such as reading, spelling, mathematics and handwriting require adequate visual perceptual skills to be successful.

4.3.2.1.2.3. TEST OF VISUAL-MOTOR INTEGRATION

Internationally respected and backed by decades of research and clinical use, the Beery VMI, now in its sixth edition, offers a convenient and economical way to screen for visual-motor deficits that can lead to learning, neuropsychological, and behavioural problems (Beery, Buktenica, & Beery, 2010)**.** Only the VMI subtest was chosen for Emily's Case to get a global overview of her visual-motor integration skills. It was presented to her at her school in a private room as per the normal instructions for an able bodied child. She held the pencil between her chin and left shoulder to perform the drawing actions. She was positioned in her wheelchair for support and used her tray table to press on. The following table illustrates the raw and scaled scores for her age group.

A scaled score of between 8 and 12 is expected per age norm.

Testing Age: 6years 1 month

Beery-Buktenica Developmental Test of Visual-Motor Integration

Table 4.3.5: Beery VMI scores

VMI tests	Raw Score	Scaled score
Visual motor integration Ability to perceive visual designs, plan and reproduce	14	**7**

Emily obtained a scaled score of 7, which fall just below the average score for her age norm. We know that her fine motor skills and drawing skills are limited due to her condition. It is the researcher's opinion that the motor aspect of her VMI score brought her score below average. We know from the TVPS scores that her pure visual scores are a strength to her. Due to her lack of limbs and dexterous manipulation of a pencil, her motor coordination skills are poorer.

It has been important in Emily's case to use developmental and compensatory approaches as part of her early intervention. The **developmental model** (Warren, 1993) is based on the concept that that higher level skills evolve from the integration of lower level skills. Thus early intervention and exposure to age appropriate toys and environmental exploration has been key in Emily's case to develop these skills. *See Theme 3: Therapeutic intervention* for more information. In **compensatory approaches**, classroom materials or instructional methods can be modified to support academic performance. Due to the fact that the motor element of her academic work is harder for her to participate in, her curriculum has been adapted to a computerised curriculum where she can practice her handwriting on the screen instead of on paper. This also allows her to keep up with the classroom pace as well as to prevent inadequate posture and fatigue. *See Theme 1: Category 5: School Participation* for more information.

4.3.2.1.2.4. OCCUPATIONAL THERAPY PRACTICE FRAMEWORK

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below, looking at a wide range of client factors and performance skills that could not be tested formally in Emily's case. The PEOP model (as described in Chapter 2) describes individual factors as being **supportive ☺ or barriers ☹** to occupational performance. The following *Table 4.3.5: Client Factors according to the Occupational Therapy Practice Framework* shows a brief summary of which factors are supportive and which factors may act as a barrier to Emily's occupational performance. A detailed description of each factor can be seen in *Annexure G.*

Table 4.3.6: Client Factors according to the Occupational Therapy Practice Framework

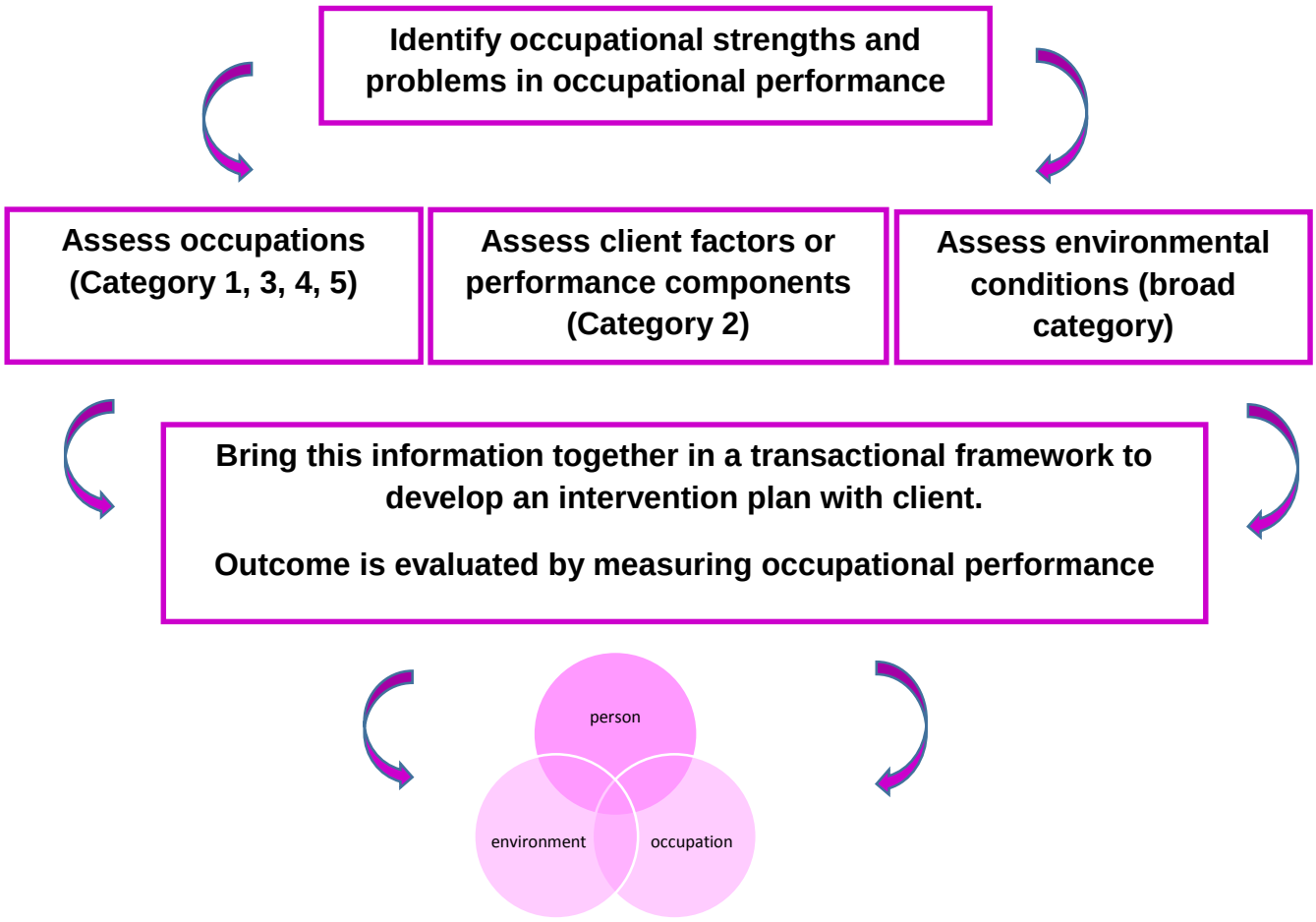
CLIENT FACTORS		
Body Functions - "The physiological functions of body systems (including psychological functions)" (WHO, 2001, p.10). This section of the table is organized according to the classifications of the International Classification of Functioning, Disability and Health (ICF)		
	Support	**Barrier**
Mental functions		
Attention	☺	
Memory	☺	
Thought	☺	
Emotional		☹ (as described above)
Perception	☺ (as described above)	
Global mental functions		
Orientation	☺	
Temperament and personality	☺ (as described above)	
Energy and drive	☺	
Sensory modulatory and discriminatory functions		
Visual	☺	
Hearing	☺	
Vestibular	☺	
Taste	☺	

Smell	☺	
Proprioceptive	☺	
Touch	☺	
Pain	☺	
Sensitivity to temperature	☺	
Neuromusculoskeletal and movement related functions		
Joint mobility (of existing joints)	☺	
Joint Stability (of existing joints)	☺	
Muscle functions		
Muscle power (of existing muscles)	☺	
Muscle tone (of existing muscles)	☺	
Muscle endurance	☺	
Movement functions		
Involuntary movement reactions	☺	
Control of voluntary movement		☹
Cardiovascular, haematological, immunological and respiratory system functions ☺		

Voice and speech functions, digestive, metabolic, and endocrine system functions, reproductive functions ☺		
Body Structures - "Anatomical parts of the body, such as organs, limbs, and their components" that support body function (WHO, 2001, p10).		
Structures related to movement		☹ (Lack of limbs -Major barrier)
PERFORMANCE SKILLS The following comments were made in conjunction with viewing videos of past play time, school and therapy sessions.		
Motor Skills - "Occupational performance skills observed as the person interacts with and moves task objects and self around the task environment" (e .g activity of daily living [ADL] motor skills, school motor skills; Boyt Schell, Gillen, & Scaffa, 2014a, p. 1237).		
☹		
Process Skills - "Occupational performance skills [e .g ADL process skills, school process skills] observed as a person (1) selects, interacts with, and uses task tools and materials; (2) carries out individual actions and steps; and (3) modifies performance when problems are encountered" (Boyt Schell et al ., 2014a, p . 1239) .		
😐		
Social Interaction Skills - Occupational performance skills observed during the ongoing stream of a social exchange" (Boyt Schell et al., 2014a, p .1241).		
☺		

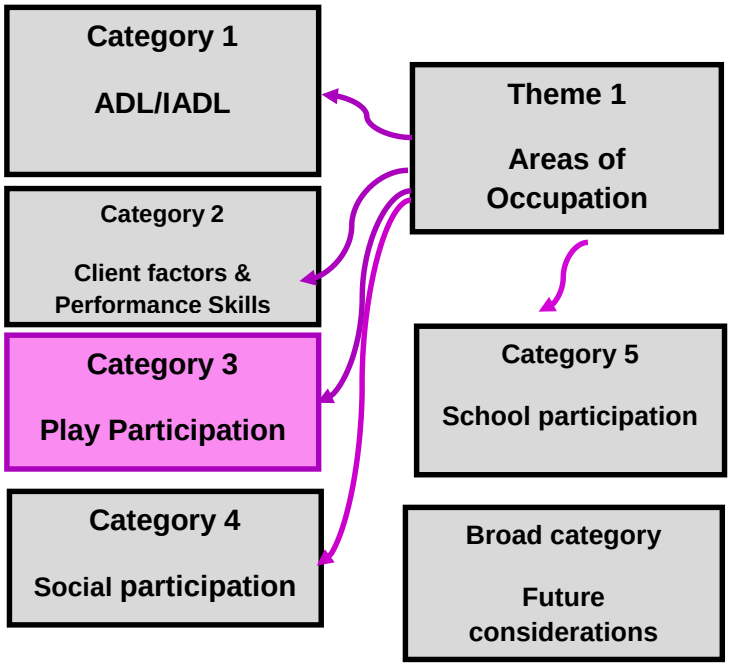
DISCUSSION: Emily's **supports** include her mental, sensory, neuro-musculoskeletal, muscle, system functions, process and social skills. These assist her in occupations like play, school and ADL / IADL activities and tasks. Her **barriers** lie in her body structure limitations, motor control and motor and process performance skills and can hinder her independence and performance in the above mentioned occupations. Although her barriers seem a lot less than her supports in the above table, the weight

of her barriers is greater than the sum of her supports. Assistive technology and adaptive approaches become relevant in this case. *See Theme 3: Assistive Technology.*



Occupational therapy intervention would begin with the client and the therapist identifying the client's occupational strengths and issue / problems in occupational performance. This is done through a number of methods including interviews, standardised and informal assessments. This information assists in determining the focus and level of intervention, which approached are suitable and whether assistive devices are necessary. Outcomes after intervention are measured in terms of changes in occupational performances (Law M. , et al., 1996). *See Theme 3: Therapeutic Intervention for more information.*

4.3.3.1. Category 3: Play Participation



Play has been identified as one of the primary occupations in which people engage, according to the American Occupational Therapy Association (AOTA) Practice Framework (AOTA, 2014). Play can be defined as "Any spontaneous or organized activity that provides enjoyment, entertainment, amusement or diversion." (Parham & Fazio, 1997)

'Play is the way the child learns what no one can teach him. It is the way he explores and orients himself to the actual world of space and time, of things, animals, structures and people. Through play he learns to live in our symbolic world of meanings and values, of progressive striving for deferred goals, at the same time exploring and experimenting and learning in his own individualized way. Through play the child practices and rehearses endlessly the complicated and subtle patterns of human living and communication, which he must master if he is to become a participating adult in our social life" (Franz, 1963).

The researcher used data from semi-structured interviews and from the Revised KNOX Pre-school scale to discuss Emily's primary occupation of play and how her physical limitations affect her ability to partake in playful engagements.

4.3.3.1.1. INTERVIEW DATA:

- *"With the **wheelchair**, she is able to ride bikes along with her siblings, they play hide and seek…*
- *"But from what I've heard she has really settled in very nicely at school, she does play in her wheelchair at break time, but if she is not in her wheelchair she tends to **sit a little bit**, and eat her lunch and kind of not play outside… rough type of play, but that I can understand as well."*
- *"I think her will is very strong, she wants to be part of the play. At the home I have observed her participate in the play, she quite often has to **ask** somebody to pick her up and take her there, she can't just make her own plans, it's **not spontaneous**, and she has to wait for somebody to help her.*
- *"I think the kids accommodate each other a lot. So I imagine that she would be able to take a **leading role in her role-play** as she has no trouble with communicating and coming up with ideas…*
- *"The play that I have seen is with her big sister…now that's just chaos. And the **wheelchair** has given her in that environment huge opportunity, they are just hooligans. Her big sister climbs on the back of the chair and off they go down the driveway at one hell of a speed up to the gate. From a play point of view I think she plays and she interacts, **she finds ways** to play."*
- *"I think for me who has played with her a lot, I just worry because there are things that another child would do and then she needs assistance for it, for example on a swing, she can't be left alone, on a slide, she is able to do it alone, but the **safety**…she doesn't have the limbs to put out her arm if she is going to fall or she can't regulate her speed coming down…she overcomes a lot of her challenges, and she is not scared to try something new, but then there always has to be someone there to **supervise and assist**."*

- *"Her condition isn't limiting her because she has a friend in class that she plays with regularly, and her friend walks in a walking frame, so no her condition **doesn't limit her attempt** to play with other kids, she socializes with every one, boys and girls, she has a very strong personality, strong leadership skills, sometimes tend to be a little bit bossy. But yes, I would say it doesn't limit her. Obviously there are certain things she can't do on the playground like climbing up the climbing apparatus and sliding down. But she knows what she can, and she obviously asks us to take her out and put her down wherever she knows she can go."*
- *"I think **technology** is going to be one of the major play areas, I remember she wants to look at my phone and she wants to look at the photos, she loves it, and she was very, very, very quick and independent, flicking through that…On her tablet she has a lot of educational play,…that also makes her play a lot more isolated…when there is a bit more social, more people then she is a bit withdrawn…I think it is more a fear factor than a confidence factor. There is nothing wrong with her ability to play, because she is a very confident child."*

4.3.3.1.2. OBSERVATIONAL DATA:

- **REVISED KNOX PRESCHOOL PLAY SCALE**

The Revised Knox Play Scale (Parham & Fazio, 1997) **(***See Annexure H)* is an observational assessment designed to give a developmental description of typical play behaviour from birth through the ages of 6 years. Play is described in 6 month increments for the first 3 years and yearly increments for ages 4 through 6. The items are grouped into four dimensions: Space management, Material management, Pretense-symbolic and Participation. Each dimension contains a number of factors, as described in Table 4.3.4.

Emily was videotaped in her school and home environments in natural play settings (both indoors and outdoors). The videos were viewed by the researcher and an external rater (occupational therapist working in private practice in Gauteng) and scored according to the play scale (see below). It was noted through the discussions

with the external rater, that Emily's play skills were enhanced by assistive technology and / or therapeutic assistance, therefore a separate scoring was done to highlight this aspect. *Scoring is described through age increments.*

Age at assessment: 72 months (6 years)

Table 4.3.7: Revised KNOX Preschool Play Scale

Play skill	Score without Assistive technology/therapeutic assistance (Free play)	Score with Assistive technology/therapeutic assistance (Therapeutic play)
Space management - the way children learn to manage their bodies and the space around them. This is achieved through the processes of experimentation and exploration. *Gross motor activity* – play involving the whole body. *Interest* – attention to specific types of activity.		
Gross motor	*Score:* 18 to 24 months Emily is able to reach out in prone, can crawl on her tummy and uses her left stump to move forwards or in a circular motion, she can sit with dynamic balance, she 'walks' on her buttocks, she can throw a ball with her left stump and neck, she can pull herself up to stand using a small chair or couch, she can cruise along furniture, she can climb up and down stairs/furniture, she can kick a ball in side-lying, she can ride a kiddie car or skateboard (lying in prone).	*Score:* 24 to 30 months With her motorized wheelchair, Emily is able to keep up in speed with running games, turning corners, moving around obstacles, moving up and down ramps. Gross motor activities like catching and kicking a ball, jumping and balancing on one foot, skipping and galloping are impossible for her due to her physical structural limitations. Although limited, Emily shows good muscle control, balance and strength in her mobility.

Interest	*Score:* 48 to 60 months Emily shows interest in anything new. She challenges herself with fine motor manipulation tasks as well as difficult tasks. She takes pride in her work and enjoys thematic play i.e. shop shop, doctor doctor, princess games etc.	*Score:* Up to 72 months In a therapeutic context with the assistance of a therapist and adequate structuring of an activity, she shows interest in permanence of products, making something useful or toys that 'really work' i.e. cameras, phones, IPad etc.
Material management - the way in which children handle materials and the purposes for which materials are used. Through material management, children learn control and use of material surroundings. *Manipulation* – fine motor control. *Construction* – combining objects and making products. *Purpose* – goals of the activity. *Attention* – length of time in independent play.		
Manipulation	*Score:* 36 to 48 months Emily tries her best and shows much perseverance and endurance in smaller muscle activity – hammering, sorting, inserting small objects, threading and even cutting. She uses her left stump and neck/cheek/mouth to manipulate tools and materials.	Elements up to 72 months In a therapeutic context with the assistance of a therapist and adequate structuring of an activity, Emily shows increased fine motor control and better tool handling. She is better able to copy, trace, combine materials, use force and quicker movements.
Construction	*Score:* 36 to 48 months Emily is able to make simple construction products like block towers, ring stacking, 3D puzzles etc.	*Score:* 48 to 60 months In a therapeutic context with the assistance of a therapist and adequate structuring of an activity, she can perform more complex constructive tasks like 24 + piece puzzles, arts and crafts (although still very difficult for her).

Purpose	*Score:* 48 to 60 months Emily shows purposeful actions in her play. The product is important i.e. building a cake in the sandpit, finishing a puzzle, dressing up like a fairy etc. The purpose of her play is to express herself.	*Score:* Up to 72 months In a therapeutic context with the assistance of a therapist and adequate structuring of an activity, Emily aims to replicate reality in her play i.e. making her own sandwich, playing mother/baby games etc.
Attention	*Score:* 60 to 72 months Emily is able to amuse herself for longer periods of time. She can play with a single object or theme for more than 15 minutes.	*Score:* 60 to 72 months Same as previous.
Pretense/Symbolic - the way children gain an understanding of the world through imitation and the development of the ability to understand and separate reality from make-believe. *Imitation* – mirroring aspects of the cultural environment. *Dramatization* – pretend, introduction of novelty and role play.		
Imitation	*Score:* 60 to 72 months Emily is able to construct new themes with the emphasis on reality and reconstruction of the real world.	*Score:* 60 to 72 months Same as previous.
Dramatization	*Score:* 60 to 72 months Emily enjoys role playing with others, can portray more complex emotions, sequence stories and themes, enjoys dress up and likes showing off.	*Score:* 60 to 72 months The therapist is able to assist with the physical assistance i.e. helping with dress up, structuring of props for dramatic play etc.
Participation - the amount and manner of interaction with persons in the environment and the degree of independence and cooperation demonstrated in play activities. *Type* – level of social interaction in play. *Cooperation* – ability to get along with others in play. *Humour* – understanding		

the expression of humorous or incongruous words or events. *Language* – communicates with others in play.		
Type	*Score:* 48 to 60 months Although hard for her to always participate physically, Emily enjoys cooperative play with groups of 2 or more children to achieve a goal. She tends to direct the play to more sedentary type play like dress up (where her friends assist her) or sandpit play.	60 to 72 months In a therapeutic context with the assistance of a therapist and adequate structuring of an activity, she enjoys competitive games, games with rules and more complex dramatic play. The therapist often assists greatly with physical structuring while the wheelchair assists with speed and the feeling of being 'part' of the group.
Cooperation	*Score:* 48 to 60 months Emily is able to take turns, attempts to control activities, can be bossy.	*Score:* 60 to 72 months In a therapeutic context with the assistance of a therapist and adequate structuring of an activity, she can foster rivalry in competitive play, games with rules and more collaborative play where roles are coordinated and themes are goal directed.
Humour	*Score:* 60 to 72 months Emily enjoys humour, she is able to laugh at multiple meanings of words, nonsense words, rhyming and enjoys distortions of the familiar.	60 to 72 months Same as previous.

DISCUSSION: Taking the above information into consideration, the following figure demonstrates the supports and barriers (Law M. , et al., 1996) present when assessing Emily's play experience. It further highlights how therapeutic intervention and adaptations assists in enhancing her occupational performance.

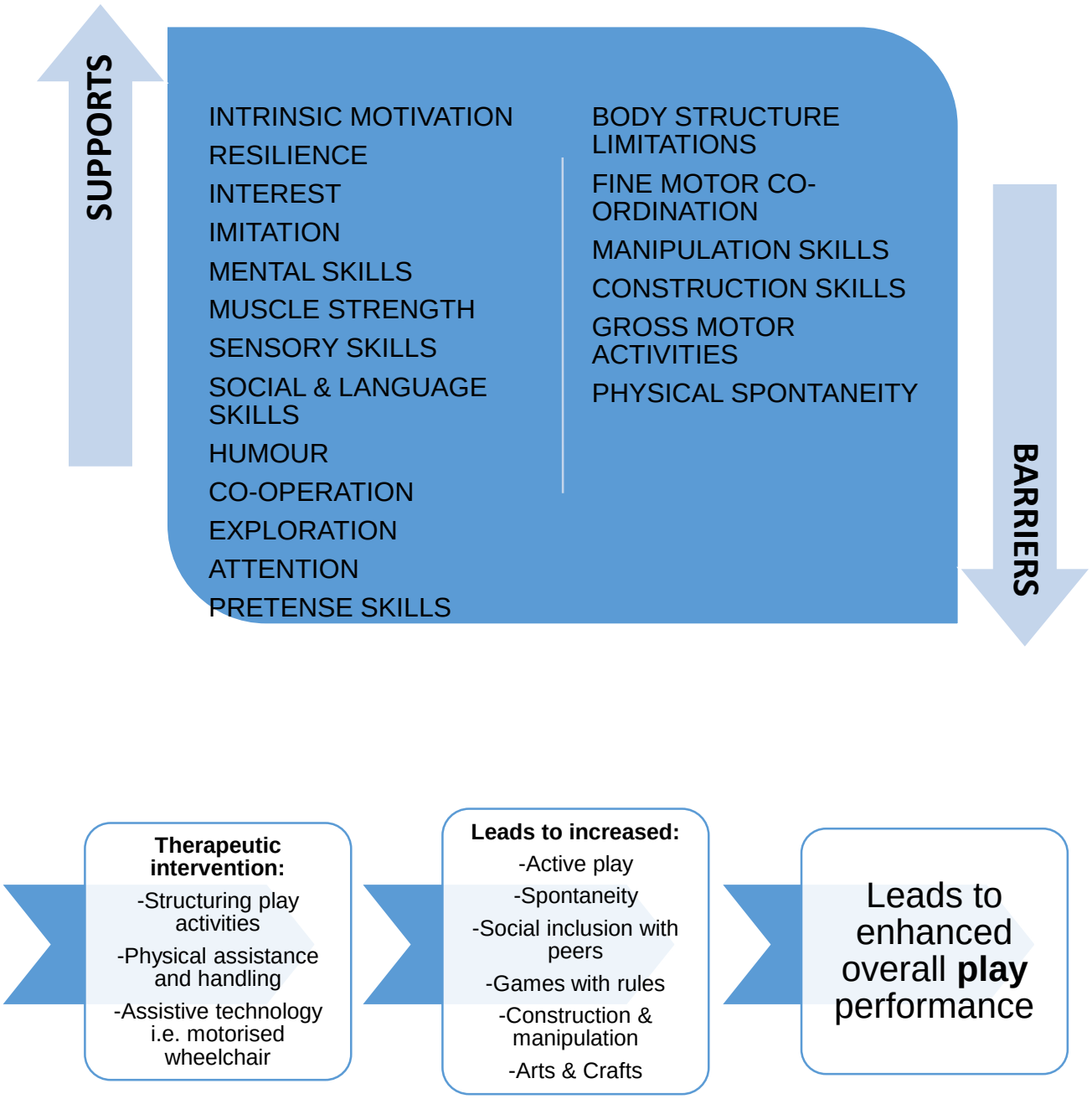


Figure 4.3.2.1.1: Supports & Barriers to play engagements. How therapeutic intervention and assistive technology enhance play performance.

The development of play as an occupation is one of the pillars of Occupational Therapy. Play is a purposeful activity, the result of mental and emotional experiences. It is the vehicle for communication and growth of the child (Richmond, 1960). According to Mary Reilly, play is the arena for the development of sensory integration, physical abilities, cognitive and language skills, and interpersonal relationships (Reilly, 1974). Assessments of play should be a part of every Occupational Therapy evaluation in order to get a complete picture of the individual's competence in her or her occupational performance and to adequately plan intervention that focuses on helping the individual participate in meaningful and self-satisfying occupations.

The play characteristics of children with physical limitations may include fear of movements, decreased active play and preferences for sedentary activities. The child may also have difficulties manipulating toys and show decreased exploration (Johnson, Christie, & Yawkey, 1999) as seen in Emily's case. Mogford (1977) described how disability stands the chance to deprive children of normal childhood experiences, their ability to explore, interact with and master the environment. It is therefore the role of the Occupational Therapist to bridge this gap by providing appropriate intervention strategies.

Play activities are used in Occupational Therapy in the following ways: *See Theme 3: Therapeutic Intervention for more information.*

- ***Play as a modality***

Three frames of reference that use play as a treatment modality include the following:
-Developmental (Blanche, 1997): play activities are used to develop physical, cognitive, emotional or social abilities. Example in Emily's case would include dancing and movement games with her foster siblings.
-Functional (Case-Smith, 2005): play is also used to meet a therapeutic end by adaptation of the activity, environment or therapeutic handling of the child while she or he is engaged in an activity. Example in Emily's case would include handling her while she 'climbs' up a ladder to slide down the slide.
-Sensory integrative (Ayres, 1979): play is valued as the arena through which sensory integration develops. Example in Emily's case would include exploration and making adequate adaptive responses to 'just right challenges' in an ASI® therapy room.

- ***Play as an intervention goal***

Due to the fact that Emily's physical disability stands the chance to affect her play potential in areas stated above, as an Occupational Therapist, play itself can be an intervention goal. Parham and Primeau (1997) stated that enhancement of play itself may be effective in promoting health and wellbeing.

- ***Facilitating playfulness***

Facilitating playfulness in the child can be an important goal in therapy. Morrison and Metzger (2001 pg. 540) stated: *"The more playful child may generalize this flexible approach into environmental interaction beyond play and into other aspects of his or her life. For the child with a condition that impedes his or her ability to interact with the social and physical environment, a flexible (playful) approach may enable a child to succeed more frequently in these difficult situations."*

- ***Adaptations***

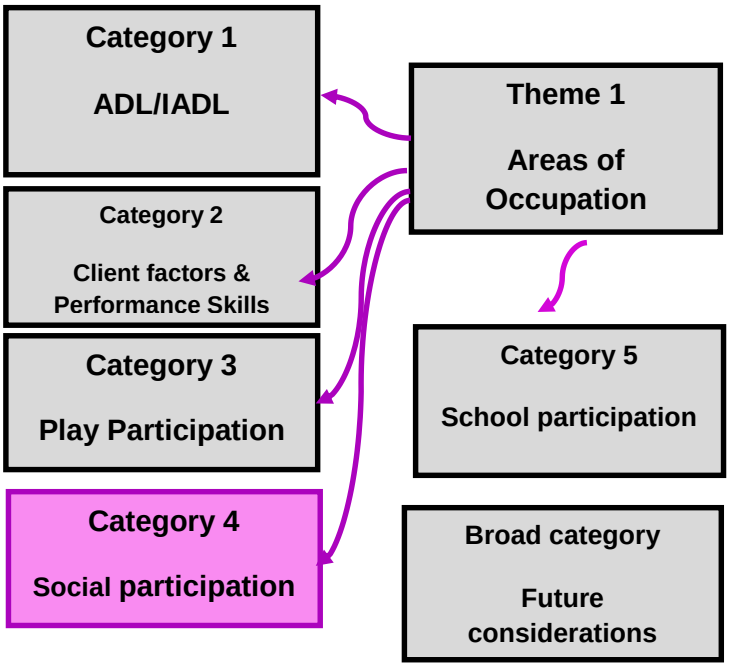
Because play is an interaction between the child and the environment, the human and physical factors in the environment can substantially influence the child's play (Knox, 1999). It is vital for an Occupational Therapist to create a play atmosphere for children considering the environment and the objects within it. In Emily's case, her environment at home needed to be adapted so that the play room was on the ground floor so that she could use her wheelchair for elements of her play i.e. playing hide and seek or races with her siblings. Her wheelchair was also used as a positioning device so that she could play with puzzles, blocks or books more optimally. An electronic tablet was also introduced so that she could more optimally keep up with her siblings when it came to puzzles or games. *See Theme 2: Assistive Technology.*

- ***Family Education and Training***

In Emily's context, there is not much time for her foster mother and caregivers to play with her. She is lucky to have older foster siblings and many volunteers who come to play with all the children at the home. As an occupational therapist, well versed relative to her home environment, it was imperative to include her older foster sister in our intervention sessions so that she could carry over the skills learnt and knowledge of how to assist Emily without disenabling her i.e. she learnt how to structure a play

activity but didn't complete the elements of the activity that she knew Emily could complete.

4.3.4.1. Category 4: Social Participation



Social participation can be defined as "The interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends (Gillen, Boyt, & Schell, 2014).

In early childhood, interaction and play *(see Theme 1: Category 3: Play above)* with peers becomes very important. Children become social beings and identify themselves as individuals. It is also important for a child to participate in home, school and community activities. Social participation can be hindered by **barriers** to play engagement or environmental barriers and this could lead to social exclusion i.e. Emily won't be able to play hide and seek with her school peers if she doesn't have her wheelchair or she will struggle to play on the jungle gym with her peers if she doesn't have physical assistance. A further barrier can be her emotional well-being (shyness, withdrawal) when meeting new peers. Factors that **support** her social engagement include her intrinsic motivation, temperament, adaptations to the immediate environment and support from known siblings, therapists or family members.

The researcher used data collected from semi-structured interviews and observation to discuss this area of occupation.

4.3.4.1.1. INTERVIEW DATA:

- *"Yes, if people in the shops say hi, then she will say hello, if they ask her what's her name then she'll tell them. And there have been kids asking her what's wrong, why doesn't she have arms, then she says to them, God made me like this. So I've tried to give her coping mechanisms."*
- *"In the home everybody has known her for 6 years and accepted her but in public I think it's terrible for her. People staring at her and feeling sorry for her and I notice she becomes withdrawn at times. A lot of people come and say hi but it's more a curiosity and feeling sorry for her then real interest. If she knows you she's friendly…"*
- *"The kids love to go to Spur, they've been to the beach a couple of times, she's been to the Zoo…we have many visitors who come to the home to help out or just play and socialise with the kids. Emily loves it and is normally in someone's arms."*

4.3.4.1.2. OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Community i.e. school, Family and peers	Her foster family encourages as much community interaction as possible i.e. attending parties, going to restaurants, public places of interest, the beach etc. They treat her as normal as possible and encourage her to be confident with strangers who want to meet her. She is well loved in her large foster family and gets along well with her foster mother and siblings. Emily can effectively terminate a conversation or social interaction. Emily produces spoken messages that are audible and clearly articulated. Although her limbs are limited, she does use her left stump to gesticulate a direction, happiness or joy.

	Even though she struggled initially to interact with her teachers and peers at school, she soon learnt to trust them and herself and she is now well known and loved at her school. She can be shy and withdrawn when meeting new people but once she gets to know them, she is bubbly and outspoken. Emily engages with peers at school although hasn't seemed to make a close friend yet. She is well integrated in structured school activities i.e. cultural and sport. Emily is able to speak in a fluent and continuous manner, with an even pace and without any pauses or delays during the message being sent. Emily does actively position or turn her body and face toward the social partner. She makes adequate eye contact. She maintains an adequate space between a social partner. Emily is often picked up by adults who wish to share a hug or a conversation. She does not make use of inappropriate touch in social interactions. She loves to 'high-five' or 'shake hands' with her left stump. Emily is able to request relevant facts and information and asks questions that support the intended purpose of the social interaction. Emily is able to keep a conversation going by replying appropriately to questions or comments. Emily likes to share information about herself to others in a socially appropriate manner. Emily is an emotional child. She will display appropriate emotion when joyous, scared or hurt. Emily is able to thank someone for the receiving of gifts, services or compliments. Emily is able to reply to social messages without delay or hesitation or without interruption. Emily is able to take turns and gives the social partner the freedom to take his or her turn.

DISCUSSION: The promotion of a child's social participation in the contexts of family, friendships, classmates, caregivers and teachers is an essential part of the occupational therapy process in all settings (Davidson & LaVessar, 1998). Social relationships are a critical part of a child's context and the mutual influences of the

individual and his or her social contexts have a large effect on quality of life and participation.

Social competence is defined as adaptive functioning within the social environment. Such competence requires abilities to achieve personal goals while maintaining positive relationships with others (Howes, 1988). The possible social separation or isolation experienced by young children with disabilities in a school setting is the result of two powerful forces. First, child characteristics, in terms of general physical, cognitive, communicative and behavioural problems associated with the child's disability, impact on the child's ability to engage in positive social interactions with peers (Guralnick, 2000). Second, the perceptions or beliefs of typically developing children or children with milder disabilities about other children may influence the likelihood that they will seek engagement with children with additional needs or needs different to their own.

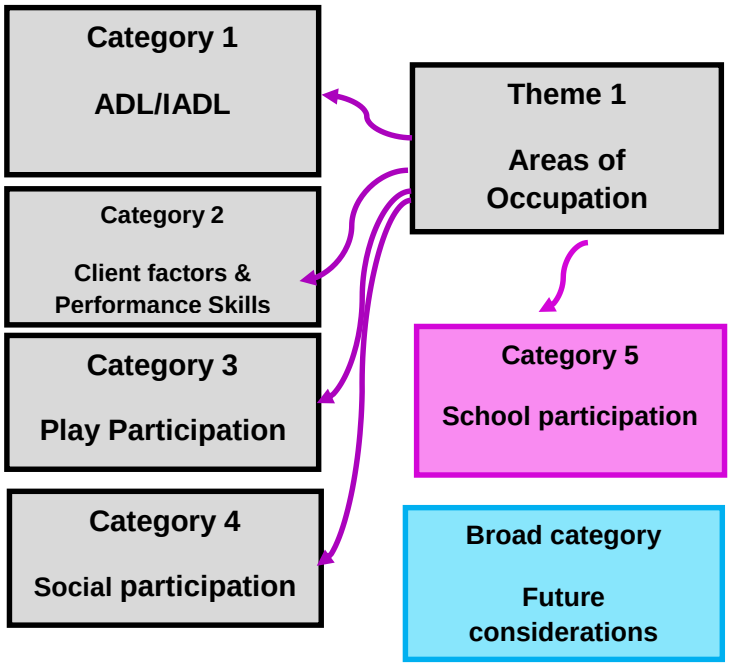
In Emily's case, she is the only child with TAS in her **school**. Her class consists of a mixed group of diagnoses ranging from mild cerebral palsy, learning disabilities or syndromes. She is the only one with such severe physical limitations. It has been noted that it is difficult for her to form a good friend at school due to the wide range of cognitive and physical disabilities. It is also noted that she sometimes doesn't venture onto the playground as it is easier to sit with her classroom assistant and eat her lunch. It could be the OT's role to educate the teacher on this to find ways to enhance her social participation at school. Strategies may include finding a more able bodied peer to be her 'buddy' and assist her in physically participating in play and social activities on the playground or social group sessions during school time occupational therapy to assist in forming greater bonds with peers.

Her social participation in her **home and community** context looks quite different. She is bubbly and outspoken. Her older foster siblings are available to physically include her in social interactions and she has a close bond with them. She is more secure in this environment as it is more predictable. A playground setting at school can be daunting to her.

Enhanced occupational engagement and social participation is seen as one of the desired outcomes in Occupational Therapy (Case-Smith & O'Brien, 2014). When OT intervention focuses on **enhancing or compensating** for limitations in client factors,

performance skills, participation in daily occupations like ADL, play and school, the child experiences more success in every day life and more confidence and security in trying new things or socializing with peers. There is less chance of social isolation, poor self-esteem and confidence, developmental delay or depression.

4.3.5.1. Category 5: School Participation



School participation comprises of activities needed for learning and participating in an educational context (AOTA, 2014). All children are required to spend considerable amount of time in school in preparation for adult roles in life. Schools prepare children to enter the community and work environment, enabling them to successfully contribute to society. Fullan (1993) stated that education should make a difference in the lives of students regardless of their background. An OT has the unique opportunity to help students become as functional as possible in their own environments.

The researcher used data from semi-structured interviews and direct observations to discuss Emily's school participation. At the time of the data collection, Emily was in Grade R. The discussion will include information about her Grade 1 year so far. Future recommendations will discuss the expected course of her academic career and what she will require to assist her on her academic journey.

4.3.5.1.1. INTERVIEW DATA:

At the time of the interviews, Emily was in Grade R. The quotes do not highlight her Grade 1 experience.

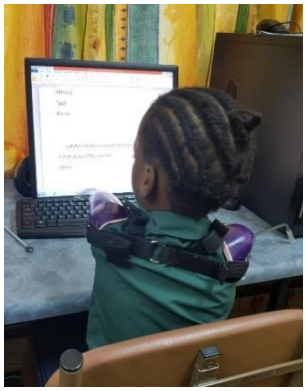
- *"I think her overall **physical challenges** are quite difficult. You really have to think outside the box because she really has so few in her favour and of course if you think of her physical problems to do perceptual work or normal developmental work of her age exploring because of her disability it's very difficult to do all those things. And another thing that's definitely counting in her favour is that she is willing to take any challenge head on. When the children come to therapy in a group, the rest would be willing to jump on something… then she would want to do that as well…so she is really amazing."*
- *"No I would say she is able to do most of the things the other kids are able to do, things like **threading**, which is difficult, you would think she would struggle, but she threads. She **sorts,** and she works with **play dough** and she **reads** a book, she pages through the book. No I would say she is able to do most of the things the other kids can do. In terms of the quality of her **drawing skills**…I wouldn't say it is on par, but like you said that is difficult to actually assess given her physical situation, obviously when she draws it is very light, she can't actually properly see when she tries to write her name or draw a picture, she struggles to push hard on the paper with her pencil, but for her it is amazing, you can't really compare her with the other kids regarding that.*

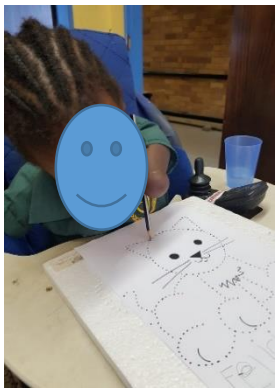
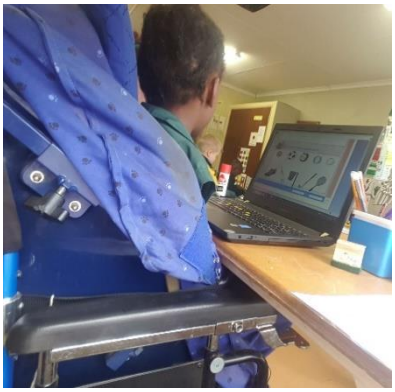
4.3.5.1.2. OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below: (this includes Grade 1)

Formal educational participation	Emily participates as best she can in an academic environment. She uses alternative methods to learn including a tablet, computerised programs, oral instruction, pointing (manual bilateral pointers), and facilitator led instruction. Her entire Grade 1 curriculum has been uploaded electronically to her laptop. She is

	able to type with her pointers and operate the mouse pad with her left stump. She is still able to perform pencil and paper tasks when needed but the computer is used to provide more speed and lessen fatigue or postural injuries. In a non-academic environment, she is able to participate with play pursuits in recess times (with structure), feed herself lunch (minimal assistance) and move around independently in her wheelchair. Extra-curricular activities that she is involved in include athletics days (wheelchair races, beanbag toss), dance mouse and horse riding.



Further analysis of her school participation, enhanced by assistive technology will be discussed under Theme 2: Assistive Technology.

DISCUSSION: According to Case-Smith (2005), an occupational therapist needs to consider the following areas of performance in a client to be able to provide appropriate intervention strategies and support in school environment in individualized education programs: *(see Table 4.3.7: Areas of Performance to be considered by an OT working with Emily specifically.)*

- Motor performance
- Sensory responsiveness
- Perceptual processing
- Psychosocial and cognitive abilities
- School environment
- Teacher and curricular expectation

Table 4.3.8: Areas of Performance to be considered by an OT working with Emily specifically.

Area of performance	Support vs. Barrier	Comment
Motor performance ***See Theme 1:Category 2: Client factors/ Performance skills***	Barrier	Emily's motor limitations make tasks like handwriting, sharpening a pencil, using a ruler or eraser difficult, classroom and playground mobility difficult. Adaptations and Assistive technology has been implemented to overcome this barrier.
Sensory Responsiveness ***See Theme 1:Category 2: Client factors/ Performance skills***	Support	Emily is alert in class and is able to follow and understand instructions. She also has an individualised facilitator to help her should she be taking longer on a specific task.
Perceptual processing ***See Theme 1:Category 2: Client factors/ Performance skills***	Support	Emily's perceptual skills are one of her strengths to learning. This will enable her enhanced participation in tasks like reading, mathematics and letter formation (on her laptop).
Psychosocial and cognitive abilities ***See Theme 1:Category 2: Client factors/ Performance skills***	Barrier & Support	Emily's cognitive skills assist her in grasping new concepts and retaining knowledge. Her emotional skills however may act as a barrier to learning should she be anxious or fearful in class.
School environment	Barrier & Support	Her school context is a support as the school incorporates individualised learning programs, facilitators and assistive technology. A mixed diagnoses classroom can be a barrier to her social interaction as

		described above under *Category 4: Social Participation.*
Teacher and curricular expectation	Barrier & Support	Emily's Grade 1 teacher is experienced in special needs education. She is understanding of many different conditions and works closely with the allied team at the school to provide the best service to each child according to their unique needs. A barrier for Emily would be the curricular expectation – even though strategies have been put in place to assist her, the teacher is concerned that she won't be able to maintain the pace of mainstream curriculum in the higher grades.

A collaborative planning procedure involves many factors, consideration of the above mentioned areas, identification of a child's strengths and needs as well considering special factors like assistive technology to be addressed in the plan. An OT has a vital role to play in this team including teachers, parents, psychologists and education specialists.

It has been imperative for the researcher as an occupational therapist to adopt a consultant role with Emily's teachers, teacher aids and facilitator. In this consultation, the active role players form a cooperative partnership and engage in a reciprocal, problem-solving process (Case-Smith, 2005 pg 812).

The following table illustrates examples of intervention strategies used in Emily's case when consulting: Adapted from Case Smith (2015: pg 813)

Table 4.3.9: Intervention Strategies used when Consulting at school

Intervention Strategies	Examples
Reframe the teacher's perspective	-Identify the consequences of poor posture in sitting in her wheelchair or normal school chair.
Improve the student's skills	-Recommend that the teacher aid provide standby assistance while Emily attempts to open her lunch box and feed herself, rather than to do the entire task for her.
Adapt the task	-Implement the Grade 1 curriculum on a computer based system to provide enhanced access to all activities.
Adapt the environment	-Recommend that Emily sit on the side of the class with her facilitator to avoid distracting the rest of the students. -Recommend that she takes regular movement breaks to reduce the incidence of fatigue.
Adapt the routine	-Recommend that Emily be given extra time to complete certain written assignments on her computer. -Recommend that Emily receive support from the school play therapist to address her emotional needs (performance anxiety and fear)

From the perspectives of the interviewees, consensus was reached in the sense that her school is the right fit for her. Her school caters for children with unique special needs, both physical and cognitive and on a varying continuum. Her school has mainstream and special need classes. She is currently completing Grade 1 (mainstream) with a facilitator. Much thought and teamwork went into deciding what

approach to education would suit her and this is proving to be an ongoing process.

In reflection and from the perspectives of key role players, the researcher has observed the positive effect of early intervention in Emily's case. To an inexperienced occupational therapist, providing intervention with a unique case like Emily can be daunting. One may equate her severe physical limitations with an inability to perform normal childhood occupations. One may want to protect a child like her and she may be placed in a school that does not cater to her potential. The OT intervention before she started Grade RR at her school focused greatly on participation in age appropriate play activities including sensory play, pretend and imaginary play, gross and fine motor activities (including block building, threading, sorting, play dough, puzzles, drawing, arts and crafts, concept development, music and dance and an introduction to books). During the interview with her teacher, it was realised that despite her limitations, she had developed skill and determination to take part in school related activities and the OT intervention from 1 year of age had assisted in her school readiness. *Early intervention in Emily's case will be discussed in more detail under Theme 3: Therapeutic Intervention.*

4.3.5.2. Broad category: Future recommendations

Vocational pursuits would incorporate the continuation of her primary and secondary education, whether it continue in the mainstream or need to become more adapted to her needs. The possibility of tertiary education comes to the fore as well as employment interests, seeking and acquisition of work and whether she would be able to work in the open labour market or sheltered / protected employment. Data from interviews was used to portray this section.

INTERVIEW DATA:

- *"We still do CAPS even beginning in Gr R, so when she goes to Gr 1 it will be CAPS, they will follow the **curriculum** like they would do in a **mainstream** school and then we also have the **life skills phase** for children that are not able to. Also, the work orientation skills for kids to get settled in a job one day. She has the ability to go all the way to matric, it is just also the time constraint, every year the pace gets faster and it picks up and one just wonders if she will be able to keep up with that, and is she going to have a **proper facilitator** throughout her school career."*
- *"I think the best thing for her will be a **voice operated typing system**…so that she can keep up with the rest of her peers and not get too tired in class…"*
- *"I thought about a few things like to **finish matric, tertiary education** and to find a job, there would be specific jobs, something in the line of computers. Obviously she will always be dependent but if you earn good money you can pay somebody to drive you around."*
- *"I would love to see her in a **mainstream school** later on when she is **proficient in her assistive technology**…I think it would be great to raise awareness that children or people with disabilities DO have the ability to fit into a normal society…I would love to see her have a job one day…I feel that she can be an activist and do motivational speaking, but she must first and foremost have her own career, where she can earn a salary. I think a **predictable routine** would be key….I see her in a career like art therapy, psychology, social work etc…"*

DISCUSSION: When discussing her future academic course with key role players in her life, a consensus was reached that the most optimal assistive device would be a voice operated typing system. This could be used for examinations, assignments as well as email or SMS correspondence as part of a vocational pursuit in the future. If she would to become proficient with this device, and with the assistance for a permanent facilitator throughout each grade, she may be able to keep up with the pace of mainstream curriculum.

It will continue to be vital for the occupational therapist to adopt a consultant role with Emily's teachers, teacher aids and facilitators throughout her academic career. An

ongoing process of assessment, implementation of classroom strategies and interventions, problem-solving and monitoring of progress will be imperative to Emily's continued success.

The role players in her life hope to see her able to complete some form of tertiary education one day and enter the realm of employment. Although not impossible, she will require tremendous support through each phase of her life to achieve this goal. Although not covered in this study, Occupational Therapy has a role to play in continued academic support, assistive technology and adaptations that support participation, vocational pursuits and vocational rehabilitation (The Association, 1980).

In Theme 1, the barriers and supports that Emily faces in her areas of occupation (areas of daily living, play, social and school), client factors and performance skills were discussed with reference to relevant quotes from the semi-structured interviews and data from assessments and direct observation. The contribution of Occupational therapy was discussed in each case. A discussion of her assistive technology will follow in the following theme.

THEME 2: ASSISTIVE TECHNOLOGY

For this theme, four categories and a broad category were identified and it will be presented in conjunction with representative quotes from interviews as well as data from assessments and direct observation.

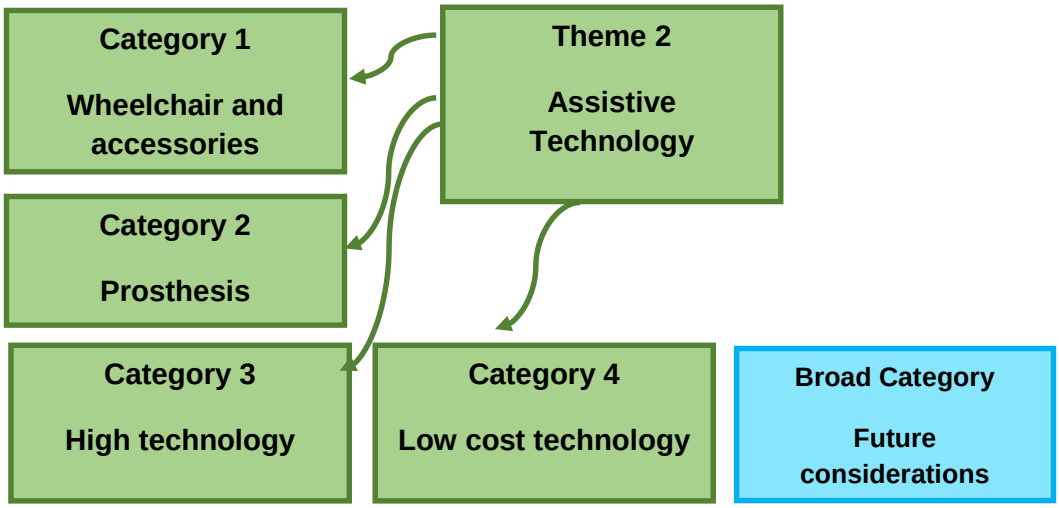


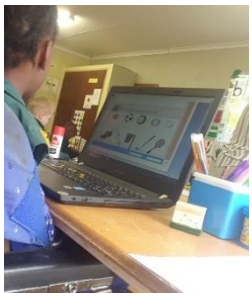
Figure 4.3.2.2: Theme 2 with categories

Assistive technology (AT) is any item, piece of equipment, software program, or product system that is used to increase, maintain or improve the functional capabilities of persons with disabilities (Assistive Technology Industry Association).

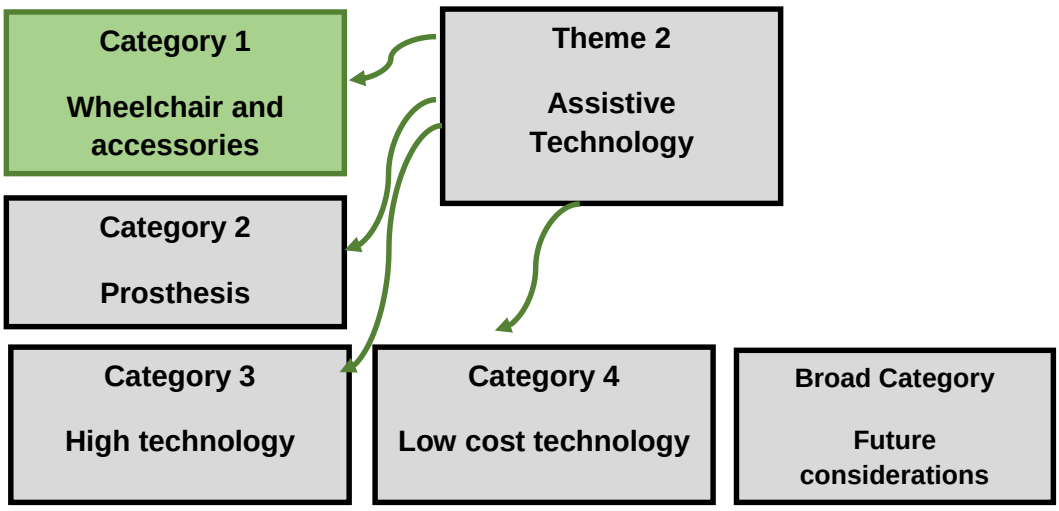
An analysis of the data and in conjunction with the interview questions, assessments and direct observation, this theme entails the various assistive technology relevant in Emily's case, the opinions and perceptions of how specific devices affect her independence and ability to participate more optimally in different environments. Qualitative data with regards to assistive technology was derived from transcribed interviews. Quantitative data with regards to assistive technology was derived from document analysis (QUEST) and direct observation using the Criteria for Evaluating Assistive Technology Devices (Scherer & Lane, 1997).

The following Table 4.3.8 represents the four categories in this theme and illustrates which assistive devices will be discussed to provide clarity for the reader:

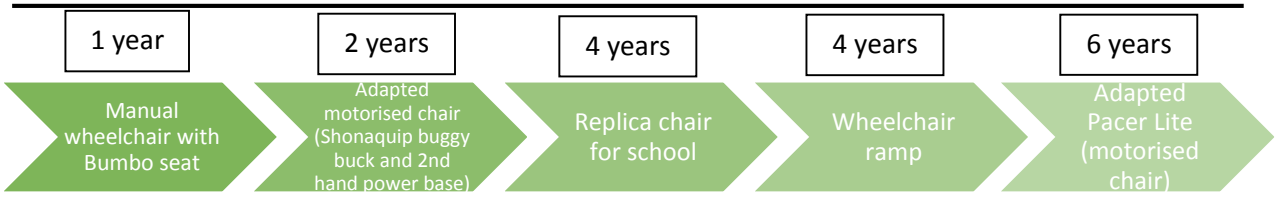
Table 4.3.10: Assistive Device illustrations

Category 1: Wheelchairs and accessories	Category 2: Prosthetics	Category 3: High Technology	Category 4: Low Technology
Adapted Madiba buggy motorised wheelchair  Adapted Pacer Lite motorised wheelchair 	Manual bilateral upper limb prosthetic arms (discontinued use)  Manual bilateral upper limb pointers 	Tablet (home)  Laptop (school)  Big Keys computer system at school (discontinued use)  SMARTNAV eye controlled computer system at school (discontinued use) 	Bumbo seat  Universal cuff  Toilet seat inner tube 

4.3.2.2. Category 1: Wheelchairs and accessories



Emily was referred to a seating specialist at the age of 2 years old. She was then being pushed around on a 2nd hand manual wheelchair, seated in a Bumbo chair for support. At 2, she was issued with an adapted motorised chair (Shonaquip Buggy buck and a 2nd hand power base). A replica chair was made for her for school use at the age of 4. Due to lack of finances, 2nd hand parts were sponsored and the chair was put together as well as possible under the circumstances. These wheelchairs were so heavy, unable to be picked up by one person. Two or more people were often required to assist when transferring the wheelchair in and out of a car. This made community outings quite a challenge especially if it was just her foster mother and the children. A wheelchair ramp was eventually sponsored for her home environment which made it much easier for her family to transfer and transport her wheelchair. Her newest wheelchair (Adapted Pacer Lite) was sponsored and issued at 6 years of age. It was a much smaller chair and customised for her unique needs.



INTERVIEW DATA:

- "*She had a **power chair (sponsored)** she was driving sitting on one of those little Bumbo chairs on the very edge of the seat. I was then asked to see if I can assist in custom making and custom building a chair specifically designed for Emily so that she can be safe. My biggest concern was her **safety**, and that's why I made the little jacket for her so that she could be zipped up in it and she could be straight. She does have the tendency to lean to one side, and that is the side where her stump is, because obviously she has got more flexibility more mobility and more control. And I just wanted her to be more central so that we are not dealing with scoliosis or anything in the pelvic region going forward."*
- *"I think the wheelchair just gives a little bit more **speed and more freedom**. Yes, they ride bikes, they play hide and seek, she goes to the movies, and she goes to the shops just in her wheelchair, that's what her wheelchair is for. And I think the wheelchair also allows her to be a bit higher off the ground so she doesn't feel as little, or unsafe, you know someone may stand on her."*
- *"Oh, yes!! In our department she plays on the carpet but if the terrain is rough then the **wheelchair helps** her a lot."*
- *"The chair is so heavy, the security guards have to help us take it in and out of the car…so mobility is quite a struggle…yes that's a problem, but any kind of chair needs to be **modified** for Emily."*
- *"Her **wheelchair** (adapted Madiba buggy) **is a bit big**, they call it the Hummer or the 4x4, so it is quite big…she can't see properly where she is driving…So no, I do feel the wheelchair is too tall, especially if one would use it in a class setting one would like it to be a bit lower. Where she is on the same level as the other kids as well. So this wheelchair is not the best practical wheelchair for her."*

The newest wheelchair (Adapted Pacer Lite) was only issued and fitted after these interviews were held. Its effectiveness was evaluated using direct observations and the QUEST (Quebec User Satisfaction of Assistive Technology) which will be discussed below.

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Adapted Madiba buggy motorised wheelchair	This wheelchair's **strengths** were that it was effective for the needs of Emily at the time. It improved her functional capability and independence in mobility, social interactions and daily activities like feeding. Further strengths included learnability (Emily was able to master the chair's workings in a very short period of time), comfort and acceptance. The **weaknesses** included that without sponsorship or donations, the wheelchair would be unaffordable for Emily's context, portability was an issue due to the weight and size, reliability was an issue as the battery was old, safety was as issue due to the size of the chair as well as maintaining the chair posed a problem due to financial constraints.
Adapted Pacer Lite motorised wheelchair	This wheelchair's **strengths** included effectiveness as per her needs for function and independence. It was more reliable, it was easily transported as it was half the size of the initial chair. Safety was ensured as the chair was lower to the ground and had a wider base of support. It was accepted by Emily and she also mastered its use very quickly. Maintenance for this chair is more optimal as the company which supplied the chair visit the school on a regular basis. The **weaknesses** included that without sponsorship or donations, the wheelchair would be unaffordable for Emily's context.

DISCUSSION: It was important for the occupational therapist to collaborate with Emily, her foster mother, teacher and seating specialist to determine the best match of wheelchair to her specific needs, as well as keeping the environment in mind and her socio-economic status.

Apart from the financial implications involved and available resources being limited, an occupational therapist must consider the following guiding elements in evaluating a child for Assistive technology (Case-Smith & O-Brien, 2014):

(The following guidelines have been described using her wheelchairs as examples)

Motor skills:

- The most reliable body part needs to be used to control movement. In Emily's case it was her left stump, therefore the joystick was modified on the wheelchairs.
- Positioning needs to be kept in mind – Emily's seating specialist consulted on both wheelchair fittings to make sure the chairs provided her with the most optimal positioning and posture.
- Overall endurance and strength should be looked at so as to not cause fatigue. A motorised wheelchair was considered in Emily's case to provide a case of minimal output, maximal impact.

Sensory and perceptual skills:

- We know that Emily's sensory (visual, auditory, tactile, vestibular) and perceptual skills are adequate, therefore following instructions, attending to visual and spatial elements in the environment and manoeuvring herself in different environments would be easy to learn and adapt to.

Cognitive and communication:

- Cognitive level: Emily is able to learn and adapt to new tasks easily. Her wheelchair training went smoothly.
- Attention span: Emily has an adequate attention span, especially when motivated.
- Language skills: Emily was able to understand (receptive) and express her needs during training of her devices.
- Multiple-step directions: Emily is able to follow multiple step directions.

Psychosocial:

- One needs to assess whether the child is motivated to use the device, what activities does the child enjoy and is the device meaningful and rewarding.

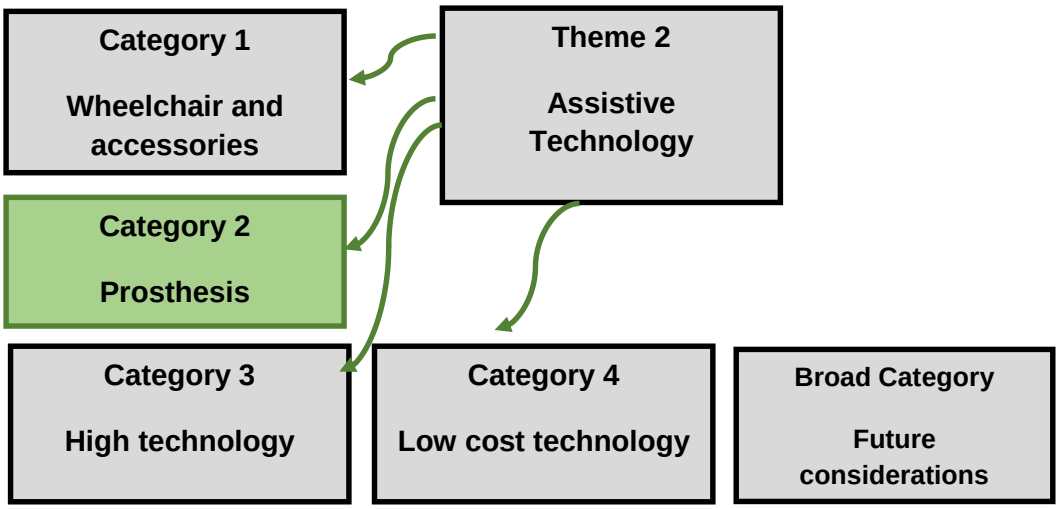
Context:

- One needs to keep her contexts in mind. Can her home, school and community environments cater for such a device?
- In Emily's case, the first chair was very heavy and bulky and it limited here access to indoor and community excursions. It was also comprised of 2nd hand parts that took long to charge and maintenance was difficult to uphold.
- As an occupational therapist, her device was continuously evaluated and new improved ways were sought out to provide a better match for Emily. Problem solving and clinical reasoning skills throughout the process of procurement, implementation and follow-up of an assistive device is vital.

The Matching Person and Technology model and assessment process are designed to help individualise the process of matching a person with the most appropriate AT. This model and process considers 1) Person, 2) Environment and 3) Function of device. OTs must consider the dynamic and constant interaction of the person with the environment through engagement in occupations. Social, spiritual and cultural factors should also be considered as potential contributors to outcomes of AT intervention.

Emily's wheelchairs have provided her a means to spontaneity and freedom in her **play,** enhanced home, school and community **mobility,** improved **social interaction and participation,** it provides for adequate **posture and safety** and allows her to be more independent in daily tasks like **feeding and eating.** Therefore assistive technology in the context of occupational therapy in Emily's case has supported her occupational engagement and provided her with enhanced independence. She will need a wheelchair for the rest of her life, and this will need to keep up with the ever-changing technology. It is vital that the Occupational Therapist stays up to date and looks at the long term goals of the client. *See Broad theme: Future recommendations.*

4.3.2.3. Category 2: Prosthetics



Emily was fitted with a manual prosthesis before the age of 2 by an Orthotist / Prosthetist. A year was spent trying to train her to use the device. It was subsequently discontinued due to the inefficiency of the device and poor fit between device and user. At the age of 3, she was taken to another Prosthetist for a myo-electric prosthesis evaluation. It was said at this stage that she was a perfect candidate but the quote came back at almost R450,000.00. At that stage it was decided that school tuition was of more importance to her and that the prosthesis would be re-looked at later on in her development.

In her Grade 1 year at school, she was assessed by the school prosthetist, who assembled manual bilateral upper limb pointers for her to use in class on her laptop. Occupational therapy is currently aiming to train her in the use and exploration of these pointers.

INTERVIEW DATA:

- *"We did ask her if she wanted them (initial manual prosthesis), but it's very heavy and bulky, and she said no, she can do everything herself."*
- *"I saw pictures of it (initial manual prosthesis), I don't think I ever saw her fit it but as I understand she didn't cope."*
- *"What worried me was that she had to sort of connect her shoulder, to connect it to get it to do something. It was all part of the shoulder movement, which I think was hard for her, she could do it, but I think it was just exhausting for her. It was painful and uncomfortable (initial manual prosthesis). Yes because it was mounted from the shoulder, and she was just so much quicker and faster with her stump."*
- *"So when I started with her…they had just started orientating her to these prosthesis, and whenever I would go there we would do about five minutes work and the tears would roll down her cheeks. And she would say to me, I don't want to use my arms ((initial manual prosthesis),), it's hard, its hurting…It wasn't a great match for her."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Manual bilateral upper limb prosthetic arms (discontinued use)	This prosthesis showed **weakness** for Emily across all areas including ineffectiveness (poor fit between user and device), reliability, portability (it was definitely too heavy and bulky in relation to her body), safety (due to the effort required, Emily often complained of pain), learnability, discomfort, rejection of the device and poor operability.
Manual bilateral upper limb pointers	This prosthesis was made for the sole function of academic work (typing on a keyboard, reaching to touch on a touch screen, operating a mouse, moving an item on her desk with bilateral pointers). It is not intended to grasp items or bring items to her mouth.

	The **strengths** of this device is that it provides effectiveness in independence in academic work. It was affordable in comparison with other devices, it poses no discomfort or danger to Emily while using it, and it is easy to use and took minimal time to master. The **weaknesses** lie in its durability (it may need to be re-made numerous times due to Emily's growth) and maintenance and reparability is reliant on the prosthetist or OT.

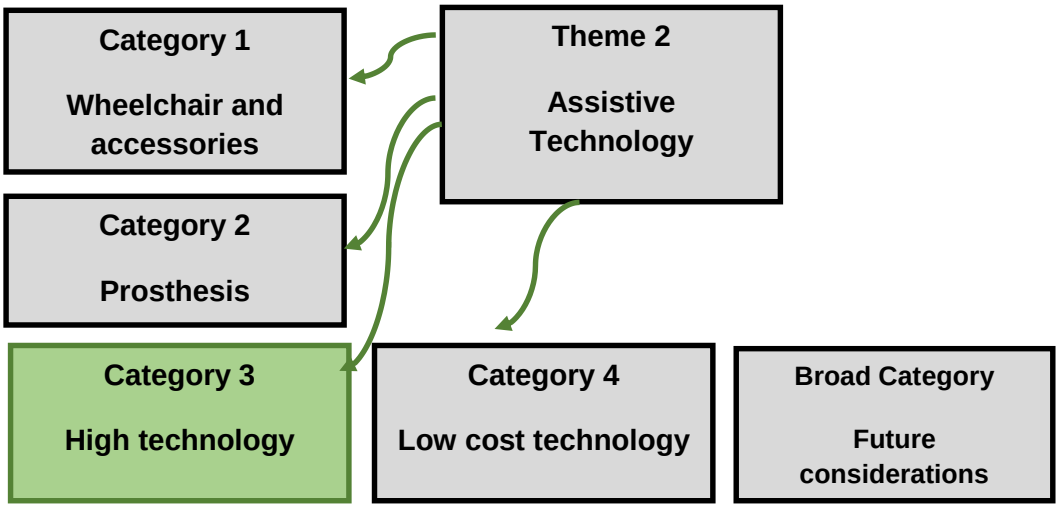
DISCUSSION: When the researcher started her journey with Emily at age 1, she had already received a manual prosthesis from a prosthetist. As noted above, it was not a good fit between user and device for many reasons. Technology abandonment often signifies a mismatch between the user and device (Case-Smith & O'Brien, 2014). When a device fails to live up to its promise of potential, freedom and independence, disillusionment with the idea of the AT may result. It is the researcher's opinion that a thorough assessment of Emily's capabilities, interests and desires was not done prior to the acquisition of the prosthesis. During her early childhood, Emily proved more functional in terms of mobility and ADL **without** the prosthesis.

As an occupational therapist, I learnt that it was important to foster and respect Emily's self-determination and self-advocacy. Self-determination is defined as "*acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference"* (Wehmeyer, 1996 pg 24). Self-advocacy refers to an individual's ability to speak and make decisions for him- or herself and voice his or her rights (Wehmeyer, 1996). It was from this initial period where one could visibly see the mismatch between person and device that the researcher as occupational therapist endeavored to let Emily lead her in the assistive device planning process.

At age 6, a bilateral pointer prosthesis was made for the sole function of academic work (typing on a keyboard, reaching to touch on a touch screen, operating a mouse, moving an item on her desk with bilateral pointers). It is not intended to grasp items or bring items to her mouth. This device was received positively by Emily and has

provided her with more independence in her **school** work. She only uses it at school. A myo-electric prosthesis still remains a future recommendation to hopefully assist Emily with finer elements of **ADL, IADL, school and vocational pursuits**. *See Broad theme: Future recommendations.*

4.3.2.4. Category 3: High technology



High technology is technology that is at the cutting edge: the most advanced technology available.

Emily was sponsored a Samsung tablet at 4 years of age for educational purposes. She learnt to use very quickly and it assisted her in learning all her basic concepts like colours, shapes, numbers, letters etc. In the school that she is in, they cater for children with various learning needs and assistive technology is a common occurrence in therapy and classrooms. She was recently (age 6) given a SMART NAV (eye-controlled computer based) system, Big Keys and laptop. She started training to use this system with the school OT in preparation for more academic work in Grade 1, but the system was discontinued due to ineffectiveness and poor fit between user and device. She now uses a laptop at school with her entire Grade 1 curriculum uploaded electronically. She is able to manipulate the keypad with her left stump, type with her manual pointers (as mentioned above) and uses a mouse. She has a class facilitator who assists with set-up of her system.

INTERVIEW DATA:

- *"She doesn't take long to learn a new skill or learn how to use the **tablet,** you almost don't have to teach her because she teaches herself. That is good for her because she can do a lot of educational things on there."*
- *"On her new laptop she uses her little stump to move the mouse on the mouse pad. She is able to type her name because we have stickers that we use to enhance her keyboard. I think the strain on her eyes might cause her to not use it for long. We use a little dot to help her focus on the middle of the screen (referring to the **SMARTNAV system).** I think if we get her the right pointer she isn't going to use this for very long.*
- *"Emily has to concentrate quite a bit to keep her eyes focused on certain things, and I feel there is no problem with her speech, possibly the ideal long term goal for her is to get a **voice operated typing system,** so she would talk and then it would type for her so if she needed to do any kind of exams later on."*
- *"I don't think that **SMARTNAV** is going to be quick enough or fast enough for Emily."*
- *"And it (referring to computer system) affects her posture at the end of the day, because she is constantly rotating and leaning forwards…and because she is only using her stump, this can result in pressure sores. She is still young and you want her to have as much movement as possible and to have as much easy accessible equipment, but we have to consider her joints…so for me I feel that the **voice recognition** is going to be the most accessible I think…"*

OBSERVATIONAL DATA:

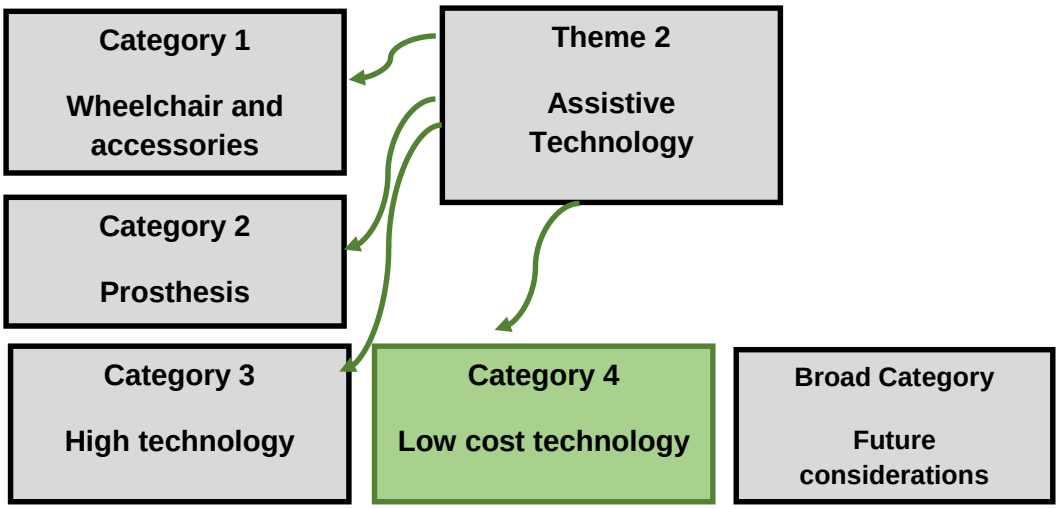
Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Tablet (home)	The **strengths** of this device include effectiveness in providing more independence on developmental tasks like games, concept development, and following of instructions, early language and reading skills. It is a reliable device, needing minimal maintenance, although it would need to be replaced after each lifespan. It is easily portable and set-up is straightforward. It is a device that provides

	no risks to the user, apart from over-use effects i.e. visual overstimulation. In Emily's case, she showed ease in learning how to operate the tablet and was quickly fluent in its workings. The **weaknesses** lie in the costs involved. Emily's tablet was sponsored, but this will need to be maintained to provide consistency in her devices.
Laptop (school)	The **strengths** of her laptop is that it is an easily re-produced assistive device. Any laptop could perform the same purpose, thus she doesn't have to rely on one specific device to perform her school work. The device allows her to follow her Grade 1 curriculum page for page and complete her tasks as best as she can. She 'draws' letters and numbers and 'colours in' by using her left stump on the keyboard. She is able to 'click' and type using her bilateral pointers (mentioned above). The device is durable, portable and reliable. Emily learnt to use it easily, possibly due to her early exposure to technology. She accepted it straight away and is motivated to perform her school work. The **weaknesses** lie in the costs involved. Emily's laptop was sponsored, but this will need to be maintained to provide consistency in her devices.
SMARTNAV eye controlled system **Big Keys computer system at school** **(discontinued use)**	The foreseen **strengths** of the SMARTNAV system was to accommodate for Emily's postural concerns. Her team wanted a device where she would make use of minimal rotation and leaning with her left stump. This later showed to be the only strength of the device for Emily's unique case. The device proved to be **ineffective** in enhancing academic participation, learnability and operability was too difficult and Emily was often fatigued and demotivated. The device is also expensive to maintain and keep up to date with the latest computerised technology. It was further not accepted by Emily and proved to be a poor fit.

DISCUSSION: High technology in Emily's case (Tablet and Laptop) have been very beneficial in her pre-academic and academic pursuits. High technology is however expensive and can pose as unaffordable to most children with disabilities. In Emily's context, there are not enough financial resources to cover the cost of these devices. It has been a team collaboration (OT, School, foster mother, private sector) consisting of writing sponsorship letters, hosting fundraisers and word of mouth. Emily's sponsors have all been private entities. She is privileged to be in a school that is well versed in different AT. It is part of the OT's role to advocate for a childlike Emily and try to eliminate financial barriers that may stand in the way to her enhanced independence and occupational performance (Carlson, et al., 2003).

4.3.2.5. Category 4: Low cost technology



Low technology is simple technology, often of a traditional or non-mechanical kind.

Emily was introduced to using a **universal cuff** for activities like feeding, brushing her teeth and drawing / scribbling at the age of 2. Furthermore, she used is to manipulate a stylus on her tablet. In hindsight, the cuff introduced her to greater mobility and activity participation, but over the years, it has been noted that Emily has more manipulation and dexterity skills without it. She currently has a universal cuff for back-up if her bilateral pointers need to be repaired or adjusted.

From birth, she has used a **Bumbo** chair. She used it predominantly in her first year of life for supported sitting. It also assisted in feeding times. It then transitioned to an early mobility device being placed on a wheelchair and now it is used at school during play and group activities that require dynamic balance i.e. balloon volleyball, reaching tasks etc.

She started using the **toilet seat inner tube** at the age of 2 – 3 years old while she was toilet training. She continues to use it up until now as it provides her with some independence on the toilet. She is able to sit independently on the toilet and enjoy some privacy.

INTERVIEW DATA:

- *"At one point we were using that **cuff** that we put the spoon in, but now she is a lot more mobile in terms of manipulating it without that…"*
- *"…but she said no, she can do everything without the **cuff** now."*
- *"But she really doesn't like gadgets and so on to help her, she prefers working with her little stump."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Bumbo seat	As mentioned above, the Bumbo seat provided effectiveness in different phases of Emily's development. She isn't reliant on it anymore, it just assists in more optimal dynamic balance and postural support. It is affordable and reliable. It provides safety and comfort.
Universal cuff	The universal cuff is easy to make and re-make. She has used more than three cuffs since the age of two years old. A cuff is inexpensive to make and can be maintained or repaired easily. In Emily's case, the cuff became more effective as a lengthening or stabilising tool i.e. to hold a spoon, toothbrush or to provide distance between her face and her tablet. She shows more manipulation and dexterity however without it.
Toilet seat inner tube	Her inner tube provides an element of independence in toileting and ease for her caregivers. It is affordable and can be replaced. It is reliable and can be moved from one place to the next. It provides safety and comfort.

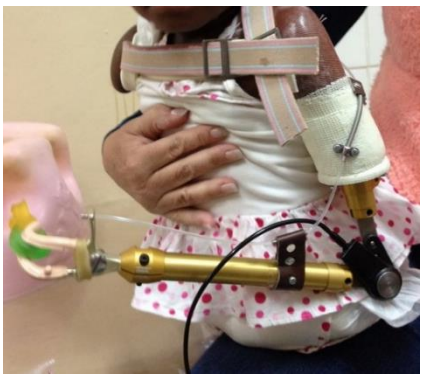
Low technology provides a more affordable way to improve or enhance activities as seen above.

Data from assessments using the QUEST is portrayed below. For the purpose of this research, only four assistive devices were chosen.

QUEST Quebec User Evaluation of Satisfaction with assistive Technology *See Annexure I.*

The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) was designed to measure the level of satisfaction attributed to assistive technologies (Demers, Weiss-Lambrou, & Ska, 2000). The technology available today has made possible a vast number of assistive technologies. With the plethora of assistive tools available it is important to have systematic methods of measuring their value to the people who use them. This is what the Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) aims to do. The scale has been designed, examined, and re-examined with the help of expert panels and it is unique in its emphasis on user directed and interactive measures of satisfaction.

Key role players in Emily's life (seating specialist, foster mother and school OT) were asked to fill in the scale for the following devices; 1) old motorised wheelchair (Adapted Madiba Buggy from Shonaquip), 2) new motorised wheelchair (Adapted Pacer Lite from CE Mobility), 3) Manual Prosthesis (discontinued use) and 4) Tablet.



For each of the 8 items in the tool, the role players were asked to rate them according to a 5 point scale (as seen below):

1	2	3	4	5
Not satisfied at all	**Not very satisfied**	**More or less satisfied**	**Quite satisfied**	**Very satisfied**

The items included the dimensions, weight, ease in adjusting, safety, durability, ease of use, comfort and effectiveness of the assistive device. The therapist added the scores for each item and illustrated the average scores in the table below:

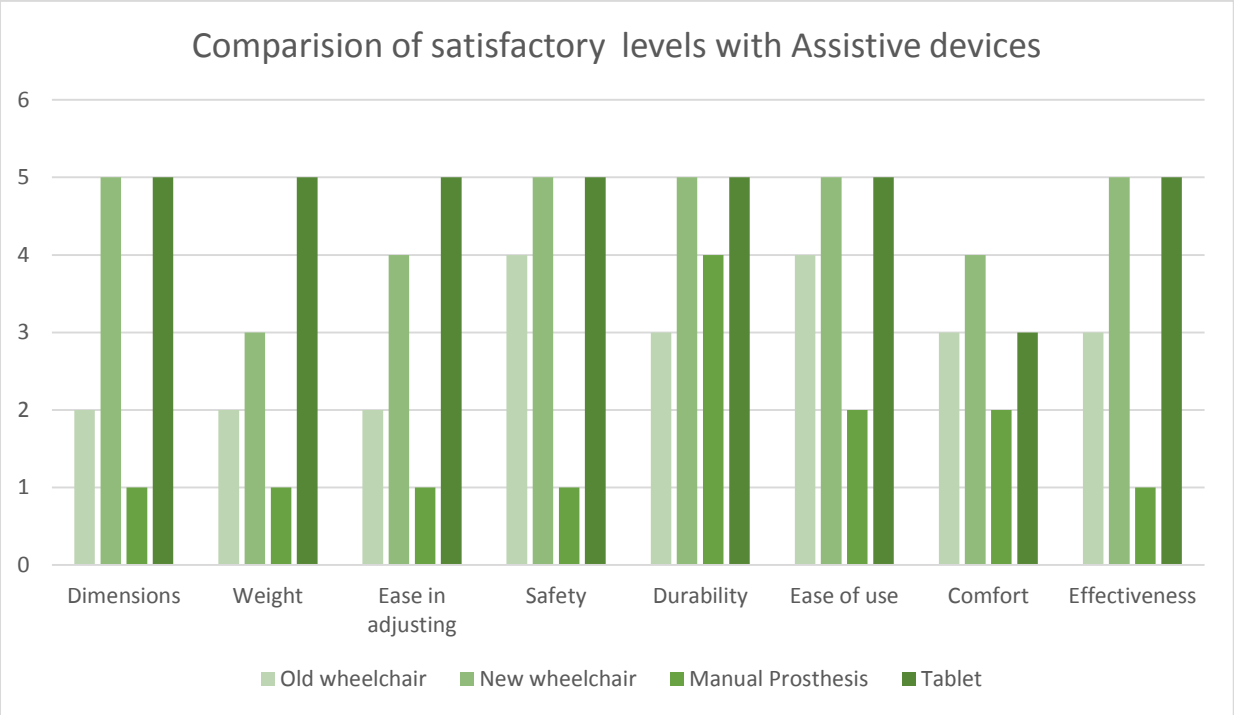


Figure 4.3.2.2.1: QUEST Comparison of satisfactory levels with assistive devices

As can be seen in the graph above, two assistive devices (new wheelchair and tablet) scored higher in levels of satisfaction than the other two (old wheelchair and manual prosthesis) which has been abandoned or are in the process of an upgrade. It is important for the occupational therapist to critically evaluate the effectiveness of assistive technology given to patients and to ascertain whether the fit between the device and person is satisfactory (Phillips & Zhao H, 1993).

DISCUSSION: Assistive technology is an important tool in the occupational therapy profession (Case-Smith, 2005; 615). For children with disabilities, introducing the appropriate types of technology systems as early as possible may assist the child to participate in important learning situations that otherwise, because of his or her disabilities, may not be possible. As children grow they may use technology to develop independence in many daily activities, complete school assignments, develop prevocational and vocational skills, increase opportunities for social participation and play games or participate in leisure activities (Case-Smith & O-Brien, 2014). The occupational therapist must consider many factors when making decisions regarding the use of assistive technology. The occupational therapy domain and process as described in the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2014) serves as the foundation and guiding structure to consider the unique interaction between a person's inherent abilities and limitations, what provides meaning for them in different contexts as well as looking at available resources.

The framework developed by the World Health Organization in its International Classification of Functioning, Disability and Health (ICF) provides an overview of important life domains that may be considered when assessing the need for and evaluating the efficiency of assistive technology device (ATD) use. ATDs are products designed to improve functioning and capabilities in such areas as mobility (e.g. wheelchairs), personal care (e.g. adapted grooming aids) and speech communication (e.g. augmentative alternative communication technologies) (Scherer, Craddock, & Mackeogh, 2011).

The need for ATDs is great in the South African context (Gedye, 2016), especially in the lower socio-economic populations. From the researcher's experience, it is apparent that government institutions are poorly resourced due to the high costs of many ATDs. Most government hospitals / clinics provide basic folding wheelchairs, crutches and walkers as well as adaptive grooming and feeding aids. Not many cater for children (i.e. smaller mobility aids) and it is rare to find the stock and provision of high tech ADL and Augmentative and Alternative Communication (AAC) technologies. Most therapists rely on making low-cost aids to assist their patients / clients.

Assistive technologies have significantly improved the quality of life for persons with disabilities. As the availability of a range of assistive technology increases, decision

making about the optimal technology to improve a child's function has become more difficult. Assistive technology must match the child's abilities and performance limitations and enable the child to perform age- and developmentally appropriate activities (Case-Smith, 2005). In Emily's socio-economic context, one must also consider the financial implications of assistive technology and the long term implications for maintenance and upgrades.

Assistive technology and environmental adaptations have formed a vital role in Emily's case due to her physical limitations. The following table briefly shows how each device has enhanced the independence and participation in meaningful occupations.

Table 4.3.11: Emily's assistive technology and how it has enhanced independence and participation in meaningful occupations

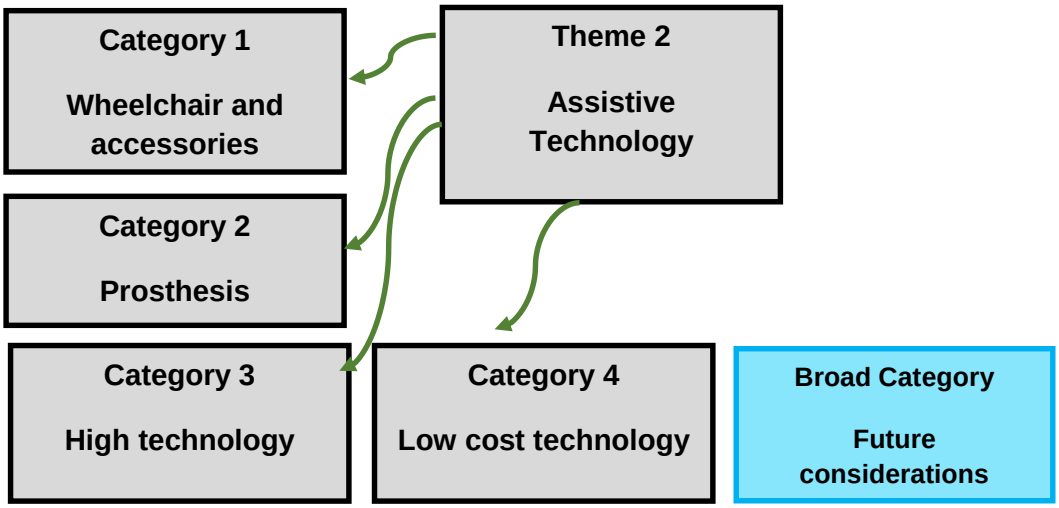
Assistive device	ADL/IADL	Play	Social	School
Motorised wheelchair(s)	☺	☺	☺	☺
Tablet		☺	☺	
Laptop				☺
Manual bilateral pointers				☺
Universal cuff	☺			☺
Toilet inner seat	☺			
Bumbo chair	☺	☺	☺	☺

The Manual prosthesis and SMARTNAV system has been left out of the above table due to abandonment of the devices.

Assistive technologies can diminish the impact of disabilities and allow children improved alternatives to participate (Gelderblom & deWitte, 2002). Occupational therapists who work with children are ideally suited to evaluate and determine appropriate match of AT tools to the child and should become familiar with the

continuum of AT options. Advances in AT allow many devices to grow and expand with the child during the developmental years and into adolescence and adulthood and as they undergo transition into higher education and community work experiences. It is the responsibility of the occupational therapist to provide a health promoting balance between occupational roles and activities consistent with the child's valued goals and interests, as well as the demands of society (Behrmann, 1984).

4.3.2.6. Broad category: Future recommendations



From the transcriptions. It was highlighted that proper planning and fundraising would be key in acquiring assistive technology across Emily's lifespan and this would continue to enhance her level of independence for many years to come.

Smaller low technology assistive devices have been mentioned previously under *Theme 1: Category 1: ADL/ADL Broad Theme: Future recommendations.* When taking her occupations into consideration, her support and barriers in terms of her condition, personality and environments, the following assistive technology forms part of her future course recommendations *(discussed below):*

- Myo-electric prosthesis
- 3D printed hand
- Voice operated typing system
- Elevating platform wheelchair
- Adapted car

INTERVIEW DATA:

- *"Well I think obviously the first thing is **funding**. So that we can provide her with the correct wheelchair at the right time, her means of study, her technology that she is going to need…"*
- *"I am very excited to see where this where this goes and what you are going to do and obviously with your assistive devices, so I think it needs **good planning**. And some planning might take place overseas because I don't think South Africa has the capacity."*
- *"I think she really needs the **voice activated laptop** that she can use for academics, writing or even communicating via SMS or email..."*
- *"What I love about Nick's (Australian motivational speaker with TAS) **wheelchair**, and I would love something like that for Emily, he's got a platform that goes, imagine a normal wheelchair, but the base, the seat part, goes up and down, so he can press a button, it would come down, she can get onto it and literally lift herself up so that she can be completely independent in a wheelchair. Someone doesn't have to put her in or take her out."*
- *Even on this new wheelchair that she gets, if someone can build an attachment , a little lift, where she can sit on, press a button and it goes up, and the same with coming down. A **simple elevating platform**."*

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below:

Myo-electric prosthesis	As mentioned previously, Emily is a good candidate for a myo-electric prosthesis due to her optimal muscle strength. This would assist her in the future with finer movements and dexterity in performing ADL like grooming, dressing, feeding or IADL like meal prep or laundry.
3D printed hand/arm	3D printed arms and hands are emerging as an alternative to myo-electric prostheses. It may pose as a more affordable option for

	Emily to enhance her participation and independence in the above mentioned occupations.
Voice operated typing system	As mentioned numerous times in the interviews, a voice operated typing system could enable her to participate in academic activities (oral examinations), prevent postural deterioration or injuries, enhance social inclusion (sms, emails, social media) and assist in independent living skills (online shopping, financial management)
Elevating platform wheelchair	Although Emily can transfer herself with great effort from the floor to her smaller wheelchair, a wheelchair with a motorised elevating seat poses a more optimal solution for her to minimise effort and injury. The researcher may need to search outside the borders of South Africa for such a device or approach an engineer for collaboration. 
Transport/ Adapted car	Future considerations of her case will need to focus on the accessibility to private transport or independent driving skills with a uniquely customised car. An Occupational therapist will usually consult with adapted driving program specialists unless he or she has had specialised training in driving adaptations and instruction.

In theme 2, various assistive technology relevant to Emily's case was discussed. A discussion of her therapeutic intervention will follow in the following theme.

THEME 3: THERAPEUTIC INTERVENTION

For this theme, two categories were identified and it will be presented in conjunction with representative quotes from participants as well as direct observations.

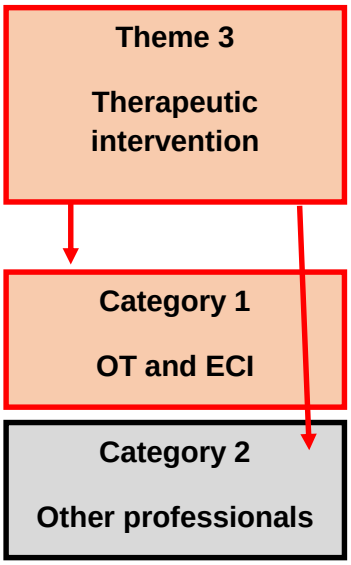


Figure 4.3.2.3: Theme 3 and categories

An analysis of the data and in conjunction with the interview questions and direct observations, this theme entails the various therapeutic intervention relevant in Emily's case, the opinions and perceptions of how of how occupational therapy, early intervention and other professionals have impacted her well-being and growth.

4.3.3.1. Category 1: Occupational therapy and Early Intervention

INTERVIEW DATA:

Emily has been exposed to occupational therapy intervention since the age of 1 year old. The role players were asked whether they thought that OT has played a vital role in Emily's life and aspects of development.

- *"Very. Especially in the **beginning**, it gave her more **coping skills**. You teach her all the **sensory** things you do with her. And **fun** things just in a safe environment. And just getting her to be more **community** participation or getting her to be more **social**. And also the **emotional** aspects, its good just having someone there to support her and someone she can talk to."*
- *"I definitely think it has helped a lot! The OTs involved have done a great job. Yes, definitely very important that OT was started at a **young age**. I think it would have been terrible for her if we started now and up until now she's just been running around and nothing happened."*
- *"Definitely, without a shadow of a doubt. I can clearly see that. It has given her a means and a way to do what she knows she can do in a **functional way**. The three OTs she's had in the while that I have known her, has done their best to make sure that she retains her **independence.** And all three of you have made sure that she leads you, not you lead her. And going back to the emotional part of it, you really have to zoom into her specific circumstances which is very different. She is abandoned, this is not her home country, she lives with a foster mom, if she was living with her family it would be one thing, she is living with a single mom who has many other foster children…So I think the OT has really helped her become more **confident**."*
- *"Through the therapy you **push her boundaries and you push her limits** to make her function. Take her out of a therapeutic environment, and she would be very prone to just let those care givers take care of her.*
- *"I would say so yes. Yes, rather **earlier intervention** than later."*
- *"I think the role of an occupational therapist has a large part to play in helping **future plans and independence**… I really do think **early intervention** is key, we see it here (at school) if they are too old then they have fixed habits so the sooner the better."*
- *I think that OT has enabled her to be more **independent in daily living skills** from a very early age and with more training and skill development through the different phases of her life…she will learn to adjust to her daily routines and challenges. I think OT has provided her with a platform for success…I think she will always need help and support however…"*

DISCUSSION: Occupational therapists are important members of the **early intervention** team and can provide services in various settings using one of several models of intervention (Case-Smith, 2005 pg 780). OT's promote a child's independence, mastery and sense of self-worth and self-confidence in their physical, emotional and psychosocial development. This enables families and caregivers to improve children's functioning within their environments. Case-Smith (1998) identified general goals of OT intervention in early chiildhood:

- To facilitate change in a child's developmental function
- Interpret and redefine behavioural responses
- Compensate for and adapt to the effects of a disability
- Provide support to family members

From the quotes above, a summary of the **perceived benefits or outcomes** of occupational therapy and early intervention in Emily's case include:

- Enhanced emotional, coping skills and confidence
- Independence and enhanced functionality in daily living skills
- Improved social and community participation
- Enhanced fun and playful engagement

Emily received her OT intervention in **natural environments** (home, immediate community and school). Natural learning environments are where planned and unplanned, structured and unstructured, and intentional and incidental learning experiences occur (Dunst, Trivette, Humphries, Raab, & Roper, 2001). Literature on early intervention supports service delivery in natural environments (Sheldon & Rush, 2001). Natural intervention strategies use incidental learning opportunities that occur throughout the child's typical activities and interactions with peers and adults, follow the child's lead and use natural consequences. In Emily's case, providing intervention for her in her natural environments was key at the therapist could make appropriate suggestions for environmental modifications, perform caregiver training and get a proper feel of her unique context and what her daily routines and activities entail. Researchers who studies acquisition of functional motor, social and communication skills have supported intervention strategies that take place in real-life contexts.

Children also tend to be more comfortable in natural environments and show greater responsiveness and interaction with the therapist (Bruder, 1993).

OBSERVATIONAL DATA:

Data from direct observations is portrayed according to the OTPF (Occupational Therapy Practice Framework) seen below. Intervention was received at home, school and community.

Table 4.3.12: Occupational Therapy Intervention according to the Occupational Therapy Practice Framework

TYPES OF OCCUPATIONAL THERAPY INTERVENTION
Occupations and Activities – Occupations and activities selected as interventions for specific clients and designed to meet therapeutic goals and address the underlying needs of the mind, body, and spirit of the client. To use occupations and activities therapeutically, the practitioner considers activity demands and client factors in relation to the client's therapeutic goals, contexts, and environments
Occupations – During the course of OT intervention with Emily, daily life activities have been used in therapy to assist in greater independence and functional skills. Examples include: • Practicing to brush her teeth • Practicing to climb on and off her bed • Practicing feeding with a universal cuff and spoon • Practicing making her own sandwich • Functional mobility (rolling, sitting balance, hopping on her buttocks, pivoting on her buttocks) was facilitated and encouraged through play and functional daily tasks • Facilitating playfulness with siblings and peers • Community outings i.e. zoo, mall, park • School related tasks
Activities – Many different play activities were used in Emily's intervention process to support the development of performance skills and performance patterns to enhance occupational engagements. Activities are often components of

occupations and always hold meaning, relevance and perceived utility for clients at their level of interest and motivation.

Developmentally appropriate play activities that were in Emily's interest and motivation level we chosen and presented. Examples included:

- Sensory exploration of textures, movement, visual, music, taste and smell i.e., sandpit, water, ball box, swings, slides, trampolines, bean box, snow box, play dough etc.
- Book exploration
- Concept formation (shapes, numbers, colours, animals)
- Drawing, painting, arts and crafts
- Block building, ring stacking, puzzles, designs
- Threading, clay exploration
- Music, movement and dance
- Dress up, pretend play, fantasy and dramatic play
- Social play and groups

Structuring of play materials and grading was of vital importance to provide success for Emily. It also raised her confidence and self-esteem and encouraged her to keep challenging herself further.

Assistive Technology and Environmental Adaptations

Assistive technology and environmental adaptations has formed a vital role in Emily's case due to her physical limitations. *Described in more detail in Theme 2.*

The assistive technology she has received include:

- Manual bilateral upper limb prosthetic arms (discontinued use)
- Bumbo seat
- Adapted Madiba buggy motorised wheelchair
- Universal cuff
- Tablet
- Adapted Pacer Lite motorised wheelchair
- Toilet seat inner tube

- Big Keys computer system at school (discontinued use)
- SMARTNAV eye controlled computer system at school (discontinued use)

The environmental adaptations include:

- Smaller bed (lower to the ground)
- Clothing adaptations
- Wheelchair ramps

Education & Training

Caregiver training was performed in terms of enhancing Emily's independence in ADLs and play activities. Discussion with her immediate family were held in terms of available resources, assistive devices and possible school placements. Further training was held for the school therapists and teacher with regards to already established skills using assistive devices, classroom adaptations and the need for a facilitator.

Advocacy - Efforts directed toward promoting occupational justice and empowering clients to seek and obtain resources to fully participate in daily life occupations. The outcomes of advocacy and self-advocacy support health, well-being, and occupational participation at the individual or systems level.

Emily has been advocated for since birth by her foster mother and other key role players in her life. Great efforts have gone into raising awareness of her condition and to inspire others with her astounding determination and will power. Financial resources have been advocated for through sponsorships using motivational letters. The researcher has contacted private businesses, radio stations, magazines, private individuals who have assisted in funding her assistive devices and schooling as well as her clothing adaptations.

The researcher will continue to advocate for her through the course of her life and plans to open a Foundation for her and others like her to assist in the acquisition of the many assistive resources they will need throughout their lifespan.

Groups – Functional groups, activity groups, social groups used in schools or the community to explore and develop skills for participation.

Emily receives group OT sessions at school with the emphasis on playful and social engagement with peers, games with rules and educational activities.

DISCUSSION: The goal of occupational therapy intervention provided to children and families is to enable childhood participation. Occupational therapists collaborate with the child and family to identify occupational performance goals and provide appropriate interventions to achieve these goals. This requires understanding and assessment of performance (doing). This may also require assessment of the person (body structure and function level), the environment (barriers and facilitators), and an analysis of the occupation. Some interventions may need to focus on impairment level, but always in the context of occupational based goals (Occupational Therapy Australia National Paediatric Taskforce, 2016).

The steps of the ***occupational therapy process*** involved in Emily's case comprises of the following:

- Developing a positive therapeutic relationship.
- Analysing and identifying the occupational roles, strengths, needs, and challenges necessary for children to engage in their everyday activities and participation in life roles *(Theme 1: Category 1, 3, 4, 5)*
- Evaluating factors affecting occupational performance activities in the contexts and environments in which those activities and occupations occur, including *(Theme 1: Category 2):*
    - Client factors, including body functions and structures such as neuromuscular, sensory and cognitive systems.
    - Performance skills and communication/interaction skills.
    - Cultural, physical, virtual, social, temporal, spiritual contexts or environments that affect performance
- Planning appropriate occupation-based intervention to promote occupational performance through *(Theme 3):*
    - The ***establishment, remediation, or restoration*** of physical, cognitive, neuromuscular, sensory functions, and behavioural skills that have not yet developed or are impaired.
    - The ***compensation, modification, or adaptation*** *(Theme 2)* of activity or environment to enhance performance and independence.
    - The ***promotion*** of health and wellness to enable or enhance performance in everyday life activities.

    - ***maintenance and enhancement*** of capabilities without which performance in everyday life activities would decline;
    - and ***prevention*** of barriers to performance, including secondary disability prevention
- Evaluating outcomes. Outcomes of intervention need to be measured and reported in relation to the goals set utilising standardised outcome measures or clinical observations.

When planning intervention procedures, the therapist must consider the child's characteristics / factors and performance skills and patterns in relation to the context and the demands of the activity. OTs need to be sensitive to parents' and other caregivers' needs and concerns. They must listen to and reassure these individuals, involve them in making observations and engage them in problem solving.

In Emily's unique case, it proved highly important and beneficial to make use of ***clinical reasoning skills***. This is when a therapist considers multiple perspectives of the child and family including their values, interests, priorities and contexts. Through this reasoning process, used initially and continuously while working with a child, the occupational therapist analyses the relevant dimensions of the case to arrive at an optimal solution. These decisions are also often made in teams, adding to the complexity of the process (Case-Smith, Occupational Therapy for Children, 2005).

The occupational therapist forms a ***therapeutic relationship*** with a child that encourages and motivates. The OT is invested in the child's success and highlights to the child his or her strengths and any attempt of effort in an activity or occupation. The establishment of trust is the most important so that when challenges are posed, the child feels confident to take risks, but also soothed if failure occurs (Case-Smith, 2005).

By using the PEOP model (described in Chapter 2) as a guiding framework for this case, analysis of **occupations, client factors and environments** were considered in planning for intervention. By looking at one's client through the framework of this model, one learns to look at a client holistically and in totality, taking intrinsic and extrinsic factors into consideration and measuring how they are affecting occupational performance and well-being.

Approaches to intervention:

Approaches to intervention are specific strategies selected to direct the process of evaluation and intervention planning, selection and implementation on the basis of the client's desired outcomes, evaluation data and evidence. See tables below for specific examples in Emily's case for 1) Client factors/Performance Skills, 2) ADL, 3) Play, 4) Social participation and 5) School participation.

- **Create, promote:**

This is an intervention approach that does not assume a disability is present or that any aspect would interfere with performance. It is designed to provide enriched contextual and activity experiences that will enhance performance for all people in the natural contexts of life. OT intervention for Emily incorporated this approach in the sense of promoting normal, everyday interaction with activities and in her environments e.g. taking her on an outing to the movies and a restaurant thereafter, a trip to the zoo with her siblings, playing on a trampoline or jungle gym in her garden at home or at a birthday party. In this sense, purposeful interaction and quality of life was promoted.

- **Establish, restore (remediation, restoration):**

This intervention approach is designed to change client variables to establish a skill or ability that has not yet developed. This approach was used in Emily's intervention. Examples include: practicing to pivot in sitting, practicing to move forward on her buttocks, establishing concept formation of shapes, numbers, and colours in playful activities, becoming independent in feeding or using her tablet.

- **Maintain:**

This intervention approach is designed to provide the supports that will allow clients to preserve the performance capabilities that continue to meet their occupational needs. The assumption is that without continued maintenance intervention, performance would decrease, thereby affecting well-being and quality of life. In Emily's case, a large maintenance component is that of her assistive devices especially her wheelchair which provides her with increased functional mobility, social

interaction and independence. Further examples are maintaining her wheelchair ramp for ease of access for community outings, maintaining her tablet and wheelchair batteries so that she can have instant access to their use.

- **Modify (compensation, adaptation):**

This approach is one of the main approaches used in Emily's intervention due to her severe physical limitations. As mentioned previously, her assistive devices act as compensations strategies for skills that she isn't able to perform without the use of fully functioning limbs. Activities are modified in her case and learning at school will follow an adapted curriculum (more oral assessments, computer based assessments etc.).

- **Prevent:**

This approach is designed to address the needs of clients who are at risk for occupational performance problems. Examples of the use of this approach for Emily include: consultations with a seating specialist to assess the risk of spinal complications with prolonged sitting in her adapted wheelchair, emphasising the importance of bilateral activities to prevent the risk for scoliosis or muscle / joint problems on a unilateral side.

Table 1.3.12.1: Approaches to improving performance in specific client factors/performance skills

Approach	Appropriate Frame of Reference	Example
Create, promote	Ayres Sensory Integration PEOP MOHO Client-centered	Promotion of *sensory processing skills* through active participation from Emily in a playful setting where the therapist creates opportunities for adaptive responses using 'just right' challenges. Promotion of *intrinsic motivation* in Emily by providing activities that are in her interest and meaningful to her.
Establish, restore (remediation, restoration)	Developmental Biomechanical Ayres Sensory Integration Learning	Establishing the ability to *pivot and 'walk'* forward on her buttocks to enhance her mobility. Establishing her *concepts formation* of colours, shapes and numbers through age appropriate educational games and tasks. Establishing the *dexterity* of holding a pencil crayon between her left stump and neck to draw or colour in a picture.
Modify (compensation, adaptation)	Compensatory	Modifying her learning apparatus at school by using assistive technology to compensate for her lack of *motor control.*
Prevent	PEOP MOHO	Consultations with a seating specialist to prevent complications of her *posture* due to prolonged sitting in a wheelchair. Prevention of *emotional distress and illness* by providing support and allowing time for adapting to change.

Table 2.3.12.2: Approaches to improving performance in Activities of Daily Living (ADL)

Approach	Appropriate Frame of Reference	Example
Create, promote	PEOP MOHO Client-centered	Promotion of *functional mobility* by encouraging movement and play in her natural environment.
Establish, restore (remediation, restoration)	Developmental PEOP Functional skill training	Establishing independence in *self-feeding skills* by practicing with graded activities i.e. no utensil initially, then utensils. Establishing independence in *tooth brushing skills* by practicing with graded assistance i.e. much assistance to little assistance.
Maintain	PEOP	Maintenance of assistive technology like her power wheelchair to continue to assist her with *community mobility.*
Modify (compensation, adaptation)	Compensatory	Adapting the task method of *self-feeding* by providing her with a universal cuff. Adapting her clothes so that *dressing* tasks are easier for caregivers.
Prevent	PEOP Environmental	Prevention of injuries during independent *self-care and mobility* pursuits by making sure the home environment is free from sharp objects or other sources of danger.

Table 3.3.12.3: Approaches to improving performance in Play

Approach	Appropriate Frame of Reference	Example
Create, promote	PEOP Ayres sensory integration	Promotion of *playfulness and spontaneity* by child-led play in her natural environment.
Establish, restore (remediation, restoration)	Ayres sensory integration Developmental	Establish *pretend play abilities* by using age appropriate play activities i.e. teacher-teacher, princess-princess. Establish *constructive play abilities* by using graded age appropriate activities i.e. blocks, towers, Lego
Modify (compensation, adaptation)	Compensatory	Modify Emily's ability to play *hide and seek or races* with her siblings by using a powered wheelchair for enhanced mobility and freedom. Adapt the task method of *climbing up a slide* so that Emily can play with her peers more independently. Provide adaptations in the form of physical assistance so that Emily can experience the vestibular and proprioceptive input on a trampoline without getting injured.
Prevent	PEOP Client-centered	Prevent *occupational dysfunction in play* by providing as many natural and age- appropriate experiences of play as possible.

Table 4.3.12.4: Approaches to improving performance in Social participation

Approach	Appropriate Frame of Reference	Example
Create, promote	PEOP MOHO	To create opportunities for Emily to partake in *social and community outings* i.e. zoo, park, mall, beach.
Establish, restore (remediation, restoration)	Developmental Client-centered Functional	To establish social skills and inclusion by proving *group therapy* sessions at school. To establish *social competence* through the stimulation of normal developmental play activities i.e. cooperative play, games with rules, pretend play
Maintain	PEOP	To maintain *social competence* by providing a 'buddy' system at school – an able bodied child that can assist her in playground pursuits.
Modify (compensation, adaptation)	Compensatory	To modify her *social inclusion opportunities* by providing Emily a wheelchair to use at break time on the playground.
Prevent	PEOP	To prevent *social exclusion* or bullying at school.

Table 5.3.12.5: Approaches to improving performance in School

Approach	Appropriate Frame of Reference	Example
Create, promote	PEOP MOHO	Promotion of *school inclusion* by providing means for Emily to participate in school sports days i.e. wheelchair races or extra-curricular activities i.e. dance classes.
Establish, restore (remediation, restoration)	Developmental Learning Ayres Sensory Integration	Establishing *school readiness* by providing early intervention focused on client factors and performance skills, play, self-care and social skills. Establish adequate *attention and arousal levels* in class by providing sensory integrative experiences in early intervention.
Maintain	PEOP Client-centered	Maintain *emotional well-being* by providing continuous support and encouragement.
Modify (compensation, adaptation)	Compensatory	Modifying her learning at school by using assistive technology so that she can optimally take part in her *curriculum.*

Outcomes of intervention:

Outcomes are the end result of the occupational therapy process: they describe what clients can achieve through occupational therapy intervention. The outcomes of occupational therapy can be described in two ways; some outcomes are measurable and are used for intervention planning, monitoring and discharge planning. Other outcomes are experienced by clients when they realise the effects of engagement in occupation and how it positively effects their habits, routines and roles. The following outcomes are described as per Emily's case:

- **Occupational Performance:**

Occupational performance can be defined as the act of doing and accomplishing a selected action. This results from the dynamic interaction among the client, context and activity (AOTA, 2014).

Improvement: outcomes targeted when a performance limitation is present i.e. Emily being able to swim with her siblings with the correct structuring and assistance from the therapists.

Enhancement: outcomes targeted when a performance limitation is not currently present i.e. enhanced confidence and competence of Emily in social and public situations.

- **Prevention:**

Education of health promotion efforts designed to identify, reduce or prevent the onset or incidence of risk factors, unhealthy conditions and injuries. Examples in Emily's case include prevention of spinal complications with frequently reviewed seating systems, education about her condition and awareness of her abilities, safety precautions for feeding and floor mobility to prevent injuries.

- **Health and Wellness:**

Health is the state of physical, mental and social well-being. Wellness is more than just a lack of disease symptoms. Examples of this outcome in Emily's case include social inclusion in a school environment, the ability to independently manoeuvre her

wheelchair at a community event, participation in play and school activities like horse-riding, and jungle gym exploration.

- **Quality of life:**

This is the dynamic appraisal of the client's life satisfaction (perceptions of progress towards goal), hope, self-concept, health and functioning. Examples in Emily's case include feelings of satisfaction when mastering a new skill like self-feeding, a greater self-concept when able to play hide and seek with her friends in her wheelchair, finding emotional balance after a transition period into a new context like school, feelings of acceptance and inclusion in the home, school and community.

- **Participation:**

This outcome can be defined at the engagement in desired occupations that are personally satisfying and congruent with expectations within the culture. An example of this in Emily's case is the family enjoying a vacation to the sea in their adapted vehicle. A further example is her participation in a school sports day by using her wheelchair to enable her to participate fully.

- **Role Competence:**

This is the ability to effectively meet the demands of roles in which the client engages. Examples include; the ability to eat dinner with the family at a restaurant, the ability to perform schoolwork on her tablet, the ability to be in a social group interaction at school / home.

- **Occupational justice:**

This is the access to and participation in the full range of meaningful and enriching occupations afforded to others. Examples of this in Emily's case include her inclusion at school and in all desired extra-curricular activities, her inclusion at home in all daily activities that she wishes to be more of a role player in, providing her with access to updated and effective assistive technology that will assist her in greater participation.

4.3.3.2. Category 2: Other professionals (or extra-curricular activities)

Looking at Emily's case holistically, other professionals or alternative interventions should also be considered to make sure all her needs are being met. As mentioned in a few themes above, it has been vital for the occupational therapist to work with other teams members in the process of intervention for Emily.

INTERVIEW DATA:

- *"Every now and again she goes and sees the **school psychologist**, especially after Susan* (foster sibling – name changed for confidentiality) died, she loves the psychologist, so every now and again I take her and then they play.*
- *"I think that **psychology** will be important through different stages of her life, like when she becomes a teenager. And because she is so intelligent, she is very much aware of you know if she can't do something, or maybe because she looks different. Or she will come to me and say she is scared, but then I'll say to her, but you can do it. My approach is I always let her try first. If she doesn't get it right her way then I try and show her a different way…"*
- *"She was seen here by our **psychologist** and by the time she reaches teenage years I think she will need guidance later on."*
- *"She does **horse riding**, she does **dance mouse** and she **swims**. I know she loves swimming but it also quite a danger, and she really needs to be I think to be able to do it independently will take a few years of practice."*
- *"She's a very clever little girl so I think **extra reading classes** will be very helpful."*
- *"Not so concerned about the **physiotherapy**, because an **OT** would be viewing her in that light anyway because you are talking function and you would be looking at body anyway. I think **play therapy** would be good for her, from a psychological view and emotional view, just to make sure everybody is on track with that. I think **music therapy** would be great for her. She is also doing **horse therapy**. I would love to when she is older to see her in an **art therapy**, I would love to see what she creates, not what everybody is drawing, but what she creates, put music on and leave her to herself without intervention. I would love to see what would come out of her."*

DISCUSSION: The following professionals or alternative therapies / activities have or may prove beneficial in Emily's case:

- **Psychology/play therapy:** these services have and will continue to be beneficial to Emily's emotional well-being and to support her through new life phases and transitions.
- **Prosthetist/Orthotist:** these services have and will continue to be beneficial to Emily by assisting in maintaining current assistive devices and to collaborate and consult on future AT endeavours.
- **Hippotherapy:** these services have and will continue to be beneficial to Emily in providing extra support for social interaction, play and leisure as well as developmental stimulation.
- **Art Therapy:** this is a possible future pursuit to explore to assist with expression of feelings.
- **Orthopaedic surgeon:** Emily has had 2 bone shaving operations due to overuse of her left stump. It is a future consideration to perform a bone lengthening procedure with an external fixator in the future to allow for greater use of her left 'arm'.
- **Extra-curricular activities:**
    - **Reading:** Due to the fact that Emily's strengths lie in her mental, perceptual and cognitive abilities, reading could be an activity and hobby that brings her much joy in the future.
    - **Dance Mouse:** this activity has and will continue to prove to be a fun and non-limiting activity for Emily. The dancing provides her with physical spontaneity, social inclusion and fun.
    - **Swimming:** Emily loves swimming but requires maximal external support in a swimming pool currently. It is our hope to spend more time on swimming lessons in the future. She loves to be on the beach and ventures into the shallow waves alone.

In Theme 3, her overall therapeutic intervention was discussed, highlighting the impact of occupational therapy and early intervention as being key to her growth and development, as well as the types of intervention, approaches to intervention and outcomes of intervention. Psychological services and alternative therapies were

highlighted to look at her furthered emotional development and support. A discussion of the child and disability rights applicable to her case will follow in the following theme.

THEME 4: CHILD AND DISABILITY RIGHTS

For this theme, two categories were identified and it will be presented in conjunction with representative quotes from participants.

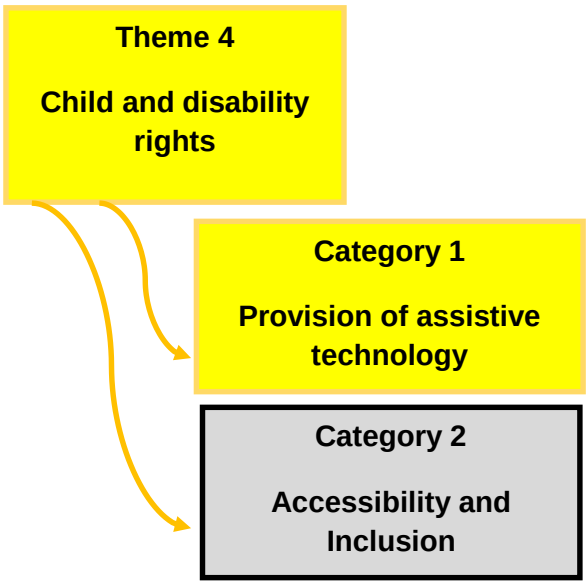


Figure 4.3.2.4: Theme 4 and categories

An analysis of the data and in conjunction with the interview questions, this theme entails the various child and disability rights relevant in Emily's case, the opinions and perceptions of the various role players in her life in terms of her access to assistive technology and inclusion to school and community environments. The Gauteng Provincial Government's approach to disability rights is informed and guided by the Integrated National Disability Strategy (1997), the UN International Convention on the Rights of Persons with Disabilities (Article 23) and relevant national legislation and regulations such as the Employment Equity Act (No. 55 of 1998) and its Code of Good Practice on the management of disability in the workplace as cited by Gauteng Provincial Government (2010). Two important principles relevant to Emily's case include:

- The **necessity for service delivery** for people with disabilities that is inclusive, integrated, barrier-free and functional for their specific needs.
- The **promotion of independent living**, social inclusion and independence among people with disabilities is crucial to their inclusion into society.

4.3.4.1. Category 1: Provision of assistive technology

INTERVIEW DATA:

- *"So I know that they (government) provide things like **simple or general things** like wheelchairs, so I do feel that they provide non customized things, like the odd wheel chair, but they don't provide electronic wheelchairs and if they do it's a huge fight, so for Emily, they are not equipped to provide for someone like her. And also it's a **very long process**, and you almost need to have someone driving the process, if the hospital doesn't have a doctor or therapist that driving the process then it's not going to happen…And I think, if I look in the future at all the assistive technology that she is going to need, all the high technology she will need is definitely going to come from **private sponsors**."*
- *"I think everything is **written in paper but in practice I am not so sure**. Obviously I deal with a lot of disabilities and there is more financial support in the private sector.*
- *"If I look at what the government does… I know that they try their best but their best is not enough, in a nut shell, money is divided for schools that is in most need and they have supplied us (school) with a lot. A few companies would discount some products on tender. We have also received some donations from private sectors. I think at the moment it is **50/50 with the public and private sectors.***
- *"With a motorized wheelchair you need to look at the **regular maintenance** but we don't get that service (from government)."*
- *"It's been really disheartening to realize that children with disabilities are really **marginalized.** Dealing with government as much as I do and going to inclusive conferences, I feel over the last 20 years they have taken a complete back step. I do not believe that the government is doing enough. But at the end of the day the onus is on the government to support Emily, but she's **foreign**…it has been an issue, because the school wanted to sponsor her a new wheelchair but because of that they couldn't…And the thing is funders are running out of money…and she is going to need **constant funding**, cause wheelchairs needs to be replaced, tablets, laptops needs to be replaced.*

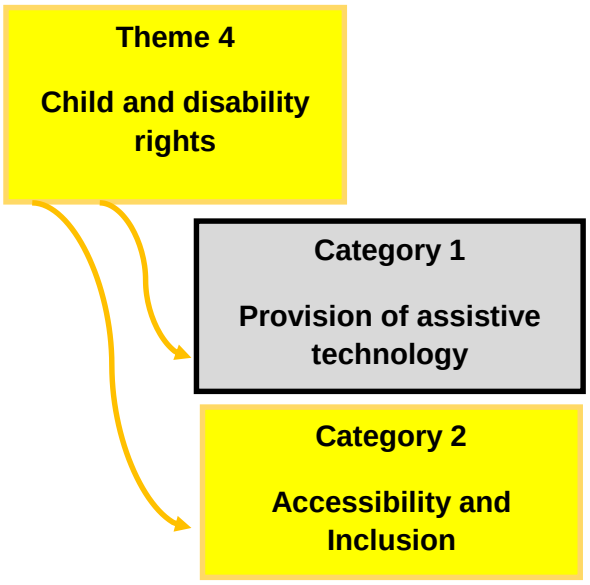
- *"I don't think the government departments are always **aware** of all the interventions that we guys implement as well, we work mostly on donations from outside and things like that. I don't think they are **fully aware of the needs** of our children especially with assisted devices and things like that.*

DISCUSSION: As stated throughout Chapter 4, a strong need for assistive technology comes to the fore in Emily's case. Assistive technology has assisted in her in successful engagement in occupations like play, social and school participations and will continue to provide a means to live more independently through all the phases of her lifespan. Emily's condition of TAS requires mostly high technology including motorized wheelchairs, laptops, tablets, voice operated typing systems, adapted cars and other powered devices for ADL and IADL participation. Opinions from the interviews reach consensus that the South African government does seem to try to align its policies with the needs of children and adults with disabilities, but falls short due to their lack of awareness of the holistic needs of such children as well as their application of principles to all context and conditions in South Africa.

Government hospital Occupational Therapy and Physiotherapy departments are often under resourced both in staff and assistive devices. Assistive devices are often general and need to be customized for unique conditions like TAS. The processes of procurement and delivery are lengthy and the specialized skills of therapists to customize such devices may be lacking in some cases.

The aspect of constant funding in Emily's case is highlighted throughout this chapter, and for her case, it is the private sector that has enabled the provision of her high technology. She will require a stream of funding throughout her life in order to maintain her current devices and upgrade when necessary. Her special needs school is sponsored both by government and private entities and is one of the few schools in the Gauteng area that caters for children with disabilities. The major barrier in Emily's case is that she is foreign and therefore she isn't able to benefit from any of the government funded or sponsored amenities at the school.

4.3.4.2. Category 2: Accessibility and Inclusion



INTERVIEW DATA:

- *"We looked at a smaller school…a **mainstream private** school for Emily…it just wouldn't work, they just **don't have the technology**. I think that everyone says she should be included in all schools, but those schools just aren't equipped for a child like her. And as it is I have to find her a **facilitator** to go with her to school. I think she is in the **best school environment**."*
- *I don't think mainstream is an option at this stage…I do think she is in the right school, especially with the **smaller classes**. Next year in Gr 1 she will have a private facilitator…Because the pace is much quicker and faster, and the teacher won't always get to her and assist her in a way that she needs…they won't be able to attend to all her needs, not just academically, but her **physical basic needs."***
- *"I would love to see her in a mainstream inclusive school but I think it would be very difficult to get her in, because she doesn't have the technology and she is also not trained in the technology. So I think a special needs school for now, to get her fluent in the technology and get her successful in it to get her into an inclusive school, but **she will always need an assistant with her**…"*

- *"Maybe in high school you can have that talking device and it can be balanced on her wheelchair, **school would have to be completely wheelchair friendly**, which is also a problem."*
- *"Yes, once her technology is streamlined, once she is coping emotionally…and then the school itself will obviously need to be **accessible** with ramps etc. Most high schools aren't really accessible…"*
- *"No, firstly, there are no places (government housing) for children not even like Emily, any form of disability, secondly, Emily is not a South-African, and she is a Zimbabwean so they won't help her. Although I am supposed to get a grant for her…I haven't yet. And when she is 18 she gets deported. That is the rule for every single child…that is the biggest gap in our **social welfare system**."*

DISCUSSION: *'Inclusive education' is based on a value system that recognises and 'celebrates diversity arising from gender, nationality, race, and language of origin, social background, level of education achievement or disability. This implies that all pupils have the right to attend the neighbourhood school, which is important for social reasons. Inclusion means that all teachers are responsible for the education of all children and the curriculum must be adapted to cope with this diversity'* (Lomofsky & Lazarus, 2001 pg 305).

When first searching for appropriate schooling for Emily, a mainstream private school approached her foster mother and extended an invitation to discuss possibilities of her attending the school. A short amount of time passed before they realised that they couldn't accommodate her for a variety of reasons including inaccessibility to the built environment of the school, inability to address her physical needs and limitations for toileting and curriculum and poor knowledge and awareness of what assistive technology could assist her. As noted in *Theme 1: Category 5: School Participation*, her current special needs school is proving to be a better fit for her unique needs.

As much as mainstream school are trying to be inclusive and accept and accommodate children with disabilities, South Africa just isn't ready to cater for such children so that their educational experience match those of children without disabilities. We also know that even though Emily has the cognitive, mental and

perceptual skills to cope with mainstream curriculum, it is her physical limitations and context that forms a barrier and may affect her academic trajectory in the years to come. Only time will tell.

According to the Gauteng Provincial Government approach to disability rights (2010), the following constraints and recommendations are laid out in terms of service provision for children with disabilities. There are factors, in addition to the historical legacy of apartheid, that constrain the provision of services for children with disabilities in South Africa. These include attitudes of society and service providers, gaps in legislation, policies and budgets.

- ***Attitudes*** - South Africa does not yet have a standard / nationally accepted measuring tool in line with the ICF (WHO, 2001). Estimates of child disability prevalence generated from various sources are therefore not directly comparable because of different definitions of disability and methods of data collection. Adults and children with disabilities are frequently viewed by society as objects of pity and deserving only of charity.
- ***Policies and plans*** - Inadequate alignment of policies to plans of Departments continues to undermine the pace of service provision. There are numerous policies in place that are intended to fulfil government's constitutional and legal obligations towards children with disabilities. However, these have not been consistently linked to national and provincial planning processes. There are also difficulties related to monitoring of budgets for children with disabilities. The lack of specific information on service provision and related budget allocations appears to be a major barrier to the monitoring and protection of the rights of children with disabilities.
- ***Difficulties around funding of NGOs*** - NGOs working in the disability sector have expressed concerns regarding accessing government funding. Some organisations have reported that even where a service level agreement is in place, funding does not always come through as agreed, and difficulties extend beyond the extent of funding and funding procedures, to a lack of understanding regarding the nature of services required for children with disabilities.
- ***Access to a disability-friendly built environment*** - Despite increasing awareness of the need for environmental accessibility for adults and children

with disabilities, many government services are not disability friendly, and severe challenges with the built environment exist.

- ***Lack of co-ordination and fragmentation of services*** - Challenges include lack of synergies between policies, limited consultations between government and NGOs, tendency to work in silos even within departments, weak mechanisms for co-ordination, disconnect between national and provincial levels, and the lack of adequate norms and standards for services

The following are recommendations of how services can be utilised:

- **Conditional grants** - Opportunities exist around amending the regulations on current grants to prioritise children with disabilities. In addition, opportunities to design conditional grants for the specific needs of children with disabilities, such as for rehabilitation and the provision of assistive devices, should be explored.
- ***Service delivery environment -*** There is a need to create a sustainable environment for service delivery partners (non-profit organisations or NPOs) through "capacity-building, collaboration and agency". This requires the development of an effective service delivery model that ensures good planning, adequate funding, improved co-ordination and appropriate monitoring of implementation.
- ***Partnerships and co-ordination*** - Partnerships between government and NGOs, different spheres of government and NGOs in the disability sector (disabled people's organisations) need to be strengthened in order to provide more effective and efficient services for children with disabilities.
- ***Changing attitudes and providing community-based support*** - Changing attitudes towards children with disabilities is an ongoing challenge. An important part of this challenge is to provide the necessary support to parents, caregivers and community members who play a critical role in the lives of their children with disabilities. Such support should include tracking developmental milestones, teaching independence and caring for children.

In theme 4, the relevant child and disability rights for her specific case were highlighted in terms of provision of assistive technology and accessibility and inclusion to her home, school and community contexts.

4.4. SUMMARY OF FINDINGS

The researcher presented her findings from three sources including 1) Content analysis of the semi-structured interviews, 2) Document Analysis and 3) Direct Observation of past photographs and videos under four direct themes and two broad themes:

- Theme 1: Areas of Occupation; highlighted data relevant to ADL (Areas of Daily Living), Client factors & Performance Skills, Play, Social interaction and School Participation.
- Theme 2: Assistive Technology; highlighted data relevant to Wheelchairs & Accessories, Prosthetics, high technology and low cost technology.
- Theme 3: Therapeutic intervention; highlighted data relevant to occupational therapy, early childhood intervention and other medical or allied professionals.
- Theme 4: Child and Disability rights; highlighted data relevant to the provision of assistive technology and the accessibility inclusion of children with disabilities in SA.
- Broad theme: Future Considerations; highlighted data relevant to ADL/IADL, vocational pursuits and assistive technology.
- Broad theme: Context and Environment

The assessment analysis portrayed the findings from the following documents (reports, questionnaires, standardized tests):

- Background profile consisted of birth certificate, medical and OT reports.
- Sensory Profile (both home and school companion).
- Beery-Buktenica test of Visual-Motor-Integration.
- Test of Visual Perception (TVPS).
- Revised KNOX Preschool Play Scale.
- QUEST Quebec User Evaluation of Satisfaction with assistive technology.

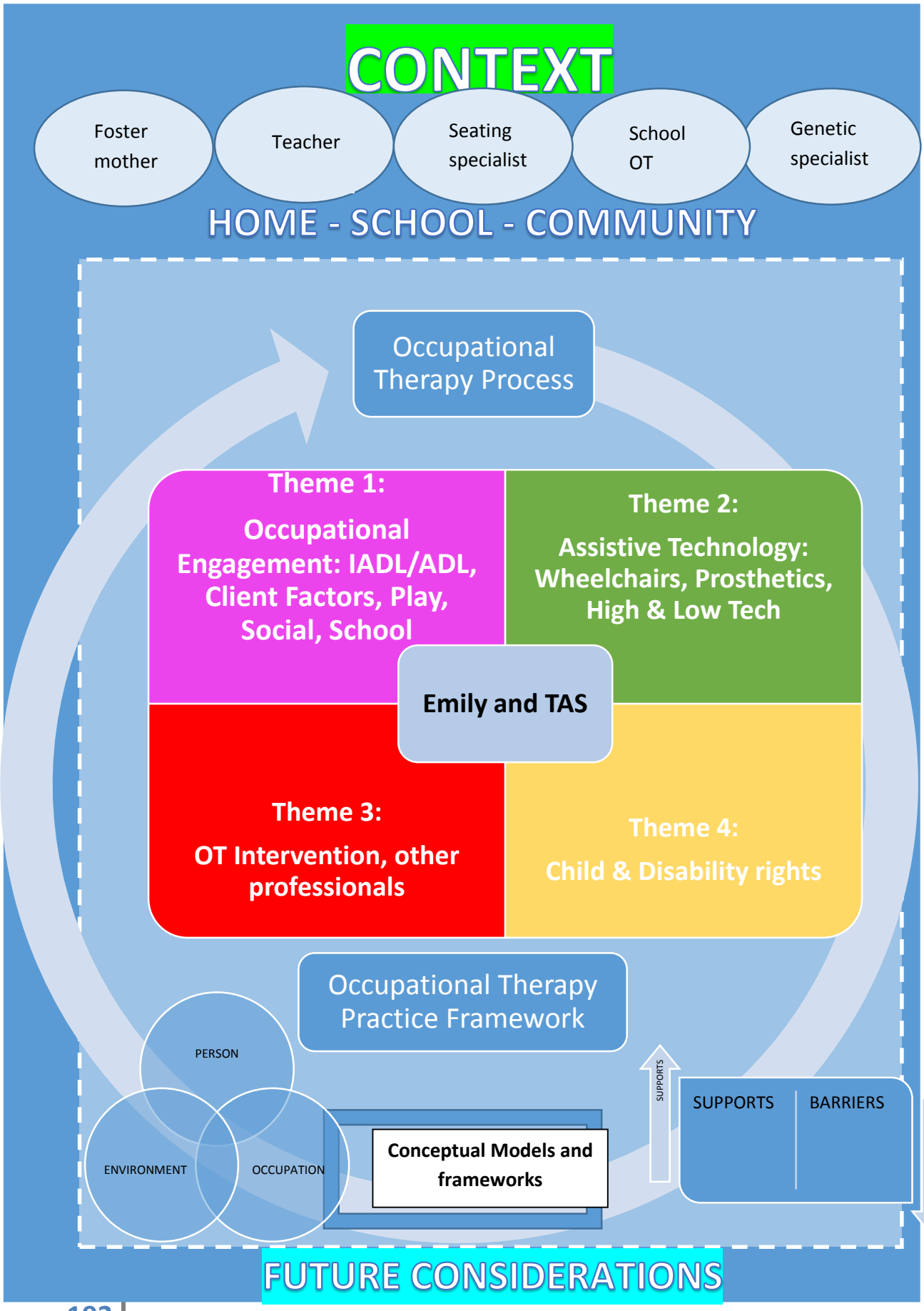
The direct observation analysis of past photographs and video's was portrayed using the OTPF Occupational Therapy Practice Framework.

4.5. CONCEPTUAL FRAMEWORK

The researcher developed an initial conceptual framework in her exploration of the contribution of occupational therapy to the management of tetra-amelia syndrome. The framework was based on literature and the researcher's personal experiences. The major constructs that were proposed by the researcher were presented in *Figure 2.4.1: Initial Conceptual Framework of Occupational Therapy and TAS in Chapter 2.*

A conceptual framework in case study research does not show the relationships between the constructs. It should be an ongoing process to develop and complete the framework as the study progresses. The relationships will emerge as the data is analysed and interpreted. A completed conceptual framework will include all the themes that emerged from the data analysis phase of the research (Baxter & Jack, 2008:553). This completed framework is illustrated in the figure below.

Figure 4.4: Completed conceptual framework of the study



4.6. SUMMARY

In this chapter, the researcher presented and discussed the qualitative and quantitative data that was analysed in the form of content analysis, assessments and direct observation. The conclusions, recommendations and limitations to the study will be discussed in Chapter 5.

CHAPTER FIVE

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1. INTRODUCTION

In this chapter the researcher will discuss the conclusions and main findings regarding the study. The research is also evaluated in terms of limitations and strengths and recommendations are made regarding future research.

5.2. SUMMARY OF THE MAIN FINDINGS OF THE STUDY

Occupational Science is defined as having it's roots as a basic science aimed at building knowledge about the characteristics, form, function and meaning of what people do (Zemke & Clark , 1996). It also looks at the occupational nature of being human (Wilcock, 2006). It involves building knowledge about the observable and phenomenological aspects. The research study of Emily looked at her occupational nature, took into consideration her unique context and built a case involving the observable and phenomenologcal aspects. Occupational therapy theory and frameworks led the researcher to view the case holistically. The results of the research assisted in providing a description of the occupational therapy contribution of a child with TAS according to the following objectives:

5.2.1. Occupational Intervention in occupational engagment (ADL, IADL, Play, Social, School):

The research showed that Emily's supports and barriers according to the PEOP Model should be considered when looking at her independence and participation in occupations like ADL, IADL, school, play and social participation. This includes client factors, performance skills, values, contexts and environments.

As an OT, priority areas of ADL should be considered such as self-feeding skills and mobility, where full independence can be achieved. Active participation should be

encouraged in caregiver led activities like bathing, dressing and grooming. Environmental adaptations and caregiver training is vital to prevent learnt helplessness and offer safety precautions. Low technology assistive devices (i.e. universal cuff, plate guard, bumbo chair) can be used to enhance participation and independence. A motorised and customised wheelchair serves as a vital tool in enhanced mobility, play, school and community involvement.

IADL should not be dismmissed an area for future intervention including household chores, futhered community involvement, care of pets, financial management and the like.

Play is a primary occupation of a child and OTs should remember to assess it. Through the research, it was concluded that according to the Revised KNOX Play Scale, Emily's age norm in play was lower in some aspects of play due to her physical limitations. Therapeutic play including physical assistance, environmental adaptations, structuring, grading and assistive technology allowed her enhanced participation in play pursuits.

Occupational therapy interventions can assist with social competence. In Emily's case it should be noted that her social competence is different in her home and community environments versus her school environment. More focus should be placed on adapting her school environment to ensure that she is socially included.

An OT needs to consider all areas of performance of a child when providing intervention at school. The OT needs to take on a collaborative team approach with teachers, psychologists, facilitators and students. A special needs school that provides a maintream curriculum has proven to be the best placement for Emily's needs currently. Due to her limitations, she requires an individual facilitator and a computerised learning system so that she can keep up with the demands of Grade 1. Successful school intervention strategies include providing assistive technology, adapting the environment, reframing the teacher's perspective and improving the student's skills.

Early intervention was seen as beneficial to her independence, confidence and emotional wellbeing. It also provided awareness to her condition and promotion of ability amongst her caregivers and teachers in her unique context. Intervention

received in her natural environment was key as the OT could make appropriate suggestions for environmental modifications, perform caregiver training and get a proper feels for her unique context and what her daily routines and activities entail.
The types of occupational therapy intervention that proved successful in this case include the use of meaningful and developmentally activities, occupations, groups, assistive technology, environmental adaptations, training and education and advocacy.

It is evident that a multi-disciplinary for this unique case is imperative to furthered success. Other important professionals include educators, facilitators, medical doctors including genetic specialists & orthopaedic surgeons, seating specialists, psychologists.

5.2.2. Assistive technology:

Assistive technology has played a vital role in this case. It has been imperative from an OT's perspective to use sharp clinical reasoning skillls in the ATD acquisition process. A child's motor, sensory, perceptual, cognitive, communication and psychsocial skills and unique context needs to be analysed to provide the best fit between ATD and user.

Emily's motorised wheelchair(s) have provided her a means to spontaneity and freedom in her play, enhanced home, school and community mobility, improved social interaction and participation, it provides for adequate posture and safety and alows her to be more independent in ADL tasks like eating and feeding.

Prosthetics in her case has proven to be controversial. Initial manual prosthesis were abandoned due to a poor fit between user and ATD. Adapted pointers are however used in a school environment and she is a good candidate for a myo-electric prosthesis or 3D printed hand in the future. Other devices that have proved beneficial to her independence and participation are her tablet, laptop, universal cuff and toilet seat.

Assistive technologies can diminish the impact of disabilities and allow children improved alternatives to participate. Occupational therapists are ideally suited to evaluate and determine appropriate match of AT tools to the child.

5.2.3. Future considerations:

The research showed that there are areas of her daily life that she may always require support in e.g. dressing, toileting and grooming. It is important however to provide the maximum independence possible for Emily in all areas of her daily life and routine to enhance her quality of life and the ability for her to live independently. Assistive technology and environmental adaptations will continue to play a role.

It is the hope of all her role-players that Emily will be able to finish her schooling and perhaps partake in tertiary studies. It is evident that the role of the occupational therapist will continue to be meaningful to the success of Emily's case due to her continuous needs for support, assistive technology, environmental adaptations and advocacy to participate in vocational and community work experiences.

Advances in Assistive technology allow many devices to grow and expand with the child during the developmental years and into adolescence and adulthood and as they undergo transition into higher education and community work experiences. Future considerations include myo-electric prosthesis, 3D printing, elevating platform wheelchairs, voice activated laptop and adapted cars.

The need for a constant flow of funding is required, thus the idea of opening a foundation for Emily and others like her should be considered for the long term success of these unique cases.

5.3. LIMITATIONS OF STUDY

The absence of systematic procedures for case study research is something that Yin (2009: 14-15) sees as traditionally the greatest concern due to a relative absence of methodological guidelines. Single case study analysis has been subject to a number of criticisms, the most common of which concern the inter-related issues of methodological rigour, researcher subjectivity, and external validity.

Due to the small sample size, the research results will be difficult to generalise to the greater population. However, both Stake and Yin (cited in Salminen, Harra, &

Lautamo, 2006) proposed that the results of case study research can be generalised theoretically as it can make theoretical suggestions and modify earlier generalisations.

The fact that the researcher was known to the participants might have had an impact on how participants responded. However, the researcher reassured participants that all information provided would be kept confidential and their names would not be included in the study report.

The element of observer bias could potentially come to the fore as the researcher herself was too close to the research subject. The researcher aimed to eliminate this bias as much as possible however by incorporating an external rater for all aspects of observational and assessment/documentation data sources. The fact that the researcher has worked with this specific individual from a young age may have stood the chance to affect the discussion of the results obtained as it was difficult to separate raw data from reflective experience of the case.

Occupational Therapy is interested in the person in their own living environment, and aims to achieve a good overall understanding of the person while also being interested in the particulars, to take several viewpoints into account, and to value the subjectivity and experience of a client. Case study research therefore offers a research methodology that respects the basic principles of the occupational therapy profession.

5.4. RECOMMENDATIONS

After commencement of the research, the researcher is very curious to know what the future outcomes will be for a unique case like Emily in the South African context. This current research study acts as a good basis for understanding the supports and barriers that she faces in her context, but future considerations in her case are based on perceptions and not factual data. It would be interesting to do a follow up study when she is in high school or early adolescence to ascertain the growth she has made as well as what constraints she has faced. Occupational therapy intervention will also need to adapt and change through her life phases.

It would be recommended that a follow-up study be conducted that could compare the occupational therapy intervention and outcomes for separate cases of TAS in South Africa. This would provide a rich description of how the person and their unique context

affects their outcomes. It could also provide more insight into the clinical reasoning of different therapists in these cases and what guides their decision making processing for planning intervention.

5.5. IMPLICATIONS FOR OCCUPATIONAL THERAPY

The findings of this study can be used to raise awareness of the unique and significant role that occupational therapists can play in the lives of a child with Tetra- Amelia Syndrome. The importance of viewing a child holistically in their unique context and taking into account their self-determination to participate in meaningful occupations was highlighted (Law M. , et al., 1996). Occupational therapists can be reminded to exercise clinical reasoning skills and to follow the guidelines of the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2014) when choosing assessment procedures, goal-setting and intervention plans.

The findings of this study can serve as a guideline for new and inexperienced therapists working with children with severe physical limitations. It can assist with ideas for assistive technology, environmental adaptations, intervention strategies and school inclusivity and participation. It highlights the need for early intervention in such a case as well as creating awareness that children born with TAS can live meaningful lives.

5.6. CONCLUSION

Occupational therapy intervention has proved to provide a significant contribution in the occupational engagement of a child with TAS. Early intervention in her case has supported and paved her way to enhanced participation and performance in ADL, IADL, play, social and school occupations. Assistive technology including wheelchairs, tablets, laptops and low technology devices have further enabled her to overcome the physical barriers she encounters on a daily basis in aspects like mobility, self-care, play and academic pursuits. By encompassing the frameworks, models and principles of occupational therapy, the ongoing process of assessment, intervention and clinical reasoning has proved imperative to the success of this case. By looking at this case holistically and considering the person, environment and what occupations are

important and meaningful, an occupational therapist can contribute greatly to the overall quality of life, wellness and satisfaction of a child with TAS.

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7. ANNEXURES

ANNEXURE A: SEMI-STRUCTURED INTERVIEW TEMPLATE

MOccTher Research study

Semi-structured interview

Name of interviewee: _____

Relationship to Emily:_____

Profession (if applicable):_____

Questions:

General

1. Tell me about your relationship with Emily?
2. What are your roles and responsibilities in her life?
3. What have been some of the challenges you have faced when caring for her OR providing intervention for her?
4. Have you ever been in contact with a child with Tetra-Amelia syndrome (or something similar) before Emily?
5. What is your knowledge on the condition?
6. Have your perceptions of her abilities been altered over the time spent with her?
7. How do you need to assist Emily in her areas of occupation/daily life? What are her strengths and limitations in the following areas? Are there any adaptive methods that you use? Please be specific. *(discuss each item in entirety)*
    a. Sleeping
    b. Feeding
    c. Dressing
    d. Bathing
    e. Grooming (tooth brushing, hair brushing, blowing her nose etc)
    f. Toileting
    g. Mobility
    h. Play
    i. School
    j. Social interaction
    k. Community mobility and participation

8. Do you think assistive/adaptive technology is and will be beneficial to her functioning and independence? Please elaborate:
    a. Tablet
    b. Powered wheelchair
    c. Manual prosthesis
    d. Myo-electric prosthesis
    e. Eye-controlled computer software for learning at school
    f. Universal cuff (for eating, brushing teeth and fine motor skills and dexterity)
    g. Wheelchair ramp (home and car)
    h. Other
9. Do you think the input of occupational therapy has helped her to be more functional and independent? Please elaborate.
10. Do you think it has been vital to her independence and functioning that intervention started at a very young age?
11. Do you think she will benefit from any other therapies?
12. Emily is currently in a school for children with special needs. Do you think this is the correct school environment for her?
13. What is your knowledge of her performance/experience of being part of this school?
14. Do you think she could be or should be accommodated in a mainstream school in our SA context?
15. Do you think the SA government makes provisions for someone like Emily with such severe physical limitations? Please elaborate on:
    a. Assistive devices i.e. wheelchair
    b. Accessibility to public attractions (shops, malls, parks etc.)
    c. Education
    d. Other
16. Has she benefited more from private or public sponsors/donations over the course of the past 5 years?
17. How do you see her future path? What will she need to assist her in reaching her potential?
    a. School
    b. Independence
    c. Vocation
    d. Independent living skills
    e. Assistive technology

18. Any other comments that you think would contribute to this research case study?

Thank you for your valuable time!

ANNEXURE B: SENSORY PROFILE

SENSORY PROCESSING								
ITEM			A. AUDITORY PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
👂	L	1	Responds negatively to unexpected or loud noises (for example, cries or hides at noise from vacuum cleaner, dog barking, hair dryer)				X	
👂	L	2	Holds hands over ears to protect ears from sound					X
👂	L	3	Has trouble completing tasks when the radio is on					X
👂	L	4	Is distracted or has trouble functioning if there is a lot of noise around				X	
👂	L	5	Can't work with background noise (for example, fan, refrigerator)					X
👂	H	6	Appears to not hear what you say (for example, does not "tune-in" to what you say, appears to ignore you)				X	
👂	H	7	Doesn't respond when name is called but you know the child's hearing is OK				X	
👂	H	8	Enjoys strange noises/seeks to make noise for noise's sake					X
			Section Raw Score Total					

Comments: Emily is not unusually overwhelmed by sound around her

ITEM			B. VISUAL PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
👁	L	9	Prefers to be in the dark					X
👁	L	10	Expresses discomfort with or avoids bright lights (for example, hides from sunlight through window in car)					X
👁	L	11	Happy to be in the dark		X			
👁	L	12	Becomes frustrated when trying to find objects in competing backgrounds (for example, a cluttered drawer)			X		
👁	L	13	Has difficulty putting puzzles together (as compared to same age children)			X		
👁	L	14	Is bothered by bright lights after others have adapted to the light					X

👁	L	15	Covers eyes or squints to protect eyes from light					X
👁	H	16	Looks carefully or intensely at objects/people (for example, stares)				X	
👁	H	17	Has a hard time finding objects in competing backgrounds (for example, shoes in a messy room, favourite toy in the "junk drawer")			X		
			Section Raw Score Total					

Comments: As with all children, looking for things in a toy box can be frustrating but if stuff packed away properly she has no problems.

ITEM			C. VESTIBULAR PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
➜	L	18	Becomes anxious or distressed when feet leave the ground					X
➜	L	19	Dislikes activities where head is upside down (for example, somersaults, roughhousing)					X
➜	L	20	Avoids playground equipment or moving toys (for example, swing set, merry-go-round)			X		
➜	L	21	Dislikes riding in a car					X
➜	L	22	Holds head upright, even when bending over or leaning (for example, maintains a rigid position/posture during activity)					X
➜	L	23	Becomes disoriented after bending over sink or table (for example, falls or gets dizzy)					X
➜	H	24	Seeks all kinds of movement and this interferes with daily routines (for example, can't sit still, fidgets)			X		
➜	H	25	Seeks out all kinds of movement activities (for example, being whirled by adult, merry-go-rounds, playground equipment, moving toys)		X			
➜	H	26	Twirls/spins self frequently throughout the day (for example, likes dizzy feeling)				X	
➜	H	27	Rocks unconsciously (for example, while watching TV)					X
➜	H	28	Rocks in desk/chair/on floor					X
			Section Raw Score Total					

Comments:

ITEM			D. TOUCH PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	29	Avoids getting "messy" (for example, in paste, sand, finger paint, glue, tape)			X		
	L	30	Expresses distress during grooming (for example, fights or cries during haircutting, face washing, fingernail cutting)				X	
	L	31	Prefers long-sleeved clothing when it is warm or short sleeves when it is cold					X
	L	32	Expresses discomfort at dental work or tooth brushing (for example, cries or fights)					X
	L	33	Is sensitive to certain fabrics (for example, is particular about certain clothes or bed sheets)			X		
	L	34	Becomes irritated by shoes or socks					X
	L	35	Avoids going barefoot, especially in sand or grass					X
	L	36	Reacts emotionally or aggressively to touch					X
	L	37	Withdraws from splashing water					X
	L	38	Has difficulty standing in line or close to other people				X	
	L	39	Rubs or scratches out a spot that has been touched					X
	H	40	Touches people and objects to the point of irritating others					X
	H	41	Displays unusual need for touching certain toys, surfaces, or textures (for example, constantly touching objects)					X
	H	42	Decreased awareness of pain and temperature					X
	H	43	Doesn't seem to notice when someone touches arm or back (for example, unaware)					X
	H	44	Avoids wearing shoes; love to be barefoot					X
	H	45	Touches people and objects		X			
	H	46	Doesn't seem to notice when face or hands are messy					X
			Section Raw Score Total					

ITEM			E. MULTI-SENSORY PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		47	Gets lost easily (even in familiar places)					X
		48	Has difficulty paying attention			X		
	L	49	Looks away from tasks to notice all actions in the room				X	
	H	50	Seems oblivious within an active environment (for example, unaware of activity)					X
	H	51	Hangs on people, furniture, or objects even in familiar situations					X
	H	52	Walks on toes					X
	H	53	Leaves clothing twisted on body			X		
			Section Raw Score Total					

Comments: Emily has no toes and she will try and fix twisted clothing with her left arm

ITEM			F. ORAL SENSORY PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	54	Gags easily with food textures or food utensils in mouth					X
	L	55	Avoids certain tastes or food smells that are typically part of children's diets					X
	L	56	Will only eat certain tastes (list:_____)					X
	L	57	Limits self to particular food textures/temperatures (list: __GETS HOT EASILY		X			
	L	58	Picky eater, especially regarding food textures					X
	H	59	Routinely smells non-food objects					X
	H	60	Shows strong preference for certain smells (list: _____)					X
	H	61	Shows strong preference for certain tastes (list: _____)					X

	H	62	Craves certain foods (list: chicken/mutton/beef/hake and rice/chips_____)					X
	H	63	Seeks out certain tastes or smells (list: as for 62)					X
	H	64	Chews or licks on non-food objects		X			
	H	65	Mouths objects (for example, pencil, hands)		X			
			Section Raw Score Total					

Comments: She will often chew on or suck on her tops

MODULATION								
ITEM			G. SENSORY PROCESSING RELATED TO TONE/ ENDURANCE	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		66	Moves stiffly					X
	H	67	Tires easily, especially when standing or holding particular body position				X	
	H	68	Locks joints (for example, elbows, knees) for stability					X
	H	69	Seems to have weak muscles					X
	H	70	Has a weak grasp					X
	H	71	Can't lift heavy objects (for example, weak in comparison to same age children)		X			
	H	72	Props to support self (even during activity)			X		
	H	73	Poor endurance/tires easily					X
	H	74	Appears lethargic (for example, has no energy, is sluggish)					X
			Section Raw Score Total					

Comments: Emily has no arms so is limited to weight of the items she can carry

ITEM			H. MODULATION RELATED TO BODY POSITION AND MOVEMENT	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
/		75	Seems accident-prone			X		
		76	Hesitates going up or down curbs or steps (for example, is cautious, stops before moving)					X
→	L	77	Fears falling or heights					X
→	L	78	Avoids climbing/jumping or avoids bumpy/uneven ground					X
→	L	79	Holds onto walls or banisters (for example, clings)					X
→	H	80	Takes excessive risks during play (for example, climbs high into a tree, jumps off tall furniture)			X		
→	H	81	Takes movement or climbing risks during play that compromise personal safety				X	
→	H	82	Turns whole body to look at you			X		
	H	83	Seeks opportunities to fall without regard to personal safety					X
	H	84	Appears to enjoy falling					X
			Section Raw Score Total					

Comments: Because Emily is 'top heavy' and has no arms to stop her from falling she usually falls on her head

ITEM			I. MODULATION OF MOVEMENT AFFECTING ACTIVITY LEVEL	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	85	Spends most of the day in sedentary play (for example, does quiet things)				X	
	L	86	Prefers quiet, sedentary play (for example, watching TV, books, computers			X		
→	L	87	Seeks sedentary play options				X	
→	L	88	Prefers sedentary activities				X	
→	H	89	Becomes overly excitable during movement activity				X	
	H	90	"On the go"		X			
	H	91	Avoids quiet play activities				X	

			Section Raw Score Total				

ITEM			J. MODULATION OF SENSORY INPUT AFFECTING EMOSIONAL RESPONSES	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
/		92	Needs more protection from life than other children (for example, defenceless physically or emotionally)				X	
	L	93	Rigid rituals in personal hygiene		X			
/	H	94	Is overly affectionate with others			X		
/	H	95	Doesn't perceive body language or facial expressions (for example, unable to interpret)				X	
			Section Raw Score Total					

Comments: Only needs protection when she is on the floor as she is so tiny and loves cuddles

ITEM			K. MODULATION OF VISUAL INPUT AFFECTING EMOTIONAL RESPONSES AND ACTIVITY LEVEL	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
	L	96	Avoids eye contact				X	
	H	97	Stares intensively at objects or people				X	
	H	98	Watches everyone when they move around the room			X		
	H	99	Doesn't notice when people come into the room					X
			Section Raw Score Total					

Comments:

BEHAVIOUR AND EMOTIONAL RESPONSE								
ITEM			L. EMOTIONAL / SOCIAL RESPONSES	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
/		100	Seems to have difficulty liking self (for example, low self-esteem)				X	

/		101	Has trouble "growing up" (for example, reacts immaturely to situations)				X	
/		102	Is sensitive to criticisms			X		
/		103	Has definite fears (for example, fears are predictable)				X	
/		104	Seems anxious				X	
/		105	Displays excessive emotional outbursts when unsuccessful at a task				X	
/		106	Expresses feeling like a failure				X	
/		107	Is stubborn or uncooperative				X	
/		108	Has temper tantrums					X
/		109	Poor frustration tolerance			X		
/		110	Cries easily				X	
/		111	Overly serious					X
/		112	Has difficulty making friends (for example, does not interact or participate in group play)				X	
/		113	Has nightmares				X	
/		114	Has fears that interfere with daily routine					X
/		115	Doesn't have a sense of humour					X
/		116	Doesn't express emotions					X
			Section Raw Score Total					

ITEM			M. BEHAVIOURAL OUTCOMES OF SENSORY PROCESSING	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
👂		117	Talks self through tasks					
👁		118	Writing is illegible					
👁		119	Has trouble staying between the lines when colouring or when writing			x		
/		120	Uses inefficient ways of doing things (for example, wastes time, moves slowly, does things a harder way than is needed)					
/	L	121	Has difficulty tolerating changes in plans and expectations				X	

/	L	122	Has difficulty tolerating changes in routines				X	
			Section Raw Score Total					

Comments: Difficult To answer as Emily has just started with learning aids

ITEM			N. ITEMS INDICATING THRESHOLDS FOR RESPONSE	ALWAYS	FREQUENTLY	OCCASIONALLY	SELDOM	NEVER
		123	Jumps from one activity to another so that it interferes with play			X		
	H	124	Deliberately smells objects				X	
	H	125	Does not seem to smell strong odours					X
			Section Raw Score Total					

Comments:

ICON KEY	
	Auditory
	Visual
	Activity Level
	Taste/Smell
	Body Position
	Movement
	Touch

THRESHOLD KEY	
	Neither low nor high
L	Low
H	High

SCORE KEY	
1	Always
2	Frequently
3	Occasionally
4	Seldom
5	Never

ANNEXURE C: SENSORY PROFILE RAW SCORES (TABLE FORMAT)

Winnie Dunn's Sensory profile *(filled out by foster mother in a home environment)*

Sections	Definite difference	Probable difference	Typical performance	Probable difference	Definite difference
	Less than others			More than others	
Auditory processing			X		
Visual processing			X		
Vestibular processing				X	
Touch processing			X		
Multisensory processing			X		
Oral sensory processing			X		
Sensory processing related to endurance/tone			X		
Modulation related to body position and movement			X		
Modulation of movement affecting activity level			X		
Modulation of sensory input affecting emotional responses					X
Modulation of visual input affecting emotional responses and activity level			X		
Emotional/Social responses			X		
Behavioural outcomes of sensory processing			X		

Factor Summary

Factors	Less than others		Similar to others	More than others	
	Much less than others	Less than others		More than others	Much more than others
	Definite difference	Probable difference	Typical performance	Probable difference	Definite difference
Sensory Seeking			X		
Emotionally reactive			X		
Low endurance/ tone			X		
Oral sensory Sensitivity			X		
Inattention/ distractibility			X		
Poor registration			X		
Sensory Sensitivity			X		
Sedentary			X		
Fine motor/ perceptual				X	

Quadrant Summary

Quadrant Raw Score Total	Less than others		Similar to others	More than others	
	Much less than others	Less than others		More than others	Much more than others
	Definite difference	Probable difference	Typical performance	Probable difference	Definite difference
Registration 63/75				X	
Seeking 108/130			X		
Sensitivity 90/100			X		
Avoiding 121/145			X		

Winnie Dunn's Sensory profile School Companion *(filled out by Grade R teacher in a school environment)*

Section Summary

Quadrant Raw Score Total	Less than others		Similar to others	More than others	
	Much less than others	Less than others		More than others	Much more than others
	Definite difference	Probable difference	Typical performance	Probable difference	Definite difference
Auditory 42/50			X		
Visual 53/55			X		
Movement 70/70			X		
Touch 60/60			X		
Behaviour 64/75			X		

Quadrant Summary

Quadrant Raw Score Total	Less than others		Similar to others	More than others	
	Much less than others	Less than others		More than others	Much more than others
	Definite difference	Probable difference	Typical performance	Probable difference	Definite difference
Registration 81/85			X		
Seeking 56/60			X		
Sensitivity 73/80		X			
Avoiding 82/85			X		

ANNEXURE D: BEERY TEST OF VISUAL MOTOR INTEGRATION

The Beery–Buktenica Developmental Test of Visual–Motor Integration

Beery™ VMI

Sixth Edition

Ages 2 through 100 (FULL FORM)

by Keith E. Beery, Norman A. Buktenica, and Natasha A. Beery

Name: _____ Last _____ First _____ Grade: _____

School: _____

Examiner: _____

Test Date: ____ year ____ month ____ day

Birth Date: ____ year ____ month ____ day

Chronological Age: ____ year ____ month (Count more than 15 days as one month.)

SUMMARY

See the Beery VMI manual (sixth edition) for norms.

	Beery VMI	Visual Perception	Motor Coordination
Raw Scores:	____	____	____
Standard Scores:	____	____	____
Scaled Scores:	____	____	____
Percentiles:	____	____	____
Other Scaling:	____	____	____

Comments and Recommendations:

PROFILE

Standard Score	Beery VMI	Visual Perception	Motor Coordination	Percentile
145	-	-	-	99.7
140	-	-	-	99.2
135	-	-	-	99
130	-	-	-	98
125	-	-	-	95
120	-	-	-	91
115	-	-	-	84
110	-	-	-	75
105	-	-	-	63
100	-	-	-	50
95	-	-	-	37
90	-	-	-	25
85	-	-	-	16
80	-	-	-	9
75	-	-	-	5
70	-	-	-	2
65	-	-	-	1
60	-	-	-	.8
55	-	-	-	.3

Begin testing on page 1. Turn booklet over with bound edge toward the examinee. If subtests are used, always test in this order: VMI → Visual → Motor.

PEARSON

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Product Number 46240/46241

ANNEXURE E: TEST OF VISUAL PERCEPTION 3 (TVPS 3)

TEST OF VISUAL PERCEPTUAL SKILLS
3RD EDITION

Name: _____ Gender: _____ Grade: _____

School: _____ Examiner: _____

Reason for Testing: _____

	year	month	day
Date of Test			
Date of Birth			
Chronological Age			

*Do not round months up by one if days exceed 15

Student has known (diagnosed) attention problems? ☐ Y ☐ N

Student has known (diagnosed) visual problems? ☐ Y ☐ N

Subtests	Subtest Scores			Index Scores			
	Raw Score	Scaled Score	Percentile Rank	Overall	Basic Processes	Sequencing	Complex Processes
1. Visual Discrimination (DIS)							
2. Visual Memory (MEM)							
3. Spatial Relations (SPA)							
4. Form Constancy (CON)							
5. Sequential Memory (SEQ)							
6. Figure Ground (FGR)							
7. Visual Closure (CLO)							
Sum of Scaled Scores							
Standard Scores							
Percentile Rank				Overall	Basic	Sequencing	Complex

Age Percentile Rank	Scaled Score	SUBTEST SCALED SCORES DIS	MEM	SPA	CON	SEQ	FGR	CLO	INDEX AND OVERALL SCORES OVERALL	BASIC	SEQUEN.	COMPLEX	Standard Score	% ile Rank
>99	19												145	>99
>99	18												140	>99
99	17												135	99
98	16												130	98
95	15												125	95
91	14												120	91
84	13												115	84
75	12												110	75
63	11												105	63
50	10												100	50
37	9												95	37
25	8												90	25
16	7												85	16
9	6												80	9
5	5												75	5
2	4												70	2
1	3												65	1
<1	2												60	<1
<1	1												55	<1

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Refer to the TVPS-3 manual for complete instructions.

VPS-3 subtests do not have basals.

Ceiling is established for each subtest when a ıdent has answered all 16 items or misses 3 items a row. Then proceed to the next subtest.

ecord the student's answers in the Response olumn. Each correct answer is scored "1"; errors re scored "0". Tally the scores for each subtest in ne spaces provided. **Do not score the examples.**

Jpon completion of the *TVPS-3*, transfer the ubtest raw scores to the front page of this protocol. Jse the norms tables in Appendix B to derive ubtest scaled scores, index standard scores, the verall standard score and percentile ranks.

Scaled and standard scores can be graphed on the ront page of this protocol. The shaded area epresents one standard deviation above and below he mean.

SUBTEST 1: Discrimination

Item #	Correct Answer	Response	Score
DIS Ex A	(3)		
DIS Ex B	(5)		
DIS 1	(3)		
DIS 2	(2)		
DIS 3	(3)		
DIS 4	(2)		
DIS 5	(1)		
DIS 6	(1)		
DIS 7	(5)		
DIS 8	(2)		
DIS 9	(4)		
DIS 10	(4)		
DIS 11	(5)		
DIS 12	(4)		
DIS 13	(2)		
DIS 14	(5)		
DIS 15	(3)		
DIS 16	(1)		
		Total Subtest 1	

Do not turn to the next plate until you've read the directions for the next subtest.

JBTEST 2: emory

minder:
sent the target
n for 5 seconds.
sponse is not
ıed.

Item #	Correct Answer	Response	Score
MEM Ex C	(3)		
MEM Ex D	(2)		
MEM 17	(3)		
MEM 18	(1)		
MEM 19	(2)		
MEM 20	(2)		
MEM 21	(3)		
MEM 22	(2)		
MEM 23	(4)		
MEM 24	(1)		
MEM 25	(2)		
MEM 26	(1)		
MEM 27	(3)		
MEM 28	(4)		
MEM 29	(2)		
MEM 30	(4)		
MEM 31	(3)		
MEM 32	(1)		
		Total Subtest 2	

o not turn to the next ıte until you've read e directions for the next btest.

SUBTEST 3: Spatial Relations

Item #	Correct Answer	Response	Score
SPA Ex E	(2)		
SPA Ex F	(4)		
SPA 33	(1)		
SPA 34	(2)		
SPA 35	(5)		
SPA 36	(3)		
SPA 37	(3)		
SPA 38	(5)		
SPA 39	(1)		
SPA 40	(2)		
SPA 41	(2)		
SPA 42	(1)		
SPA 43	(4)		
SPA 44	(3)		
SPA 45	(4)		
SPA 46	(5)		
SPA 47	(2)		
SPA 48	(4)		
		Total Subtest 3	

Do not turn to the next plate until you've read the directions for the next subtest.

Refer to the TVPS-3 manual for complete instructions.

SUBTEST 4: Form Constancy

Item #	Correct Answer	Response	Score
CON Ex G	(3)		
CON Ex H	(5)		
CON 49	(2)		
CON 50	(1)		
CON 51	(4)		
CON 52	(4)		
CON 53	(5)		
CON 54	(3)		
CON 55	(5)		
CON 56	(4)		
CON 57	(1)		
CON 58	(5)		
CON 59	(3)		
CON 60	(2)		
CON 61	(3)		
CON 62	(1)		
CON 63	(2)		
CON 64	(2)		
		Total Subtest 4	

Do not turn to the next plate until you've read the directions for the next subtest.

SUBTEST 5: Sequential Memory

Reminder: Present the target item for 5 seconds. Response is not timed.

Item #	Correct Answer	Response	Score
SEQ Ex I	(2)		
SEQ Ex J	(3)		
SEQ 65	(1)		
SEQ 66	(4)		
SEQ 67	(1)		
SEQ 68	(4)		
SEQ 69	(3)		
SEQ 70	(1)		
SEQ 71	(4)		
SEQ 72	(2)		
SEQ 73	(2)		
SEQ 74	(3)		
SEQ 75	(1)		
SEQ 76	(3)		
SEQ 77	(2)		
SEQ 78	(3)		
SEQ 79	(2)		
SEQ 80	(4)		
		Total Subtest 5	

Do not turn to the next plate until you've read the directions for the next subtest.

SUBTEST 6: Figure Ground

Item #	Correct Answer	Response	Score
FGR Ex K	(2)		
FGR Ex L	(1)		
FGR 81	(3)		
FGR 82	(2)		
FGR 83	(4)		
FGR 84	(1)		
FGR 85	(4)		
FGR 86	(1)		
FGR 87	(4)		
FGR 88	(3)		
FGR 89	(2)		
FGR 90	(3)		
FGR 91	(1)		
FGR 92	(2)		
FGR 93	(4)		
FGR 94	(3)		
FGR 95	(1)		
FGR 96	(2)		
		Total Subtest 6	

Do not turn to the next plate until you've read the directions for the next subtest.

SUBTEST 7: Visual Closure

Item #	Correct Answer	Response	Score
CLO Ex M	(4)		
CLO Ex N	(2)		
CLO 97	(2)		
CLO 98	(3)		
CLO 99	(1)		
CLO 100	(4)		
CLO 101	(2)		
CLO 102	(2)		
CLO 103	(3)		
CLO 104	(4)		
CLO 105	(1)		
CLO 106	(4)		
CLO 107	(3)		
CLO 108	(1)		
CLO 109	(4)		
CLO 110	(3)		
CLO 111	(1)		
CLO 112	(2)		
		Total Subtest 7	

Do not turn to the next plate until you've read the directions for the next subtest.

STOP – End of Test

ANNEXURE F: VISUAL PERCEPTUAL TEST SCORE SUMMARY

Visual perception:

Is a cognitive function where visual information (e.g. symbols, shapes, numbers, and letters) is recognized and interpreted in order to ascribe meaning to the visual information.

The following table illustrates a summary of her level of participation in select perceptual skills. *Average Scaled Scores should be between 8-12.*

PERCEPTUAL SKILL	LEVEL OF PARTICIPATION	SCALED SCORE
Figure ground: a property of perception in which there is a tendency to see parts of a visual field as solid, well-defined objects standing out against a less distinct background e.g. finding the red pen amongst others in the pencil case.	Average	11
Visual closure: the ability to visualise an object of which a part is hidden as a whole, e.g. building a puzzle, putting words together s-i-t = sit	Average	11
Form constancy: the ability to recognize forms and objects as the same in spite of variation in environment, position, and size e.g. the door is a rectangle and so is an A4 sheet.	Average	9
Visual discrimination: to identify similarities and differences in objects, e.g. the dog is big and white; the cat is small and grey.	Average	8
Visual memory: to be able to visually store and recall what one has seen which is important for learning letters and numbers.	Below Average	7
Spatial relations: the awareness of the relation of the one's body's position in relation to objects e.g. I sit on the chair behind the desk.	Average	10

Visual sequential memory: the ability to store and recall objects seen in their correct order, which is important for learning spelling words.	Average	12
Visual motor integration: the ability of the brain to coordinate the eye movements with those of the hand movements e.g. copying three dimensional tasks such as a block tower or copying written work in terms of spacing, size and correctness.	Below Average	7

ANNEXURE G: CLIENT FACTOR SUMMARY

CLIENT FACTORS	
Body Functions - "The physiological functions of body systems (including psychological functions)" (WHO, 2001, p.10). This section of the table is organized according to the classifications of the International Classification of Functioning, Disability and Health (ICF)	
Mental functions This considers higher order thinking skills and planned sequential behaviour, which includes memory, organizational skills, and attention. Higher order thinking skills are necessary for learning and processing more intricate information and the development of more complex reasoning and sustained attention for learning. Executive functioning is thus the capacity to use certain thinking skills together in order to stop, think, plan and then act so that a child is able to function optimally in any situation. The child should be able to sustain attention and maintain a consistent behavioural response during activity, but he must also be able to shift his attention to something else and back again to the task on hand. Being able to work at the desired pace, understanding how much time it takes to accomplish something and how to plan for allowing enough time for completion, is important for successful task completion. In order to think, analyze, plan and do, a child has to hold all needed information in mind, while doing a specific complex task. Hence combining both memory and processing.	
Attention	Emily is able to concentrate adequately for her age and if performing something of interest. She does tend to get distractible in class but it is currently not affecting her academic performance. She is able to sustain, shift and divide her attention.
Memory	Emily shows no difficulty in short and long term memory. She also has good working memory for new tasks learned. It was noted that she struggled with fluctuating concept consolidation of shapes/numbers in her Grade R year.

Thought	Emily shows logical and coherent thought appropriate for her age.
Emotional	Over the years, Emily has shown an increasing range of appropriate emotions for her circumstances and contexts. She is able to express how she feels and also regulate her emotions. She does not show any signs of tantrums, meltdowns etc. She does show emotional distress with new changes, too much pressure or if someone raises their voice at her.
Global mental functions	
Orientation	Emily is orientated to person, place, time, self and others.
Temperament and personality	As mentioned before, Emily is shy at first meeting of new people or in new environments, thus making her a possible introvert. She does however show her bubbly, outspoken personality once she feels comfortable around people. She is agreeable, conscientious, shows emotional stability and strength, openness to experience, self-control, self-expression, confidence, is highly motivated and shows appropriate impulse control.
Energy and drive	Emily has an appropriate energy level for age. She is a highly motivated child who never gives up on a task. She has an increased inner drive to succeed at challenges thrown her way.
Sensory discriminatory functions	
Visual	According to a full eye examination, Emily shows adequate quality of vision, visual acuity, visual stability and visual field functions to promote visual awareness of environment at various distances for functioning.
Hearing	According to a hearing test, Emily shows adequate sound detection and discrimination, awareness of location and distance of sounds.
Vestibular	The vestibular system enables us to sense gravity, movement and head position in space and is important for ongoing eye control.

	The vestibular system develops knowledge about what is right side up, upside down, left, right, horizontal and vertical. It has a strong influence on postural muscle tone, postural control, balance and bilateral integration and sequencing. It seems as though Emily registers vestibular information adequately in terms of the position of her head against gravity. She does not show signs of gravitational insecurity and enjoys activities like jumping on the trampoline, swings, and slides, rolly polly's and the like. She has also developed astonishing balance in sitting and moving on her buttocks. Due to the fact that her ability to protect herself when she is thrown off balance is minimal, she does stand the risk of getting hurt and falling. Her protective mechanisms of lifting her face away from the ground when she is falling is intact.
Taste	Emily is able to distinguish between different tastes. She has no taste aversions.
Smell	Emily is able to distinguish between different odours.
Proprioceptive	Proprioception provides knowledge about the orientation of the body in space. It relates position of the different parts of the body to each other. Proprioceptive input is sent to the brain through receptors in the muscles, joints, tendons and ligaments. Emily shows appropriate proprioceptive registration and grading abilities. She shows awareness of where her body is in space. She shows good force grading of movement when building blocks, opening a lid of a container, throwing a ball etc.
Touch	Our tactile sense is our sense of touch (Tactile discrimination is the ability to distinguish between different textures, shapes, temperatures, deep pressure and vibration through the tactile organ, namely the skin – and tactile discrimination influences the development of fine motor skills.)

	Although, the amount of skin over limbs is limited, Emily seems to process tactile information effectively, if not more advanced than other children her age. Somatosensory testing also indicated that she has effective feedback from her tactile system. She is able to discriminate between different textures, shapes, temperatures and deep pressure through the tactile organ, namely the skin. Emily seems to register tactile information adequately. She is also able to distinguish between different textures using her left stump. She is able to locate light and deep touch inputs accurately.
Pain	Emily seems to feel pain adequately i.e. cuts, mosquito bites, stomach cramps etc.
Sensitivity to temperature	Emily is able to distinguish between hot and cold temperatures. She also shows a sensitivity to heat. Since she was a baby, she has been more prone to overheating, possibly due to the smaller surface area of her body used to release heat.
Neuromusculoskeletal and movement related functions	
Joint mobility	Emily shows no difficulty in her bilateral shoulder joint and hip joint range of motion. Her neck and spine ROM is also normal.
Joint Stability	Emily shows no difficulty in her bilateral shoulder joint and hip joint stability. Her neck and spine stability is also normal.
Muscle functions	
Muscle power	Emily shows a grade 5 strength in the existing muscles of her body as classified using the Manual Muscle Testing Grading System (Kendall, McCreary, Provance, Rodgers, & Romani, Muscles Testing and Function with Posture and Pain, 2005). This was tested by a prosthetist using a myo-electric sensor and computer program.

Muscle tone	Emily shows adequate muscle tone in her existing muscles. No spasticity, flaccidity or fluctuation present.
Muscle endurance	Emily shows no difficulty in sustaining muscular contractions in her existing muscles. This was tested by the prosthetist and can be seen in her many functional and play activities.
Movement functions	
Involuntary movement reactions	Emily is able to adjust her posture in her wheelchair, on a chair, or when sitting on the carpet. She is able to sit upright against gravity, although she does tend to sit slightly more slouched after a period of time. Due to the fact that her ability to protect herself when she is thrown off balance is minimal, she does stand the risk of getting hurt and falling. Her protective mechanisms of lifting her face away from the ground when she is falling is intact.
Control of voluntary movement	Emily's control of her voluntary movement is astonishing taking into consideration her physical limitations. In terms of a skill like eye-hand coordination, she has adapted to using her left stump as her 'hand' and has developed to be quite functional in fine and gross movement tasks. Although motor co-ordination tasks are not on par for her age and are challenging for her, she tries her best with what she has. In her early years, she mainly only used the left side of her body for tasks, but over time and with intervention, she now makes use of both sides of her body in tasks like climbing, floor mobility, holding a large object i.e. ball.
Cardiovascular, haematological, immunological and respiratory system functions Normal	
Voice and speech functions, digestive, metabolic, and endocrine system functions, reproductive functions	

Normal	
Body Structures - “Anatomical parts of the body, such as organs, limbs, and their components” that support body function (WHO, 2001, p10).	
Structures related to movement	Due to the fact that Emily has the absence of all four limbs, and only a partial upper left arm stump, she has limitations in certain movement activities and has compensated over her lifespan to complete activities in other ways and by using other body parts i.e. mouth.
PERFORMANCE SKILLS The following comments were made in conjunction with viewing videos of past play time, school and therapy sessions.	
Motor Skills - “Occupational performance skills observed as the person interacts with and moves task objects and self around the task environment” (e .g activity of daily living [ADL] motor skills, school motor skills; Boyt Schell, Gillen, & Scaffa, 2014a, p. 1237).	
Emily is able to align her posture to more optimally partake in an activity but does tend to make use of more propping actions to achieve the best posture or position. Although her core muscles are very strong, Emily does often lose her balance in interacting with tasks or a task environment due to her small base of support and lack of limbs for protective extension. Emily often has to position herself very close by to an object or task that she is interacting with due to the shortness of her left functional stump. This does often lead to awkward positioning. Emily attempts to reach for objects with her left stump. She is able to extend her stump at her shoulder and can bend her trunk to reach for objects that are not placed too far out of reach. If the object is out of reach, she will rather lie on her stomach and creep forward to reach the object. Emily is able to flex and rotate her trunk slightly, but doesn’t achieve full ROM due to balance difficulties. If she flexes too much, she will fall forward, and with	

rotation, she prefers to pivot on her buttocks to rotate her trunk more optimally. Emily has effectively learnt to grip objects with her teeth and mouth to compensate for her lack of dexterity (lack of hands and fingers).

Emily manipulates mostly with her left stump, mouth and inner neck on the left side of her body. Examples include holding a pencil, eating utensil, building blocks, puzzle pieces, balls etc…She is unable to perform very dexterous motions like tying a button, laces, zips etc. Emily is able to use 2 or more body parts together to manipulate, hold or stabilize task objects. As said above, she mainly uses her left stump, mouth and inner neck. She occasionally tries to bring in her right shoulder joint to stabilize a larger object. Even though she is becoming more proficient, she often drops objects and there is evidence of slipping and tumbling.

Emily is able to push and pull at objects like opening and closing drawers, pushing a toy along the floor etc. She makes use of full body movements and her left stump to hold or stabilise the object. She is also able to push and pull her control on her wheelchair to manoeuvre it. Emily is able to lift and raise objects that are not too heavy.

During task performance, Emily is able to 'walk' on her buttocks. This motion is slower than walking and takes more effort. If the surface is unstable, she has the risk of falling over. She mainly uses her wheelchair for speed and longer distances. If 'walking' without her wheelchair, it is very difficult to also be carrying something. If in her wheelchair, she is able to carry an object on the tray of her wheelchair. She obviously requires assistance to place the object on her tray.

Even though Emily is physically very limited, she has a great awareness of her strength and what force is needed in specific activities. I.e. less force in building blocks, more force in opening a sliding door etc. Emily does not always show fluid movements as she has to exert more effort and compensated forms of manipulation to achieve a desired action. Emily shows amazing endurance and a never give up attitude. She doesn't show evidence of physical fatigue, only asks for assistance if she knows she is unable to complete a task.

Process Skills - "Occupational performance skills [e .g ADL process skills, school process skills] observed as a person (1) selects, interacts with, and uses task tools

and materials; (2) carries out individual actions and steps; and (3) modifies performance when problems are encountered" (Boyt Schell et al ., 2014a, p . 1239) .

Emily doesn't always maintain a consistent and effective rate or tempo of performance throughout a task as some elements of the task may have more of a physically challenging component to it. Emily attends to the task at hand appropriately. Her focus and determination is good and she likes to complete a task. It has been said that she sometimes gets distracted in class in a multi-sensory environment.

She is able to follow instructions given by another person. She is not always able to complete all the steps, and she may look to compensatory ways of completing the task. Example: if the teacher asks for everyone to sit on the floor and build a tower, she may lie on the floor or build the tower on a small step/table/chair.

She is able to choose the correct tools and equipment needed for a task. She has a good concept of this. She may need assistance however in using different types of tools. She is able to use tools like a pencil, spade in a sandpit, eraser, fork etc. as they are intended. The quality and speed however may be compromised in any given task and she may need assistance with bilateral tasks like sharpening a pencil, opening a lid of a container etc.

As mentioned above, Emily will always try to use a utensil/tool as should be or as she see others use it, but she often has to compensate by using her mouth and at times struggles to effectively manipulate a tool with adequate quality. Emily will definitely inquire should she need assistance with a task. Emily is able to initiate a task. She is more comfortable with known tasks. She is sometimes hesitant with new tasks and may need to see a demonstration first.

Emily is able to continue with a task if the physical demands are in her abilities. If not, she will pause and ask for assistance. Emily has a good concept of the correct sequencing of known activities. Emily is able to terminate a task. She has an adequate concept of task completion. If she is left to do a task that is beyond her

physical abilities, she will stop the task before it is finished and move on to another task, or as for assistance.

She is able to look and locate tools and materials in a logical manner, both within and beyond the immediate environment. Emily struggles to organise tools on her workspace in a non-cluttered way due to her limited base of support and limited ability to reach to the farther corners of her workspace. She is able to pack away the tools used in any given task if within reach. She is able to navigate herself effectively in her wheelchair and without her wheelchair without bumping into objects or people.

Emily is able to adjust her body and tools within reach for any given task. She does however need assistance with minor adjustments like opening a tap, reaching to wash her stump at a high basin, opening a lid etc. Emily accommodates her actions on a daily basis and from task to task. She makes use of compensatory mechanisms and unique ways of completing tasks. She also often needs a facilitator or someone to structure her activity so that she can participate optimally and effectively.

Emily is a smart little girl. If she sees that the method she is using is not effective, she will try another way of completing or interacting in a task. She has good feed forward and feedback mechanisms in knowing what she has done in the past to be successful and to prevent problems from persisting or recurring.

Social Interaction Skills - Occupational performance skills observed during the ongoing stream of a social exchange" (Boyt Schell et al., 2014a, p .1241).

Although a shy personality initially, once she knows someone she is easily able to approach a friend and start a social interaction. Emily can effectively terminate a conversation or social interaction. Emily produces spoken messages that are audible and clearly articulated. Although her limbs are limited, she does use her left stump to gesticulate a direction, happiness or joy.

Emily is able to speak in a fluent and continuous manner, with an even pace and without any pauses or delays during the message being sent. Emily does actively

position or turn her bod and face toward the social partner. She makes adequate eye contact. She maintains an adequate space between a social partner.

Emily is often picked up by adults who wish to share a hug or a conversation. She does not make use of inappropriate touch in social interactions. She loves to ‘high-five’ or ‘shake hands’ with her left stump. Emily is able to request relevant facts and information and asks questions that support the intended purpose of the social interaction. Emily is able to keep a conversation going by replying appropriately to questions or comments.

Emily likes to share information about herself to others in a socially appropriate manner. Emily is an emotional child. She will display appropriate emotion when joyous, scared or hurt. Emily is able to thank someone for the receiving of gifts, services or compliments. Emily is able to reply to social messages without delay or hesitation or without interruption. Emily is able to take turns and gives the social partner the freedom to take his or her turn.

ANNEXURE H: REVISED KNOX PLAY SCALE

REVISED KNOX PRESCHOOL PLAY SCALE

Adapted from: *Play and Occupational Therapy for Children*, Parham and Fazio. Mosby, 1997*

0 TO 6 MONTHS	6 TO 12 MONTHS	12 TO 18 MONTHS
Space Management		
Gross motor: swipes, reaches, plays with hands and feet, moves to continue pleasant sensations	**Gross motor**: reaches in prone, crawls, sits with balance, able to play with toy while sitting, pulls to stand, cruises	**Gross motor**: stands unsupported, sits down, bends and recovers balance, walks with wide stance, broad movements involving large muscle groups, throws ball
Interest: people, gazes at faces, follows movements, attends to voices and sounds, explores self and objects within reach	**Interest**: follows objects as they disappear, anticipates movement, goal directed movement	**Interest**: practices basic movement patterns, experiments in movement, explores various kinesthetic and proprioceptive sensations, moving objects (i.e., balls, trucks, pull toys)
Material Management		
Manipulation: handles, mouths toys, bangs, shakes, hits	**Manipulation**: pulls, turns, pokes, tears, rakes, drops, picks up small object	**Manipulation**: throws, inserts, pushes, pulls, carries, turns, opens, shuts
Construction: brings two objects together.	**Construction**: combines related objects, puts object in container	**Construction**: stacks, takes apart, puts together, little attempt to make product, relates two objects appropriately (i.e., lid on pot)
Purpose: sensation-uses materials to see, touch, hear, smell, mouth	**Purpose**: action to produce effect, cause and effect toys	**Purpose**: variety of schemas, process important, trial and error, relational play
Attention: follows moving objects with eyes, 3 to 5 sec attention	**Attention**: 15 sec for detailed object, 30 sec for visual and auditory toy	**Attention**: rapid shifts
Pretense/Symbolic		
Imitation: of observed facial expressions and physical movement (i.e., smiling, pat-a-cake), imitates vocalizations	**Imitation**: Imitates observed actions, emotions, sounds and gestures not part of repertoire, patterns of familiar activities	**Imitation**: of simple actions, present events and adults, imitates novel movements, links simple schemas (i.e., puts person in car and pushes it)
Dramatization: not evident	**Dramatization**: not evident	**Dramatization**: beginning pretend using self (i.e., feeds self with spoon), pretend on animate and inanimate objects
Participation		
Type: solitary, no effort to interact with other children, enjoys being picked up, swung	**Type**: infant to infant interaction, responds differently to children and adults	**Type**: combination of solitary and onlooker, beginning interaction with peers
Cooperation: demands personal attention, simple give and take interaction with caretaker (tickling, peek-a-boo)	**Cooperation**: initiates games rather than follows, shows and gives objects	**Cooperation**: seeks attention to self, demands toys, points, shows, offers toys but somewhat possessive, persistent
Humor: smiles	**Humor**: smiles, laughs at physical games and in anticipation	**Humor**: laughs at incongruous events
Language: attends to sounds and voices, babbles, uses razzing sounds	**Language**: gestures intention to communicate, responds to familiar words and facial expressions, responds to questions	**Language**: jabbers to self during play, uses gestures and words to communicate wants, labels objects, greets others, responds to simple requests, teases, exclaims, protests, combines words and gestures

*Modified from Knox, S., (1974). A Play Scale. In M. Reilly (Ed:), *Play as Exploratory Learning*. Beverly Hills, CA: Sage Publications. Reprinted from Bledsoe, N., Shepherd, J. (1982), A study of reliability and validity of a preschool play scale. *American Journal of Occupational Therapy*, 36, 783-788, with permission from the publisher.

REVISED KNOX PRESCHOOL PLAY SCALE

18 TO 24 MONTHS	24 TO 30 MONTHS	30 TO 36 MONTHS
Space Management		
Gross motor: runs, squats, climbs on and off chairs, walks up and down stairs (step to gait), kicks ball, rides kiddy car	**Gross motor**: beginning integration of entire body in activities-concentrates on complex movements, jumps off floor, stands on one foot briefly, throws ball in stance without falling	**Gross motor**: runs around obstacles, turns corners, climbs nursery apparatus, walks up and down stairs (alternating feet), catches ball by trapping it, stands on tiptoe
Interest: means-end, multipart tasks	**Interest**: explores new movement patterns (i.e., jumping), makes messes	**Interest**: rough and tumble play
Material Management		
Manipulation: operates mechanical toy, pulls apart pop beads, strings beads	**Manipulation**: feels, pats, dumps, squeezes, fills	**Manipulation**: matches, compares
Construction: uses tools	**Construction**: scribbles, strings beads, puzzles 4 to 5 pieces, builds horizontally and vertically	**Construction**: multi-stage combinations
Purpose: foresight before acting	**Purpose**: process important-less interested in finished product (Le., scribbles, squeezes), plans actions	**Purpose**: toys with moving parts (i.e., dump trucks, jointed dolls)
Attention: quiet play 5 to 10 min; play with single object 5 min.	**Attention**: intense interest, quiet play up to 15 min, plays with single object or theme 5-10 min	**Attention**: 15 to 30 min.
Pretense/Symbolic		
Imitation: representational, recognizes ways to activate toys in imitation, deferred imitation	**Imitation**: of adult routine's with toy related mimicry (i.e., child feeding doll); imitates peers, representational play	**Imitation**: toys as agents (i.e., doll feeds self) more abstract representation of objects, multi-scheme combinations (i.e., feed doll, pat it, put to bed)
Dramatization: acts on doll (i.e., dresses, brushes hair), pretend actions on more than one object or person, combines two or more actions in pretend, imaginary objects	**Dramatization**: personifies dolls, stuffed animals, imaginary friends, portrays single character elaborates daily events with details	**Dramatization**: evolving episodic sequences (i.e., mixes cake, bakes it, serves it)
Participation		
Type: onlooker, simple actions and contingent responses between peers	**Type**: parallel (plays beside others but play remains independent), enjoys the presence of others, shy with strangers	**Type**: parallel, beginning associative, plays with 2 to 3 children, plays in company 1 to 2 hr
Cooperation: more complex games with a variety of adults (hide and seek, chasing), commands others to carry out actions	**Cooperation**: possessive, much snatch and grab, hoarding, no sharing, resists toys being taken away, independent, initiates own play	**Cooperation**: understands needs of others
Humor: laughs at incongruous labeling of objects or events	**Humor**: laughs at simple combinations of incongruous events and use of words	**Humor**: laughs at complex combinations of incongruous events and words
Language: comprehends action words, requests information, refers to persons and objects not present, combines words together	**Language**: talkative, very little jabber, begins to use words to communicate ideas, information, questions, comments on activity	**Language**: asks wh- questions, relates temporal sequences

REVISED KNOX PRESCHOOL PLAY SCALE

36 TO 48 MONTHS	48 TO 60 MONTHS	60 TO 72 MONTHS
Space Management		
Gross motor: more coordinated body movement, smoother walking, jumping, climbing, running, accelerates, decelerates, hops on one foot 3 to 5 times, skips on one foot, catches ball, throws ball using shoulder and elbow, jumps distances	**Gross motor**: in creased activity level, can concentrate on goal instead of movement, ease of gross motor ability, stunts, tests of strength, exaggerated movement, clambers, gallops, climbs ladder, catches ball with elbows at side	**Gross motor**: more sedate, good muscle control and balance, hops on one foot 5 + times, hops in a straight line, bounces and catches ball, skips, somersaults, skates, lifts self off ground
Interest: anything new, fine motor manipulation of play materials, challenges self with difficult tasks	**Interest**: takes pride in work (i.e., shows and talks about products, compares with friends, likes pictures displayed), complex ideas, rough and tumble play	**Interest**: in reality-manipulation of real-life situations, making something useful, permanence of products, toys that "really work"
Material Management		
Manipulation: small muscle activity - hammers, sorts, inserts small objects, cuts	**Manipulation**: increased fine motor control, quick movements, force, pulling, yanks	**Manipulation**: uses tools to make things, copies, traces, combines materials
Construction: makes simple products, combines play materials, takes apart, three-dimensional, design evident	**Construction**: makes products, specific designs evident, builds complex structures, puzzles 10 pieces	**Construction**: makes recognizable products, likes small construction, attends to detail, uses products in play
Purpose: beginning to show interest in finished product	**Purpose**: product very important and used to express self, exaggerates	**Purpose**; replicates reality
Attention: span around 30 min, plays with single object or them 10 min	**Attention**: amuses self up to 1 hr, plays with single object or theme 10 to 15 min	**Attention**: plays with single object or theme 15 + min
Pretense/symbolic		
Imitation: more complex imitation of real world, emphasis on domestic play and animals, symbolic, past experiences	**Imitation**: pieces together new scripts of adults (i.e., dress-up), reality important	**Imitation**: continues to construct new themes with emphasis on reality reconstruction of real world
Dramatization: complex scripts for pretend sequences in advance, story sequences, pretend with replica toys, uses one toy to represent another, portrays multiple characters with feelings (mostly anger and crying), little interest in costumes, imaginary characters	**Dramatization**: uses familiar knowledge to construct a novel situation (i.e., expanding on theme of a story or TV show), role playing for or with others, portrays more complex emotions, sequences stories, themes from domestic to magic, enjoys dress-up, shows off	**Dramatization**: sequences stories, costumes important, props, puppets, directs actions of three dolls-making them interact, organizes other children and props for role play
Participation		
Type: associative play, no organization to reach a common goal, more interest in peers than activity, enjoys companions, beginning cooperative play, group play	**Type**: cooperative, groups of 2 to 3 organized to achieve a goal, prefers playing with others to alone, group games with simple rules	**Type**: cooperative groups of 3 to 6, organization of more complex games and dramatic play, competitive games, understands rules of fair play
Cooperation: limited, some turn taking, asks for things rather than grabbing, little attempt to control others, separates easily, joins others in play	**Cooperation**: takes turns, attempts to control activities of others, bossy, strong sense of family and home, quotes parents as authorities	**Cooperation**: compromises to facilitate group play, rivalry in competitive play, games with rules, collaborative play where roles are coordinated and themes are goal directed
Humor: laughs at nonsense words, rhyming	**Humor**: distortions of the familiar	**Humor**: laughs at multiple meanings of words
Language: uses words to communicate with peers, interest in new words, sings simple songs, uses descriptive vocabulary, changes speech depending on listener	**Language**: plays with words, fabricates, long narratives, questions persistently, communicates with peers to organize activities, brags, threatens, clowns, sings whole songs, uses language to express roles, verbal reasoning	**Language**: prominent in socio-dramatic play, uses words as part of playas well as to organize play, interest in present, conversation like adults', uses relational terms, sings and dances to reflect meaning of songs

ANNEXURE I: QUEST ASSISTIVE DEVICE OUTCOME MEASURE

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Quebec User Evaluation of Satisfaction with assistive Technology

QUEST (Version 2.0)

Technology device: _____

User name: _____

Date of assessment :_____

The purpose of the **QUEST** questionnaire is to evaluate how satisfied you are with your assistive device and the related services you experienced. The questionnaire consists of 12 satisfaction items.

- For each of the 12 items, rate your satisfaction with your assistive device and the related services you experienced by using the following scale of 1 to 5.

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

- Please circle or mark the **one number** that best describes your degree of satisfaction with each of the 12 items.
- D**o not** leave any question unanswered.
- For any item that you were not "very satisfied", please comment in the section ***comments***.

Thank you for completing the QUEST questionnaire.

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

ASSISTIVE DEVICE ***How satisfied are you with,***	
1. the **dimensions** (size, height, length, width) of your assistive device? *Comments*:	1 2 3 4 5
2. the **weight** of your assistive device? *Comments*:	1 2 3 4 5
3. the **ease in adjusting** (fixing, fastening) the parts of your assistive device? *Comments*:	1 2 3 4 5
4. how **safe and secure** your assistive device is? *Comments*:	1 2 3 4 5
5. the **durability** (endurance, resistance to wear) of your assistive device? *Comments*:	1 2 3 4 5
6. how **easy** it is to use your assistive device? *Comments*:	1 2 3 4 5
7. how **comfortable** your assistive device is? *Comments*:	1 2 3 4 5
8. how **effective** your assistive device is (the degree to which your device meets your needs)? *Comments*:	1 2 3 4 5

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

SERVICES ***How satisfied are you with,***	
9. the **service delivery** program (procedures, length of time) in which you obtained your assistive device? *Comments*:	1 2 3 4 5
10. the **repairs and servicing** (maintenance) provided for your assistive device? *Comments*:	1 2 3 4 5
11. the quality of the **professional services** (information, attention) you received for using your assistive device? *Comments*:	1 2 3 4 5
12. the **follow-up services** (continuing support services) received for your assistive device? *Comments*:	1 2 3 4 5

- Below is the list of the same 12 satisfaction items. PLEASE **SELECT THE THREE ITEMS** that you consider to be **the most important to you**. Please put an X in the **3 boxes** of your choice.

☐	1. Dimensions	☐	7. Comfort
☐	2. Weight	☐	8. Effectiveness
☐	3. Adjustments	☐	9. Service delivery
☐	4. Safety	☐	10. Repairs/servicing
☐	5. Durability	☐	11. Professional service
☐	6. Easy to use	☐	12. Follow-up services

QUEST
Scoring Sheet

This page is for scoring the answers to your questions.

DO NOT WRITE ON THIS PAGE.

- Number of non-valid responses _____ ☐

- **Device** subscale score _____ ☐

  For items 1 to 8, add the ratings of the valid responses and divide this sum by the number of valid items in this scale.

- **Services** subscale score _____ ☐

  For items 9 to 12, add the ratings of the valid responses and divide this sum by the number of valid items in this scale.

- Total QUEST score _____ ☐

  For items 1 to 12, add the ratings of the valid responses and divide this sum by the number of valid items.

- The 3 most important satisfaction items:

  _____

  _____

  _____

QUEST
(version 2.0)

1	2	3	4	5
not satisfied at all	not very satisfied	more or less satisfied	quite satisfied	very satisfied

ANNEXURE J: GAUTENG DEPARTMENT OF EDUCATION LETTER OF APPROVAL

GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

8/4/4/1/2

GDE AMENDED RESEARCH APPROVAL LETTER

Date:	04 April 2017
Validity of Research Approval:	06 February 2017 – 29 September 2017 2017/61AA
Name of Researcher:	Pretorius M.N
Address of Researcher:	P.O. Box 37611
	Faerie Glen
	Pretoria, 0043
Telephone Number:	083 391 0773
Email address:	Melissa.n.lowe@gmail.com
Research Topic:	The contribution of occupational therapy in the holistic management of a child with "Tetra-Amelia Syndrome"
Number and type of schools:	One LSEN School
District/s/HO	Tshwane North

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

23/08/2017

The following conditions apply to GDE research. The researcher may proceed with the

1

Making education a societal priority

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

1. *The District/Head Office Senior Manager/s concerned must be presented with a copy of this letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
4. *A letter / document that outlines the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
5. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
6. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
7. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
8. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
9. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
10. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
11. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
12. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
13. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
14. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

.....

Ms Faith Tshabalala
CES: Education Research and Knowledge Management

DATE: 23/08/2017

Making education a societal priority

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za

ANNEXURE K: INFORMED CONSENT TEMPLATE

Informed consent form

Good day

The researcher, Ms Melissa Pretorius aims to undertake a Masters research study exploring the contribution of occupational therapy in the holistic management of a child with Tetra-Amelia Syndrome. You have been chosen to take part in this specific study due to the role you have played in this specific child's life. Semi-structured interview sessions will be used to collect the necessary data required. Your assistance and co-operation in this regard would be greatly appreciated.

1. Title of research project:

"The contribution of occupational therapy in the holistic management of a child with Tetra-Amelia Syndrome."

2. I …… hereby voluntarily grant my permission (provisional) for participation in the project as explained to me by the researcher (Ms Melissa Pretorius).

3. The nature, objective, possible safety and health implications have been explained to me and I understand them.

4. I understand my right to choose whether to participate in the project and that the information furnished will be handled confidentially. I am aware that the results of the investigation may be used for the purposes of publication.

5. Upon signature of this form, you will be provided with a copy.

Signed: _____ Date: _____

Witness: _____ Date: _____

Researcher: _____ Date: _____

ANNEXURE L: DECLARATION REGARDING PLAGIARISM

FORM A

UNIVERSITY OF PRETORIA

FACULTY Health care Sciences

DEPARTMENT Occupational Therapy

The Department Occupational Therapy places specific emphasis on integrity and ethical behaviour with regard to the preparation of all written work to be submitted for academic evaluation.

Although academic personnel will provide you with information regarding reference techniques as well as ways to avoid plagiarism, you also have a responsibility to fulfil in this regard. Should you at any time feel unsure about the requirements, you must consult the lecturer concerned before you submit any written work.

You are guilty of plagiarism when you extract information from a book, article or web page without acknowledging the source and pretend that it is your own work. In truth, you are stealing someone else's property. This doesn't only apply to cases where you quote verbatim, but also when you present someone else's work in a somewhat amended format (paraphrase), or even when you use someone else's deliberation without the necessary acknowledgement. You are not allowed to use another student's previous work. You are furthermore not allowed to let anyone copy or use your work with the intention of presenting it as his/her own.

Students who are guilty of plagiarism will forfeit all credit for the work concerned. In addition, the matter can also be referred to the Committee for Discipline (Students) for a ruling to be made. Plagiarism is considered a serious violation of the University's regulations and may lead to suspension from the University.

For the period that you are a student at the Department Occ Therapy, the under-mentioned declaration must accompany all written work to be submitted. No written work will be accepted unless the declaration has been completed and attached.

I (full names) Melissa Nicole Pretorius

Student number 28000308

Subject of the work Paediatrics

Declaration

1. I understand what plagiarism entails and am aware of the University's policy in this regard.
2. I declare that this dissertation (e.g. essay, report, project, assignment, dissertation, thesis etc) is my own, original work. Where someone else's work was used (whether from a printed source, the internet or any other source) due acknowledgement was given and reference was made according to departmental requirements.
3. I did not make use of another student's previous work and submitted it as my own.
4. I did not allow and will not allow anyone to copy my work with the intention of presenting it as his or her own work.

Signature 

ANNEXURE M: DECLARATION OF STORAGE

Principal Investigator's Declaration for the storage of research data and/or documents

I, the Principal Investigator(s), Melissa Pretorius of the following trial/study titled **"The contribution of occupational therapy in the holistic management of a child with Tetra-Amelia Syndrome."**

will be storing all the research data and/or documents referring to the above mentioned trial/study at the following non-residential address:

University of Pretoria

Department of Occupational Therapy

Faculty of Health Sciences

School of Healthcare Sciences

Prinshof Medical Campus

H W Snyman South Building

Bophelo Road 31

Gezina, 0002

I understand that the storage for the abovementioned data and/or documents must be maintained for a minimum of 15 years from the end of this trial/study.

START DATE OF TRIAL/STUDY: 15/07/2017 END DATE OF TRIAL/STUDY: 30/11/ 2017

SPECIFIC PERIOD OF DATA STORAGE AMOUNTING TO NO LESS THAN 15 YEARS:

July 2017 until August 2032

Name _____

Signature _____ **Date** _____

ANNEXURE N: DECLARATION OF HELSINKI

Special Communication

World Medical Association Declaration of Helsinki
Ethical Principles for Medical Research Involving Human Subjects

World Medical Association

Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964, and amended by the:
29th WMA General Assembly, Tokyo, Japan, October 1975
35th WMA General Assembly, Venice, Italy, October 1983
41st WMA General Assembly, Hong Kong, September 1989
48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996
52nd WMA General Assembly, Edinburgh, Scotland, October 2000
53rd WMA General Assembly, Washington, DC, USA, October 2002 (Note of Clarification added)
55th WMA General Assembly, Tokyo, Japan, October 2004 (Note of Clarification added)
59th WMA General Assembly, Seoul, Republic of Korea, October 2008
64th WMA General Assembly, Fortaleza, Brazil, October 2013

Preamble

1. The World Medical Association (WMA) has developed the Declaration of Helsinki as a statement of ethical principles for medical research involving human subjects, including research on identifiable human material and data.

   The Declaration is intended to be read as a whole and each of its constituent paragraphs should be applied with consideration of all other relevant paragraphs.

2. Consistent with the mandate of the WMA, the Declaration is addressed primarily to physicians. The WMA encourages others who are involved in medical research involving human subjects to adopt these principles.

General Principles

3. The Declaration of Geneva of the WMA binds the physician with the words, "The health of my patient will be my first consideration," and the International Code of Medical Ethics declares that, "A physician shall act in the patient's best interest when providing medical care."

4. It is the duty of the physician to promote and safeguard the health, well-being and rights of patients, including those who are involved in medical research. The physician's knowledge and conscience are dedicated to the fulfilment of this duty.

5. Medical progress is based on research that ultimately must include studies involving human subjects.

6. The primary purpose of medical research involving human subjects is to understand the causes, development and effects of diseases and improve preventive, diagnostic and therapeutic interventions (methods, procedures and treatments). Even the best proven interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality.

7. Medical research is subject to ethical standards that promote and ensure respect for all human subjects and protect their health and rights.

8. While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects.

9. It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects. The responsibility for the protection of research subjects must always rest with the physician or other health care professionals and never with the research subjects, even though they have given consent.

10. Physicians must consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration.

11. Medical research should be conducted in a manner that minimises possible harm to the environment.

12. Medical research involving human subjects must be conducted only by individuals with the appropriate ethics and scientific education, training and qualifications. Research on patients or healthy volunteers requires the supervision of a competent and appropriately qualified physician or other health care professional.

13. Groups that are underrepresented in medical research should be provided appropriate access to participation in research.

14. Physicians who combine medical research with medical care should involve their patients in research only to the extent that this is justified by its potential preventive, diagnostic or therapeutic value and if the physician has good reason to believe that participation in the research study will not adversely affect the health of the patients who serve as research subjects.

15. Appropriate compensation and treatment for subjects who are harmed as a result of participating in research must be ensured.

Risks, Burdens and Benefits

16. In medical practice and in medical research, most interventions involve risks and burdens.

    Medical research involving human subjects may only be conducted if the importance of the objective outweighs the risks and burdens to the research subjects.

17. All medical research involving human subjects must be preceded by careful assessment of predictable risks and burdens to the individuals and groups involved in the research in comparison with foreseeable benefits to them and to other individuals or groups affected by the condition under investigation.

    Measures to minimise the risks must be implemented. The risks must be continuously monitored, assessed and documented by the researcher.

18. Physicians may not be involved in a research study involving human subjects unless they are confident that the risks have been adequately assessed and can be satisfactorily managed.

    When the risks are found to outweigh the potential benefits or when there is conclusive proof of definitive outcomes, physicians must assess whether to continue, modify or immediately stop the study.

Vulnerable Groups and Individuals

19. Some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm.

    All vulnerable groups and individuals should receive specifically considered protection.

20. Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research.

Scientific Requirements and Research Protocols

21. Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and adequate laboratory and, as appropriate, animal experimentation. The welfare of animals used for research must be respected.

22. The design and performance of each research study involving human subjects must be clearly described and justified in a research protocol.

    The protocol should contain a statement of the ethical considerations involved and should indicate how the principles in this Declaration have been addressed. The protocol should include information regarding funding, sponsors, institutional affiliations, potential conflicts of interest, incentives for subjects and information regarding provisions for treating and/or compensating subjects who are harmed as a consequence of participation in the research study.

    In clinical trials, the protocol must also describe appropriate arrangements for post-trial provisions.

Research Ethics Committees

23. The research protocol must be submitted for consideration, comment, guidance and approval to the concerned research ethics committee before the study begins. This committee must be transparent in its functioning, must be independent of the researcher, the sponsor and any other undue influence and must be duly qualified. It must take into consideration the laws and regulations of the country or countries in which the research is to be performed as well as applicable international norms and standards but these must not be allowed to reduce or eliminate any of the protections for research subjects set forth in this Declaration.

    The committee must have the right to monitor ongoing studies. The researcher must provide monitoring information to the committee, especially information about any serious adverse events. No amendment to the protocol may be made without consideration and approval by the committee. After the end of the study, the researchers must submit a final report to the committee containing a summary of the study's findings and conclusions.

Privacy and Confidentiality

24. Every precaution must be taken to protect the privacy of research subjects and the confidentiality of their personal information.

Informed Consent

25. Participation by individuals capable of giving informed consent as subjects in medical research must be voluntary. Although it

may be appropriate to consult family members or community leaders, no individual capable of giving informed consent may be enrolled in a research study unless he or she freely agrees.

26. In medical research involving human subjects capable of giving informed consent, each potential subject must be adequately informed of the aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, post-study provisions and any other relevant aspects of the study. The potential subject must be informed of the right to refuse to participate in the study or to withdraw consent to participate at any time without reprisal. Special attention should be given to the specific information needs of individual potential subjects as well as to the methods used to deliver the information.

    After ensuring that the potential subject has understood the information, the physician or another appropriately qualified individual must then seek the potential subject's freely-given informed consent, preferably in writing. If the consent cannot be expressed in writing, the non-written consent must be formally documented and witnessed.

    All medical research subjects should be given the option of being informed about the general outcome and results of the study.

27. When seeking informed consent for participation in a research study the physician must be particularly cautious if the potential subject is in a dependent relationship with the physician or may consent under duress. In such situations the informed consent must be sought by an appropriately qualified individual who is completely independent of this relationship.

28. For a potential research subject who is incapable of giving informed consent, the physician must seek informed consent from the legally authorised representative. These individuals must not be included in a research study that has no likelihood of benefit for them unless it is intended to promote the health of the group represented by the potential subject, the research cannot instead be performed with persons capable of providing informed consent, and the research entails only minimal risk and minimal burden.

29. When a potential research subject who is deemed incapable of giving informed consent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorised representative. The potential subject's dissent should be respected.

30. Research involving subjects who are physically or mentally incapable of giving consent, for example, unconscious patients, may be done only if the physical or mental condition that prevents giving informed consent is a necessary characteristic of the research group. In such circumstances the physician must seek informed consent from the legally authorised representative. If no such representative is available and if the research cannot be delayed, the study may proceed without informed consent provided that the specific reasons for involving subjects with a condition that renders them unable to give informed consent have been stated in the research protocol and the study has been approved by a research ethics committee. Consent to remain in the research must be obtained as soon as possible from the subject or a legally authorised representative.

31. The physician must fully inform the patient which aspects of their care are related to the research. The refusal of a patient to participate in a study or the patient's decision to withdraw from the study must never adversely affect the patient-physician relationship.

32. For medical research using identifiable human material or data, such as research on material or data contained in biobanks or similar repositories, physicians must seek informed consent for its collection, storage and/or reuse. There may be exceptional situations where consent would be impossible or impracticable to obtain for such research. In such situations the research may be done only after consideration and approval of a research ethics committee.

Use of Placebo

33. The benefits, risks, burdens and effectiveness of a new intervention must be tested against those of the best proven intervention(s), except in the following circumstances:

    Where no proven intervention exists, the use of placebo, or no intervention, is acceptable; or

    Where for compelling and scientifically sound methodological reasons the use of any intervention less effective than the best proven one, the use of placebo, or no intervention is necessary to determine the efficacy or safety of an intervention

    and the patients who receive any intervention less effective than the best proven one, placebo, or no intervention will not be subject to additional risks of serious or irreversible harm as a result of not receiving the best proven intervention.

    Extreme care must be taken to avoid abuse of this option.

Post-Trial Provisions

34. In advance of a clinical trial, sponsors, researchers and host country governments should make provisions for post-trial access for all participants who still need an intervention identified as beneficial in the trial. This information must also be disclosed to participants during the informed consent process.

Research Registration and Publication and Dissemination of Results

35. Every research study involving human subjects must be registered in a publicly accessible database before recruitment of the first subject.

36. Researchers, authors, sponsors, editors and publishers all have ethical obligations with regard to the publication and dissemination of the results of research. Researchers have a duty to make publicly available the results of their research on human subjects and are accountable for the completeness and accuracy of their reports. All parties should adhere to accepted guidelines for ethical reporting. Negative and inconclusive as well as positive results must be published or otherwise made publicly available. Sources of funding, institutional affiliations and conflicts of interest must be declared in the publication. Reports of research not in accordance with the principles of this Declaration should not be accepted for publication.

Unproven Interventions in Clinical Practice

37. In the treatment of an individual patient, where proven interventions do not exist or other known interventions have been ineffective, the physician, after seeking expert advice, with informed consent from the patient or a legally authorised representative, may use an unproven intervention if in the physician's judgement it offers hope of saving life, re-establishing health or alleviating suffering. This intervention should subsequently be made the object of research, designed to evaluate its safety and efficacy. In all cases, new information must be recorded and, where appropriate, made publicly available.

ARTICLE INFORMATION

Corresponding Author: World Medical Association, 13, ch. du Levant, CIB - Bâtiment A, 01210 Ferney-Voltaire, France; wma@wma.net.

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Online-Only Content: Audio podcast is available at www.jama.com.

ANNEXURE O: FACULTY OF HEALTH SCIENCES POST-GRADUATE COMMITTEE APPROVAL LETTER

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.
- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee

25/08/2017

Approval Certificate
New Application

Ethics Reference No: 289/2017

Title: The contribution of Occupational Therapy in the holistic management of a child with Tetra-Amelia syndrome

Dear Melissa Nicole Pretorius-Lowe

The **New Application** as supported by documents specified in your cover letter dated 29/06/2017 for your research received on the 29/06/2017 was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 25/08/2017.

Please note the following about your ethics approval:
- Ethics Approval is valid for 1 year.
- Please remember to use your protocol number (**289/2017**) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, or monitor the conduct of your research.

Ethics approval is subject to the following:
- The ethics approval is conditional on the receipt of **6 monthly written Progress Reports**, and
- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Additional Conditions:
- **The publication of photographic material must be restricted. The University must be prohibited from publishing the thesis with the material in on the internet.**

We wish you the best with your research.

Yours sincerely

Dr R Sommers; MBChB; MMed (Int); MPharMed,PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

☎ 012 356 3084 deepeka.behari@up.ac.za http://www.up.ac.za/healthethics
✉ Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60, 9 Bophelo Road, Gezina, Pretoria

ANNEXURE P: OCCUPATIONAL THERAPY PRACTICE FRAMEWORK OBSERVATIONAL GUIDE

Occupational Therapy Practice Framework
Name of client: *Emily

Only applicable sections of the OTPF have been selected for the purposes of this study.

1. OCCUPATIONS	
Category	Description
Activities of Daily Living (ADLs) – Activities oriented to taking care of one's own body	
Bathing/showering	
Toileting and toilet hygiene	
Dressing	
Swallowing/eating	
Feeding	
Functional mobility	
Personal device care	
Personal hygiene and grooming	
Instrumental Activities of Daily Living (IADLs) – Activities to support daily life within the home and the community that often require more complex interactions than those in ADLs	
Communication management	
Community mobility	
Meal preparation	

Rest and Sleep – Activities related to obtaining restorative rest and sleep to support healthy, active engagement in other occupations

Rest

Sleep preparation and participation

Education – Activities needed for learning and participation in the educational environment

Formal educational participation

Play – Any spontaneous or organized activity that provides enjoyment, entertainment, amusement or diversion

Play exploration

Play participation

Social Participation – "The interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends" (Gillen & Boyt Schell, 2014, p . 607)

Community i.e. school

Family

Peer, friend

2. CLIENT FACTORS

Body Functions - "The physiological functions of body systems (including psychological functions)" (WHO, 2001, p.10). This section of the table is organized according to the classifications of the International Classification of Functioning, Disability and Health (ICF)

Mental functions

Attention

Memory

Thought

Emotional

Global mental functions

Orientation

Temperament and personality

Energy and drive

Sensory functions

Visual

Hearing

Vestibular

Taste

Smell

Proprioceptive

Touch

Pain

Sensitivity to temperature

Neuromusculoskeletal and movement related functions

Joint mobility

Joint Stability

Muscle functions

Muscle power

Muscle tone

Muscle endurance

Movement functions

Involuntary movement reactions

Control of voluntary movement

Body Structures - “Anatomical parts of the body, such as organs, limbs, and their components” that support body function (WHO, 2001, p10) .

Structures related to movement

3. PERFORMANCE SKILLS

Motor Skills - “Occupational performance skills observed as the person interacts with and moves task objects and self around the task environment” (e .g activity of daily living [ADL] motor skills, school motor skills; Boyt Schell, Gillen, & Scaffa, 2014a, p. 1237).

Aligns

Stabillises

Positions

Reaches

Bends

Grips

Manipulates

Coordinates

Moves

Lifts

Walks

Transports

Calibrates

Flows

Endures

Paces

Process Skills - “Occupational performance skills [e .g ADL process skills, school process skills] observed as a person (1) selects, interacts with, and uses task tools and materials; (2) carries out individual actions and steps; and (3) modifies performance when problems are encountered” (Boyt Schell et al ., 2014a, p . 1239) .

Paces

Attends

Heeds

Chooses

Uses

Handles

Inquires

Initiates

Continues

Sequences

Terminates

Searches/locates

Gathers

Organizes

Restores

Navigates

Notices/responds

Adjusts

Accommodates

Benefits

Social Interaction Skills - Occupational performance skills observed during the ongoing stream of a social exchange" (Boyt Schell et al ., 2014a, p .1241).

Approaches/starts

Concludes/disengages

Produces speech

Gesticulates

Speaks fluently

Turns toward

Looks

Places self

Touches

Regulates

Questions

Replies

Discloses

Expresses emotion

Disagrees

Thanks

Transitions

Times response

Times duration

Takes turns

Matches language

Clarifies

Acknowledges and encourages

Emphasizes

Heeds

Accommodates

Benefits

4. CONTEXT AND ENVIRONMENT

Context

Cultural

Personal

Temporal

Virtual

Environments

Physical

Social

5. TYPES OF OCCUPATIONAL THERAPY INTERVENTION

Occupations and Activities - Occupations and activities selected as interventions for specific clients and designed to meet therapeutic goals and address the underlying needs of the mind, body, and spirit of the client. To use occupations and activities therapeutically, the practitioner considers activity demands and client factors in relation to the client's therapeutic goals, contexts, and environments

Occupations

Activities

Preparatory methods and tasks - Methods and tasks that prepare the client for occupational performance, used as part of a treatment session in preparation for or concurrently with occupations and activities or provided to a client as a home-based engagement to support daily occupational performance

Preparatory methods

Splints

Assistive technology and environmental adaptations

Wheeled mobility

Preparatory tasks

Education & Training

Training

Advocacy - Efforts directed toward promoting occupational justice and empowering clients to seek and obtain resources to fully participate in daily life occupations. The outcomes of advocacy and self-advocacy support health, well-being, and occupational participation at the individual or systems level.

Advocacy

6. APPROACHES TO INTERVENTION

Create, promote

Establish, restore (remediation, restoration)

Maintain

Modify (compensation, adaptation)

Prevent

7. OUTCOMES

Occupational Performance

Improvement

Enhancement

Prevention

Health and Wellness

Quality of life

Participation

Role Competence

Well-being

Occupational justice

ANNEXURE Q: ASSENT DOCUMENT

PATIENT OR PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT

STUDY TITLE: The contribution of occupational therapy to the holistic management of a child with Tetra-Amelia Syndrome

Principal Investigators: Mrs M N Pretorius

Institution: Private

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers: 0833910773

Afterhours: 0833910773

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Dear Patient

Consent and assent:

If there are children younger than 7 years in your study, the parents give consent on their behalf and you will need to adapt the information leaflet by substituting "you" with "your child".

For children between 7 and 18 years, parents give consent for their child to participate in the study and the child gives assent. Adapt the form below for that purpose too. Both information leaflets and the consent /assent form have to be included with your application.

Dear date of consent procedure …...../…...../…...

1) INTRODUCTION

Your child is invited to volunteer for a research study. This information leaflet is to help you to decide if you give consent for her to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

Your child is invited to take part in a research study. The aim of this study is to evaluate the contribution of occupational therapy to the management of Tetra-Amelia Syndrome. By doing so we

wish to learn more about the effectiveness of early intervention, assistive devices and school inclusivity.

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves participation in standardized testing (non-invasive), video recordings and semi-structured interviews.

4) POSSIBLE BENEFITS OF THIS STUDY.

It will provide greater awareness and insight with regards to the effectiveness of occupational therapy for a child with Tetra-Amelia syndrome. It will raise awareness of the condition amongst other health professionals. It will provide insight for future planning of the management for children born with Tetra-Amelia syndrome.

5) I may at any time withdraw my child from this study.

6) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding doctors in biomedical research involving human/subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

7) INFORMATION

If I have any questions concerning this study, I should contact:

Ms Melissa Pretorius cell: 0833910773

8) CONFIDENTIALITY

All records obtained whilst in this study will be regarded as confidential. Results will be published or presented in such a fashion that patients remain unidentifiable.

9) CONSENT TO PARTICIPATE IN THIS STUDY.

I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not give consent for my child to participate it will not alter her management in any way. I hereby give consent for my child to take part in this study.

I have received a signed copy of this informed consent agreement.

.....	.....
Guardian name	Date
.....	.....
Guardian signature	Date
.....	.....
Investigator's name	Date
.....	.....
Investigator's signature	Date
.....	.....
Witness name and signature	Date