

# UNIVERSITEIT VAN PRETORIA UNIVERSITY OF PRETORIA YUNIBESITHI YA PRETORIA

**Faculty of Health Sciences** School of Health Care Sciences Department of Occupational therapy

# The impact of Ayres Sensory Integration® on occupational performance in a child with bilateral cochlear implants

# Masters of Occupational Therapy (MOccTher)

Submitted by:

# Stefanie Marguerite Kruger

Student number: 94285269

A dissertation submitted to the Faculty of Heath Sciences

in fulfilment of the requirements for a Master's Degree in Occupational Therapy

# Contact details:

- Address: Nr. 482 The Wishbone North, Lynnwood, Pretoria
- Cell: 082 820 1837
- E-mail: stefanie@dreamnet.co.za

Supervisor:Prof Kitty UysCo-supervisor:Dr Ronell Leech

4 February 2020

# DECLARATION

I, Stefanie Kruger (student number 94285269) hereby declare that:

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- 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
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 Control 12 356 3084
 Private Bag X323, Arcadia, 0007
 - Tswelopele Building, Level 4, Room 60 / 61, 31 Bophelo Road, Gezina, Pretoria 1 http://www.up.ac.za/healthethics

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# ABSTRACT

Children with profound hearing impairments are receiving cochlear implants at an increasingly younger age resulting in the need for early therapeutic support and intervention. Besides the obvious concerns regarding speech and language development, children with cochlear implants are also at risk for motor and balance deficits.

This was a retrospective, longitudinal, experimental holistic single case study. The aim was to determine the impact of Ayres Sensory Integration® on occupational performance in a child with bilateral cochlear implants within the first four years after implantation. Six objectives were addressed. Quantitative and qualitative methods were used including designing an observation tool, administering stardardised tests, conducting a parent interview and obtaining perspective from the cochlear team to obtain rich in-depth knowledge and perspective. Pre- and post-intervention results were compared to determine changes in sensory perception, sensory reactivity, motor development and participation in occupations. Intervention adhered to the fidelity requirements of Ayres Sensory Integration®.

Results indicated that there were positive changes in the child's sensory processing and participation in occupations. Ayres Sensory Integration® was therefore an effective therapeutic approach for this child with cochlear implants. The cochlear team gained valuable insights and the parents indicated that occupational therapy intervention had a significant impact on the whole family unit. This study can contribute to the professional body of knowledge by building onto the knowledge base and skills repertoire regarding the application of therapeutic principles to children with cochlear implants. The occupational therapist can make a valuable contribution to the cochlear team. Optimal integration of sensory input can assist with promoting cochlear usage, not only for acquiring language, but also for developing age-appropriate skills at a critical stage of development to facilitate successful participate in childhood occupations.

#### Key words:

Ayres Sensory Integration® Cochlear Implants Childhood Occupations Occupational Therapist Sensory Over-reactivity Sensory Perception Sensory Integrative Dysfunction

# **DEFINITION OF TERMS**

**Ayres Sensory Integration (ASI®)** refers to the theory and concepts identified by Dr AJ Ayres which includes the development of standardised assessments and interventions within the field of occupational therapy.<sup>1</sup> ASI® is rooted in neuroscience literature and makes the connection between the brain and behaviour.<sup>2</sup> Sensory input is enhanced by motor activity, and are important mediators for neuroplasticity. Changes in behaviours are linked to changes in neural processes. Dr Ayres defined sensory integration as the "*organisation of sensory input for use*".<sup>1</sup> The "*use*" may be a perception of the body or environment, an adaptive response, a learning process or development of some neural function. Through ASI®, many parts of the nervous system work together so that a person can interact with the environment effectively, and experience appropriate satisfaction in life. Nervous system integration of sensory information is crucial for use in adaptive behaviour such as dealing with changes and challenges in the environment.<sup>3,4</sup>

**Cochlear implants (CIs)** are medical devices that are surgically implanted into the cochlea, inside the inner ear, to provide sound to profound hearing-impaired individuals. The purpose is to allow access to sound to improve listening, speech and language skills. CIs convert sound into an electrical stimulus that bypasses the cochlear hair cells and directly stimulates the cochlear nerve.<sup>5,6,7</sup>

**The vestibular system** is situated in the inner ear with the cochlea on both sides of the head. The vestibular system contains two types of receptor cells: (i) gravity receptors (otolith organs) to detect changes in head position and pull of gravity, and (ii) three pairs of closed tubes (semicircular canals) which contain fluid detecting changes in speed and direction of rapid head movements.<sup>1</sup>

**The proprioceptive system** refers to the sensations from the body's muscles and joints. Proprioceptive input tells the brain when and how the muscles are contracting or stretching and how the joints are being moved e.g. extending or being pulled or compressed. Proprioceptive information tells the brain where each part of the body is, and how it is moving.<sup>1</sup>

**Body scheme / percept** refers to an individual's perception of his/her own body. It consists of sensory pictures or "maps" of the body which are stored in the brain.<sup>1</sup>

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**Occupations** within the context of occupational therapy are described as daily life activities in which people engage. Occupations are categorised by the Occupational Therapy Practice Framework (OTPF) as activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation.<sup>8</sup>

**Occupational performance** is the act of doing and accomplishing a selected action, activity, or occupation. Improving or enabling occupational performance that leads to engagement in occupations or activities that can be observed.<sup>8</sup>

**Occupational therapy** is the therapeutic use of everyday life activities (occupations) for the purpose of enhancing or enabling participation in roles, habits, routines, and rituals in a meaningful setting such as home, school, workplace and community.<sup>8</sup>

**Sensory processing** refers to the method and manner of sensation detection and transmission through the central nervous system.<sup>1</sup>

**Sensory perception** is the ability of an individual to take in sensory information from the physical environment and to interpret and perceive qualities of this information. This includes the spatial and temporal features of an input e.g. what is it, and where is it coming from?<sup>9</sup>

**Sensory discrimination** is the ability to perceive various details of sensation. It can occur within one system such as light touch, texture and deep touch pressure through the tactile system. It can also occur between different sensations such as smell and taste, or vision and hearing<sup>1</sup>. It also refers to the ability to interpret the spatial and temporal qualities of sensation to provide an individual with clear, rapid and precise details of the body and the environment (such as quality, quantity, type, location, size, speed, shape of input).<sup>3</sup>

Sensory reactivity refers to an individual's level of behavioural responses to sensation.9

**Sensory over-reactivity** can be identified by observing behaviour and is considered as a modulation disorder where the behavioural reaction is out of proportion to sensory input.<sup>1</sup>

**Self-regulation** is the ability of an individual to apply strategies so that he/she can achieve an organised state of behaviour to successfully adapt behaviour to match environmental demands.<sup>9,10</sup>

**Sensory modulation** is the brain's regulation of its own activity. It involves facilitating some neural messages to produce more of a perception or response, and inhibiting other messages to reduce excess or extraneous activity.<sup>1,11</sup>

**The Sensory Integration and Praxis Tests (SIPT)** serve primarily as a standardised diagnostic and descriptive tool to identify patterns of sensory integration dysfunction.<sup>12</sup> The SIPT measures sensory perception, practic abilities, balance, motor coordination and major behavioural manifestations of deficits in integration of different sensory systems for children between 4 years and 8 years 11 month of age.<sup>13</sup> The SIPT is currently considered as the golden measure to identify patterns of sensory integrative dysfunction.<sup>12</sup> The SIPT is accepted as a reliable test and may be used on children in South Africa.<sup>14</sup>

# LIST OF ABBREVIATIONS AND ACRONYMS

ADL:	ACTIVITIES OF DAILY LIVING
ASI®:	AYRES SENSORY INTEGRATION®
CIS:	COCHLEAR IMPLANTS
CNS:	CENTRAL NERVOUS SYSTEM
CN VIII:	CRANIAL NERVE VIII: VESTIBULAR-COCHLEAR NERVE
DDDM:	DATA DRIVEN DECISION-MAKING MODEL (SCHAAF AND MAILLOUX)
GAS:	GOAL ATTAINMENT SCALE
OT:	OCCUPATIONAL THERAPIST
OT/SI:	OCCUPATIONAL THERAPISTS USING AYRES SENSORY INTEGRATION®
	FRAME OF REFERENCE
OT-PICS:	OCCUPATIONAL THERAPY (OT) PAEDIATRIC (P) INTERVENTION
	OUTCOMES (I) FOR COCHLEAR IMPLANTS (C) USING SENSORY-BASED
	(S) ACTIVITIES (OT-PICS) OBSERVATION TOOL
SID:	SENSORY INTEGRATIVE DYSFUNCTION
SA:	SOUTH AFRICA
USA:	UNITED STATES OF AMERICA
VPBIS:	VESTIBULAR AND PROPRIOCEPTIVE BILATERAL INTEGRATION AND
	SEQUENCING PATTERN OF SI DYSFUNCTION
SIPT:	SEQUENCING PATTERN OF SI DYSFUNCTION SENSORY INTEGRATION AND PRAXIS TESTS

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# **CHAPTER 1: INTRODUCTION**

#### **1.1 INTRODUCTION**

In order to optimise the developmental window of opportunity of early intervention for children with cochlear implants (CIs), individual developmental history, sensory perception and environmental factors should be taken into consideration.<sup>5,15,16,17</sup> Ayres Sensory Integration (ASI®) is one of the most used approaches in occupational therapy to frame clinicians' reasoning when working with individuals whose limitations in participation appear related to having difficulty with processing and integrating sensory information.<sup>18</sup> ASI® is an evolving theory, it is adaptable to various ages and diagnostic groups and has the unique needs of an individual at heart.<sup>18,19</sup> ASI®, was chosen as the preferred therapeutic approach for the child with CIs who experienced difficulties related to processing and integrating sensory information, impacting the child's participation in occupations. The ASI® theory is discussed in more detail in Chapter 2.

#### 1.2 BACKGROUND

A three-year-old child with bilateral cochlear implants (CIs) was referred for occupational therapy by the cochlear team. The main concern at the time was that the child kept on removing and hiding her CIs after 45 – 60min of usage, that she did not have access to language, and that she would not acquire language if she was not wearing her CIs. It was reported that she changed her clothes up to eight times per day and sometimes had up to three baths per day to help her relax in an attempt to cope with everyday life while wearing her newly implanted cochlear devices. She could not tolerate anything on her head such as hair clips or Alice bands, and could not tolerate the feeling of dirty/wet clothes on her body. These behaviours had a significant impact on the family unit and the roles of the parents to provide for their child's emotional, physical and financial needs.

For young children with profound hearing loss who received CIs, it is imperative to have their apparatus on the whole day or "ears on when their eyes are open". This term refers to the principle that the CIs are to be switched on the whole time the child is awake during daytime hours. This will allow full-time access to auditory stimuli to facilitate optimal listening and communication skills while the auditory centers of the brain are developing. Practitioners and families should strive for maximum access to the child's hearing technology. This requires that the child's CIs are programmed accurately, that the family understands the importance of, and is equipped to facilitate full-time cochlear usage.<sup>17</sup>

In typical developing children, play is the dominant occupation. Early childhood (0-2 years) is characterized by exploration of sensory, motor and affective experiences. During middle childhood (2 – 6 years) the dominant feature is the child's drive towards competency. Play facilitates the mastery of skills which serves as a platform for choice and broadening of interests. There is an emerging independence in tasks of daily living as well as the regulation of everyday behaviour.<sup>20</sup>

The child in this case study was diagnosed with profound hearing impairment at the age of two years. She had no access to sound and language during a critical developmental phase. As a result, the child was not able to experience typical early and middle developmental childhood phases like her hearing peers. The lack of access to auditory input negatively impacted her participation in childhood occupations, especially the lack of access to sound and language. In addition to her hearing loss, the surgical CI procedures and recovery time, limited her ability to move her body and explore freely (especially outdoors) like her hearing peers. This caused an interference in the child's development which lead to atypical behaviours and limited participation in occupations such as activities of daily living, play and social interaction.

The child received bilateral CIs to provide an auditory channel for sound and language. However, she removed her CIs regularly and did not have optimal access to the auditory input from everyday life. Therefore, her occupational performance skills and emotional well-being were negatively impacted by poor cochlear usage such as understanding natural sounds from her environment and making sense of language.<sup>5,16</sup> Although it was considered that hearing was a new sensory experience, her behaviours were an extreme over-reaction in relation to the sensory input she received from her body and the environment. The child appeared to be in survival mode i.e. fight or flight mode and attempted to avoid unpleasant sensory experiences by removing her CIs, isolating herself or hiding under tables.<sup>21</sup> Her behavioural responses were out of proportion to typical expectations of other children her age with bilateral CIs.<sup>17</sup>

The child appeared to have difficulty with coping with the tactile sensation of wearing her CIs. She also appeared to be having difficulty with tolerating and processing the electrical auditory input of the CIs. These challenges in her sensory perception and reactivity had a significant negative impact on her occupational performance and required intervention. The sensory input from her external environment alone however, did not fully explain possible triggers for her behaviour. There seemed to be a mismatch between the sensory perception of her body and environment, and her overreactive behaviour. The behaviour the child exhibited lead the to further investigation about possible causes and triggers.

In adults with CIs, postoperative vertigo is a well-known complication after cochlear implantation. However, when the sound processor is on, and vertigo is still experienced it is different from postoperative vertigo. This phenomenon is described as sound-induced vertigo by environmental noise and is referred to as Tullio's phenomenon. Sound induced vertigo seems to be primarily caused by electrical co-stimulation of the saccule as part of the otolith organs (gravity receptors) in the vestibular system. The saccule is neuroanatomically adjacent to the cochlea where the electrode is inserted. The close proximity between the cochlea and otolith organs may be one reason for the vestibular co-stimulation of the cochlear electrode. Tullio's phenomenon is further discussed in Chapter 2.<sup>22</sup>

Ayres Sensory Integration (ASI®) was selected by the clinical occupational therapist, as a bottom-up evidence based therapeutic approach as the preferred therapeutic framework. ASI® is rooted in the theory of neurophysiology and has neuroplasticity at the core for facilitating adaptive responses during graded "just-right" challenges for improved participation in childhood occupations.<sup>23</sup> This case sparked a particular interest for further investigation and identified the need for gathering information and documenting evidence.

#### **1.3 PROBLEM STATEMENT**

In children with severe hearing impairment, the strategic use of CIs may have a profoundly positive effect on communication skills to facilitate optimal participation in childhood occupations. If they are supported with experiences that engage their interest through speech, they can overcome early deprivation effects to understand and produce speech that can approximate those of hearing children. For each year that a child with hearing loss does not receive a CI, he/she will lag behind in the rate of improvement in language development.<sup>24</sup> Postoperative rehabilitation and consistent use of the devices are essential for achieving optimal CI functioning and language development.<sup>5</sup>

The child had her first cochlear implant at the age of two and a half years. Although the surgery appeared to have been successful, there were some complications following her cochlear implantation. It was reported that the child experienced acceptance difficulties of the first cochlear implant. There were device issues that caused intermittent signals and led to extensive testing, and consequently exchanging of parts. The child also developed granuloma annulare (reddish bumps on the skin) localised in the area of her device and coil, which were believed to have impacted on her acceptance of the device. Although the bumps were surgically removed, they re-occurred from time to time.

The child received the second cochlear implant at the age of three and a half years. Tolerance issues were magnified which were evident in behaviours that included frequently removing and hiding her CIs. She would often isolate herself and hide away. She also had a tendency to bite her hair brush in times of stress to the point where her parents had to replace it almost every second week. The case was referred for occupational therapy to pursue possible sensory modulation issues, particularly relating to sound and light touch.

The child's ability to process multi-sensory input from the CI devices, her body and the environment appeared problematic. This resulted in significant adaptive and tolerance issues towards wearing her CIs. Her extreme sensory over-reactivity resulted in behavioural over-reactions that had a negative impact on her listening skills, language development and participation in childhood occupations. She could not effectively deal with her sensory over-reactivity which resulted in inappropriate coping behaviours in times of sensory overload and discomfort.<sup>10</sup> The child had a tendency to remove and hide her CIs after approximately 30 - 45 minutes. This caused great concern to the cochlear team and parents as the child did not have full access to all the sound ranges and language on a daily basis. She was not able to explore and master skills and started lagging more behind her typical peers as time went by. This compromised her participation in activities of daily living, play, social participation and education.<sup>25</sup>

The less time the child used her CIs, the less opportunity she had to develop her skills to keep up with her peers and attend a mainstream school.<sup>8</sup> The expectation that children with CIs might be attending a mainstream school, could change the course of their life.<sup>24</sup> This expectation created pressure and anxiety for the child and her parents, as their wish was that she could attend a mainstream school, to have the same opportunities and learn like her peers. The child was at risk for losing out on the benefits of early cochlear implantation as the cochlear team was considering sign language as opposed to spoken language. It appeared if the window of opportunity for developing critical age-related skills was getting smaller. These consequences could have a negative impact on her developing skills pertaining to childhood occupations and overall development.<sup>8,20</sup> Furthermore, the impact of poorly developed listening skills and spoken language could potentially also interfere with future employment opportunities, independence and quality of life as an adult.<sup>26</sup>

## 1.4. RESEARCH QUESTION

What is the impact of Ayres Sensory Integration (ASI®) on occupational performance in a child with bilateral cochlear implants within the first four years after implantation?

## **1.5 AIM AND OBJECTIVES**

#### <u>1.5.1 Aim</u>

To determine the impact of ASI® on occupational performance in a child with bilateral cochlear implants within the first four years after implantation.

#### 1.5.2 Objectives

1) To develop a measurement instrument that can identify and describe sensory-motor factors and functional participation challenges in occupations for children with cochlear implants (CIs).

2) To identify challenges related to sensory-motor factors and functional participation in a child with bilateral CIs.

3) To determine changes in sensory-motor factors and functional participation in a child with bilateral CIs across a four-year period of ASI® intervention.

4) To determine the pattern of sensory integration dysfunction in a child with bilateral CIs by means of using the Sensory Integration and Praxis Tests (SIPT).

5) To compare the pre- and post-intervention SIPT results of a child with bilateral CIs to determine changes in sensory integrative functions.

6) To obtain perspectives of the cochlear team and parents regarding changes in the child's behaviour and participation in occupations.

#### **1.6 RESEARCH DESIGN**

A retrospective, longitudinal, experimental holistic single case study design.<sup>27,28,29</sup> Refer to Chapter 3 for more specific information on the chosen design.

#### 1.6.1 Quantitative components:

Quantitative data was gathered to determine the child's level of performance at the time of the initial referral and identify the extent of the problematic behaviours.<sup>28</sup> Numerical data was further gathered to identify and measure changes in the child's performance pre- and post-intervention. Measurement tools included the SIPT and a newly developed observation tool, namely the OT-PICS (*Occupational Therapy (OT) Paediatric (P) Intervention outcomes (I) for Cochlear Implants (C) using Sensory-based (S) activities)*. Descriptive statistics were used to identify changes and to determine the impact of ASI® on the occupational performance of a child with bilateral CIs.

#### 1.6.2 Qualitative components:

The qualitative features of this single case study were done in a real-life situation which were described in depth to promote an understanding of people's beliefs, actions and complex events. The intention was to understand the findings in context and not primarily to generalize findings.<sup>30</sup> The case was investigated over a four-year period through detailed and in-depth data collection. Multiple sources of information, rich in context, were used to describe the case. The case study is experimental in nature to understand, analyse, and interpret a particular phenomenon.<sup>28</sup> Qualitative components included reviewing previous records (including other reports, a parent and Sensory Profile<sup>10</sup>), a semi-structured parent interview, (see Annexure A) and an electronic questionnaire (See Annexure B) completed by the cochlear team.

## **1.7 DEFINING THE CASE: SINGLE UNIT OF ANALYSIS**

An extreme, unusual and unique case was identified to investigate a particular phenomenon that fell outside the typical expectations of clinical procedures.<sup>31</sup> This single case study focused on performance in childhood occupations as applied to this particular child with bilateral CIs. The boundaries of this case are described by (a) time and place; and (b) time and activity:<sup>32</sup>

a) The case study investigation started from the time the child was initially referred for occupational therapy by the cochlear team, after both CIs had been implanted, wounds had healed and the devices had been switched on. The in-depth investigation concluded when the child proceeded to Gr. R in a mainstream school.

b) Time and activity include the review of relevant clinical procedures performed on the child by the occupational therapist over a four-year period, focusing on ASI® principles and techniques (including relevant documents, clinical notes and intervention procedures).

#### **1.8 RATIONALE**

Therapeutic services for children with CIs revolve around speech and language therapy and audition.<sup>7</sup> This unique case indicated the need to further investigate disturbances in sensory perception, sensory reactivity and motor performance in children with bilateral CIs and the impact of multi-sensory demands on participation in childhood occupations. This provided a more holistic perspective in terms of their difficulties in relation to their functional performance, including but not limited to language and communication skills, and vestibular performance and motor skills.

From clinical experience it appears if there is an increase in children with CIs being referred to occupational therapists who use ASI® for difficulties related to inadequate sensory processing and motor development. However, there is a gap in the literature to guide occupational therapists in terms of evidence-based assessments and interventions for children with CIs and sensory integrative difficulties. The child in this case study had difficulty with participation in childhood occupations such as activities of daily living (e.g. dressing, eating, grooming), play and socialisation. A profound hearing impairment, a significant delay in language skills, and problems with sensory integration, interfered with adapting to her CIs. These difficulties created barriers to the child's development. She could not optimally benefit from having the CIs to develop age related skills pertaining to activities of daily living, play, social participation and education like her typical peers.<sup>20</sup> This child was a good candidate for ASI® intervention to improve sensory perception, sensory reactivity and motor skills for optimal development and participation in childhood occupations.

#### **1.9 SIGNIFICANCE OF THE STUDY**

This case study has the potential to contribute to the professional body of knowledge by expanding the existing skills repertoire for occupational therapists applying ASI® to children with CIs. The depth in knowledge may empower occupational therapists to adapt clinical processes to children with cochlear implants and to optimally facilitate a child's development by means of tapping into neuroplasticity through the sensory awakening of sound.<sup>1,33</sup> Children with CIs and their families may also benefit from occupational therapy using ASI® assessment and intervention techniques to address sensory integration difficulties, specifically their vestibular functioning and ability to process electrical auditory input in a constantly changing multi-sensory environment. In addition, the cochlear team may benefit from the occupational therapist's perspective and contributions towards children who receive CIs.<sup>7,34</sup>

#### 1.11 PHILOSOPHICAL ASSUMPTIONS

This case study was based on a particular phenomenon within the complexity of varying realities.<sup>31</sup> To obtain in-depth knowledge and understanding, the researcher used a transparadigmatic approach.<sup>35,36,37</sup> A proverbial bridge existed between paradigms where distinctive qualitative and quantitative contributions were mutually informative.<sup>31</sup> The quantitative methods were approached from a post-positivism orientation within the paradigm of critical realism.<sup>38,39</sup> The qualitative methods were approached from an interpretivist perspective within the paradigm of constructivism.<sup>40</sup> It implies that this specific case was investigated in depth within its specific context.<sup>28</sup> According to Yin, a realist orientation presents the researcher's questions and interpretations about the case being studied.<sup>27,36</sup>

#### 1.11.1 Ontological assumptions:

The child's reality was constructed by social authors and people's perceptions.<sup>40</sup> Individuals have varied backgrounds, assumptions and experiences. This contributed to the reality that human experiences and perspectives were subjective, that their social reality could change and have multiple perspectives.<sup>40</sup> Therefore, the child's reality could be defined in words by means of describing observations of the possible causes and effects on her behavioural responses.

The child's reality was based on non-verbal cues from the child (e.g. gesturing), responses in relation to her sensory environment, and other people's feedback. The child's environment was an open system of sensory variables impacting on her immediate experiences, and possible delayed responses after the actual sensory input has stopped. The child's behaviour was described and explained in the context of a changing sensory environment.<sup>1</sup> The child's social reality was viewed as external and objective. This implies separation between the researcher and the case being researched to take the stance of an outsider's perspective.<sup>40</sup>

#### 1.11.2 Epistemology

For the quantitative components, a scientific approach was used to obtain numerical data to generate acceptable knowledge about the case. A hypothesis was created by means of considering statistical information.<sup>40</sup> The relationship between cause-and-effect was be determined and described to gain more knowledge about the case.<sup>39</sup>

For the qualitative components, knowledge about the child's reality expanded and evolved as it arose from the meaning and understanding of her behaviour in relation to her context.<sup>28,41</sup> For example, the child's reality of feeling uncomfortable and having difficulty with adapting to the Cls, was observed in her behaviour and non-verbal communication by means of isolating herself, and removing and hiding her Cls. Multiple perspectives existed from various participants rather than a single reality.<sup>28</sup> Theme analysis and rich descriptions of social constructs was used to analyse and describe detail. Specific information about the case was obtained from the various participants (e.g. parents and cochlear team).<sup>40</sup>

#### 1.12 THEORETICAL FRAMEWORK

ASI® is deeply rooted in systematic and methodical measurement which marked the first effort by an occupational therapist to build a theory for clinical application with an evidence-based approach. ASI® is an evolving theory rather than a static collection of facts. It is based on nonlinear relationships between among neurobiological and functional systems that are dynamically interrelated.<sup>3</sup> It has shown a trajectory of growth since the 1950's with continual advancements from the ongoing contributions since Ayres' original work.<sup>42</sup> In order to support the evolving nature of the ASI® theory, occupational therapists have to use terminology that is clear, roles that are clearly delineated, expertise that is defined and intervention that is evidence-based. This implies that as new findings are revealed through research and practice, theoretical paradigms are adapted to capture and integrate new findings with existing knowledge. Findings are therefore documented in ways that will guide practice and research.<sup>18</sup> It is noted that the foundations in measurements that were originally established by Ayres, have evolved, and that her earlier work connects with current and future trends.<sup>42</sup> ASI® was therefore a suitable approach for this child.

#### 1.13 OUTLINE OF STUDY

This dissertation has six chapters as follows:

- Chapter 1 Introduction
- Chapter 2 Literature review
- Chapter 3 Research Methods
- Chapter 4 Results
- Chapter 5 Discussion
- Chapter 6 Conclusion and recommendations

# **CHAPTER 2: LITERATURE REVIEW**

#### 2.1 INTRODUCTION TO THE LITERATURE REVIEW

The following aspects will be discussed to provide relevant information and context about the child, cochlear implants, and ASI® theory to provide a platform for understanding the impact of the child's difficulties on her participation in childhood occupations:

- Five senses and beyond
- The sense organs of the inner ear: the link between sound and movement
- Ayres sensory Integration® (ASI®) theory
- Cochlear implants
- The link between cochlear implants and sensory integration
- Participation in childhood occupations
- The impact of cochlear implants on the family unit

#### 2.2 FIVE SENSES AND BEYOND

Sensation is considered to be "food", or nourishment for the nervous system. The brain receives a constant flow of sensory information from the sensory receptors in the body, about the body itself as well as the environment. In order to develop and adapt appropriately, the nervous system needs a balanced supply of sensory information, not too much and not too little. Sensory receptors that provide sensory information from outside the body include the visual (sight), auditory (sound), gustatory (taste), olfactory (smell) and tactile (touch) senses. Sensory receptors that provide sensory information about the body's position and movement include the proprioceptive (joint positions e.g. push and pull forces in body) and vestibular (gravity, head movement and balance) senses. Sensory receptors that provide sensory information inside the body e.g. visceral organs are referred to the interoceptive system.<sup>1</sup> Dr Ayres was the first to emphasize the importance of the body centered senses, or "hidden" senses, and specifically refer to the vestibular, proprioceptive and interoceptive systems.<sup>3</sup> In sensory integration intervention, the three main sensory systems that are being targeted are the tactile, vestibular and proprioceptive systems, which prevent occupational therapists working within the ASI® frame of reference from attempting to keep a child seated at a desk for the duration of the session. The children participating in ASI® intervention need to be actively using their bodies in play-based activities. This will be further discussed in Section 2.4.7.34

The vestibular system is considered as the unifying sensory system as it provides a framework for the other senses. It forms the basic relationship of a person to gravity and the physical world. When the vestibular system does not function optimally, the interpretation of other sensory information will be inconsistent and inaccurate.<sup>1</sup>

This is particularly relevant to the child in this case study, due to the impact of the CIs on the child's ability to perceive sensory information from her body and the environment, especially from her vestibular system. This will be discussed in Section 2.3 The sense organs of the inner ear and the link between sound and movement.

#### 2.2.1 The importance of sensation and the nervous system

Over 80% of the human nervous system is involved in processing or organising sensory input. Sensory processing is extremely complex due to the different types of sensory input that intermingle with each other in the different parts of the nervous system. The different motor commands are sent from different parts of the brain, each with a specific function. Sensory integration is the neural process of organising the sensory input so that the brain can produce useful responses, perceptions, emotions and thoughts. When the functions of the brain are whole and balanced, body movements are highly adaptive, learning is possible and appropriate behaviour is a natural outcome. It is therefore considered that learning and behaviour are the visible aspects of sensory integration when all the sensory input is sorted, ordered and puttogether as a whole-brain function. Although the whole central nervous system is involved in the process of sensory integration (including the spinal cord, brainstem, cerebellum and cerebrum), for the purpose of this case study, the neurological structures will not be discussed.<sup>1,33</sup> Some of the relevant structures in relation to this case will be discussed in the sections to follow.

#### 2.2.2 The tactile system

The sense of touch is considered to be the largest and the most primitive of the sensory systems. Touch is the first sensory system to develop at around 8 weeks gestation and fully functional in-utero (e.g. as seen in reflexes to touch). Touch is the first language of a new born baby as it mediates experiences with the outside world. The sense of touch assists with boding, as is essential to our well-being (e.g. feeling a sense of emotional security) and survival (e.g. to pull our hand away from a sharp object or hot stove). Difficulties within the tactile system may results in difficulties with activities of daily living such as being sensitive towards grooming, or having strong food or clothing preferences. When a child has diminished touch perception, he/she may difficulties with manipulating objects such as a pencil or scissors, or buttoning a shirt, or tying shoe laces. There are various tactile receptors that detect pain, temperature, hair displacement, light touch, deep touch pressure, vibration, skin stretch and joint movement.

The tactile and the proprioceptive systems together form the somatosensory system.

Information from the somatosensory system carries information from the body to the brain via two subdivisions, namely the dorsal column medial lemniscal (DCML) and anterolateral (AL) pathways. Receptors associated with the DCML respond to mechanical stimuli (e.g. vibration, deep touch pressure, and proprioceptive input). The DCML is associated with tactile discrimination as it assists with the perception or detection of size, two-point discrimination shape, contour, textures and movement across the skin as well as information about body and limb position in space. The AL system is often also referred to as the spinothalamic pathway due to its connections with the thalamus and mediates projections to the reticular formation, cranial nerves and hypothalamus for survival by tapping into the autonomic nervous system. The AL is associated with pain, crude touch, temperature, tickle and neutral warmth. Knowledge about the AL may assist with explaining the emotional reaction of tactile defensiveness due to its connections with the limbic system, the reticular formation and the hypothalamus. The trigeminothalamic pathway transmits somatosensory information from the face.<sup>1,11,33,43</sup> Refer to Section 2.4.6 for a more detailed discussion of the role of the nervous system on sensory modulation and reactivity are discussed.

The child's responses to light touch and proprioceptive input were consistent with what is known from the literature and did not warrant further elaboration on the tactile system. For the purpose of the child's behaviour in relation to the CI, the emphasis will be on the sense organs of the inner ear, due to the gap in available literature and the apparent mismatch between what was known and what was observed. This will be discussed in the sections to follow.

# 2.3 THE SENSE ORGANS OF THE INNER EAR AND THE LINK BETWEEN SOUND AND MOVEMENT

For the purpose of understanding the link between movement and sound, the focus will be on the development and neurophysiology of the sense organs of the inner ear.

#### 2.3.1 Sense organs of the inner ear: development of vestibular and auditory systems

In-utero, hearing and balance begin with nearly identical hair cells that form the sensory receptor cells in both of these sensory systems. Although the hair cells of both these sensory systems are within the inner ear and have similarity in transduction, the auditory and vestibular systems are completely separate and different in their functioning. The sense of movement or the *vestibular system* is the first sensory system to develop fully in-utero. It is noted that the vestibular nuclei begin to function by week 10 to 11 weeks in-utero and that by the 5<sup>th</sup> month, is fully operational.

Throughout pregnancy, the vestibular system of the foetus is stimulated by the mother's movements. In typical development, the vestibular system is fully developed and functional at birth, but not yet mature. Movement is required to activate the vestibular system.<sup>1</sup>

A baby's sense of hearing or the *auditory system* is fully developed at 28 weeks gestation. By 28 to 35 weeks' gestation, the foetus is able to move different body parts in response to different phonemes of a mother's speech, demonstrating the ability to differentiate amongst speech sounds. At birth, babies already have 12 weeks' listening experience. In the womb, all sounds are muted and reach the baby's ears through water, making the sound waves slow down (receiving sound at a lower frequency). In the outside world, sound travels through air and babies then have to adapt to and give new meaning to the sounds in their environment. In typical developing children, the echo of one's own voice, the sound of footsteps, or the distance of falling objects in 3D space contribute to the child's perception of his/her environment and contributes to the development of body scheme and spatial awareness. The auditory system is vital for survival (i.e. early warning signs of danger), communication (language development and social interaction) as well as education.<sup>11,33,44</sup>

Auditory information is often at the forefront of our consciousness to detect and locate sounds, as well as to perceive and interpret nuances. On the other hand, vestibular information often operates unnoticed in maintaining equilibrium and coordinating and calibrating movements.<sup>33</sup> When the vestibular system operates normally, we are usually unaware of it and take it for granted. When the functioning of the vestibular system is disrupted, the results can include unpleasant feelings associated with motion sickness, vertigo, or nausea as well as a sense of disequilibrium, and uncontrollable eye movements.<sup>33</sup>

#### 2.3.2 Anatomy of the sense organs of the inner ear

The human ear consists of three parts namely the outer, middle and inner ear.<sup>45</sup> The inner ear consists of the cochlea, or the auditory system, and the labyrinth. The labyrinth (from the Greek work "maze", or "winding passages") forms an important part of the vestibular system which is responsible for movement and balance.<sup>1</sup>

Refer to Figure 2.1: Sense organs of the inner ear to illustrate the anatomical and neurophysiological connection between the auditory and vestibular systems.<sup>33,43,45</sup>

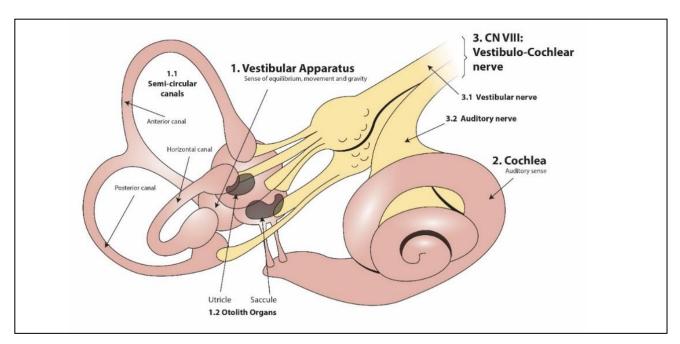


Figure 2.1 Sense organs of the inner ear (SimplySenseable©)

#### (i) The vestibular system:

Gravity is always present on our planet. There is a constant downward pull of gravity on our bodies and sends a constant stream of vestibular and proprioceptive messages throughout life. Vestibular receptors are considered to be the most sensitive of all the sense organs.<sup>1</sup>

There is a set of vestibular organs on each side of the head, mirror images of each other, sending bilateral movement input to the brain.<sup>11</sup> The vestibular system consists of two types of vestibular receptors namely the otolith organs, and semi-circular canals. (Refer to structure 1 The vestibular apparatus of Figure 2.1). The otolith organs consist of tiny calcium carbonate crystals (or otoconia after the Greek word "ear stones") and are primarily responsible for static functions.<sup>33,43</sup> The otolith organs respond to the pull of gravity e.g. slow linear displacement, changes in head position, or vibration that shake the crystals. The otoliths consist of two organs, namely the utricle and saccule. The utricle is sensitive to horizontal displacement, and the saccule to vertical displacement. The semi-circular canals are the dynamic component of the vestibular system.<sup>43</sup>

There are three pairs of <u>semi-circular canals in the vestibular system</u> that are filled with fluid called endolymph, the <u>same fluid that fills the medial chamber of the cochlea</u>. They are orientated in such a manner that movement in all three planes can be detected i.e. up and down, front and back, left and right. and respond to rapid changes in movement such as rotation and angular acceleration and deceleration. There approximately 20 000 vestibular axons within each vestibular system.

The hair cells in both the vestibular structures, transduce the relevant movement input into an electrical signal for further processing by the vestibular-cochlear nerve.<sup>1,33</sup>

#### (ii) The auditory system:

The cochlea is the sense organ for sound which can be detected as periodic waves of air pressure. The cochlea (meaning "snail" in Latin) is a spiral shaped structure, about the size of a pea, inside both the inner ears (refer to structure 2 Cochlea in Figure 2.1). The cochlea is filled with three fluid-filled chambers, and separated by the basilar membrane. The auditory receptors are hair cells that are situated in the spiral organ of Corti, upon the basilar membrane of the cochlea. When the hair cells bend, sound is transduced into a neural signal that can be sent via the vestibular-cochlear nerve (CN VIII) to the cortex (Refer to structure 3 CN VIII vestibular-cochlear nerve in Figure 2.1). A substantial amount of integration with vestibular and other sensory input (such as vision) is needed to make the most sense out of sounds such as orientating ourselves in our environment.<sup>11,33</sup>

# 2.3.3 The vestibular-cochlear nerve (CN VIII): The neurophysiological link between sound and movement

The vestibular-cochlear nerve is the eight cranial nerve (CN VIII). It consists of two separate pathways namely the cochlear nerve and the vestibular nerve.<sup>33</sup> The cochlear nerve fibres conduct impulses that are generated in the spiral organ of Corti inside the cochlea to the cochlear nuclei.<sup>46</sup> The vestibular nerve fibres transmit impulses from the hair cells of the otoliths (namely maculae) and the three semi-circular canals (namely ampullae) to the vestibular nuclear complex. The complexity of the vestibular pathways for the maintenance of balance and equilibrium reflect the influence of the vestibular system throughout the cortex.<sup>45,46</sup> Refer to Figure 2.3 and 2.4 for the vestibular pathways and a primary auditory pathway respectively.<sup>33,45,46,47</sup>

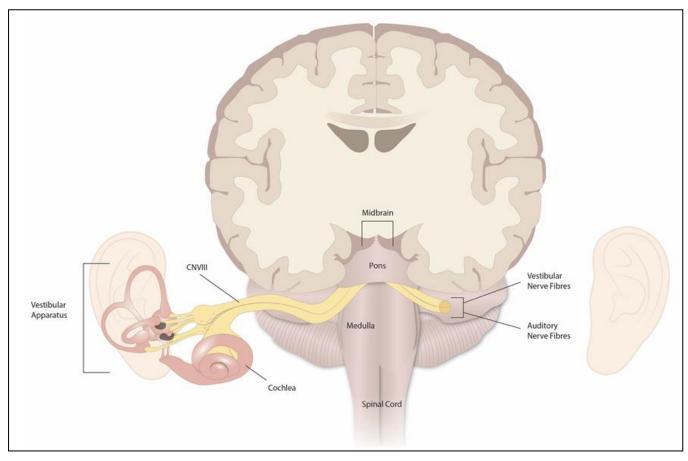


Figure 2.2 Illustration of the vestibular and auditory nerve fibres of the vestibular-cochlear nerve CN VIII (SimplySenseable©)

#### (i) The central vestibular pathways

The primary function of the central vestibular system is to generate appropriate motor responses to gravity and movement. These motor responses involve postural and balance responses as well as eye movements. Other responses include the regulation of arousal levels where vestibular input can be used to either increase or decrease alertness which can be observed e.g. in the organisation of behaviour, quality of motor output, eye contact or vocalisation.<sup>1,13,33,47</sup> The vestibular cell bodies which are in contact with the vestibular hair cells in the inner ear, are situated in the vestibular ganglion, or scarpa ganglion. The axons of these cells form the vestibular nerve fibres of the vestibular-cochlear nerve (CN VIII). From these cell bodies the vestibular nerve carries information to the four central vestibular nuclei at the base of the fourth ventricle in the brain stem at the juncture of the pons and medulla. It is noted that the vestibular system is the only sensory system that directly projects to the cerebellum. There are many reciprocal connections with the cerebellum, reticular formation, muscle and joint receptors as well as collateral vestibular nuclei. The central vestibular pathways integrate information about head and body movement from both sides of the head.

These pathways also use the information from the head and body movement to control the output of motor neurons that adjust head, eye and body positions. The vestibular nuclei also receive information from the cerebellum as well as visual and somatosensory systems. These connections enable the ability to combine vestibular information with the motor system and other sensory modalities such as touch and joint perception.<sup>33</sup>

Vestibular nuclei	Primary afferents	Primary efferents
Superior	Semi-circular canals	Extra-ocular muscles
Medial	Semi-circular canals	Neck and upper trunk
Lateral	Otolith organs	Trunk and upper limbs
Inferior	Otolith organs	Trunk and upper limbs

Table 2.1: Summary of the vestibular nuclei

There are many fibre pathways from the vestibular nuclei that connect the vestibular system with the cerebellum, the ocular motor nuclei and the spinal cord.

The vestibula nuclei send projections down to the spinal cord via the **lateral and medial vestibular spinal tracts** (LVST and MVST). More specifically the LVST receives information from the semi-circular canals, the otolith organs, cerebellum and spinal cord. The LVST is mainly responsible for influences on muscle tone and ongoing postural adjustments such as postural control and stability of flexor and extensor muscles in the trunk. Motor responses are ipsilateral facilitation of extensor muscles, and inhibition of flexion muscles which can be observed in a prolonged prone extension posture during clinical observations.<sup>33</sup>

The MVST receives information from the cerebellum and from the skin and joints. The MVST assists with the maintenance of a consistent position of the head in space. Both of these descending vestibular spinal tracts illustrate a connection between the vestibular and proprioceptive inputs (feedback from muscles and joints). Motor responses are bilateral facilitation and inhibition of neck and upper trunk muscles which can be observed in a prolonged supine flexion position during clinical observations.<sup>33,43,47</sup>

Vestibular afferents also descend indirectly via the **reticulospinal tract** to both flexor and extensor motor neurons which has both excitatory and inhibitory influences due to projections to the autonomic nervous system. Hence the powerful effect of the vestibular system on the autonomic nervous system pertaining to the regulation of alertness and activity levels. For example: slow rhythmical motion tends to decrease arousal, whereas fast, irregular motion tends to increase arousal.

In addition to the above, rotation or movement in a vehicle may trigger autonomic reactions such as pallor, dizziness, sweating, and hipotention.<sup>33,43,47</sup> In ASI® this may be observed in autonomic reactions to vestibular input which is the main characteristic of aversive responses or intolerance to movement.<sup>1,11</sup>

Ascending pathways from the vestibular nuclei form connections with the ventral posterior (VP) nucleus of the thalamus and then to the neocortex (regions close to the representation of the face in the primary somatosensory and primary motor cortex. At a cortical level, there is a considerable amount of integration of information about movements of the body, the eyes and the visual scene in our three-dimensional space. The vestibular system is therefore responsible for continually maintaining a representation of body position, awareness of and orientation in space, which is essential for our perception of equilibrium and for planning and executing complex coordinated movements.<sup>33,43,47</sup>

One particularly important function of the vestibular system is to maintain a stable visual field during movement and is critical to operating in the environment e.g. when driving on a bumpy road, or during sport / dancing, or when writing in class while maintaining a seated posture.

The **vestibular-ocular reflex (VOR)** performs this compensatory function. As mentioned by Haines (1997) in Bundy et al (2002) the term compensatory is used seeing that the eye movements are "equal in direction and opposite in direction to the head movement perceived by the vestibular system".<sup>43</sup> When the head is not moving, the eyes are still. However, when the head is moving, the VOR is initiated to enable the visual field to remain stable during movement. The effectiveness of the VOR depends on complicated connections from the semi-circular canals to the central vestibular nuclei to the cranial nuclei that control eye movements. Vestibular inputs from the medial and superior vestibular nuclei ascend bilaterally in the medial longitudinal fasciculus to the extra-ocular muscles via the ocular motor, trochlear and abducens cranial nerves (CN III, IV and VI).<sup>13,33,43</sup>

During the Sensory Integration and Praxis Tests (SIPT), the **post-rotary nystagmus (PRN)** evaluates the integrity of the relatively discrete VOR. Postrotary nystagmus is produced by stimulation of the semi-circular canals, which is one type of vestibular receptor cell. If there is no peripheral damage to the vestibular system, the PRN is considered as an indicator of how efficiently the central nervous system (CNS) processes rotational input from the semi-circular canals. A particularly low score indicates low CNS responsivity to rotation. Whereas a particularly high PRN score indicates insufficient inhibition of the VOR. Neither condition is favourable.<sup>13</sup>

The other vestibular receptor cells, namely the otolith organs, are concerned with body balance. The only test in the SIPT that taps into the integration of input from the gravity receptors is Standing and Walking balance. Therefor Ayres (1989) recommended that the Standing and Walking Balance test and the PRN should be considered when assessing vestibular functions and interpreting CNS integration of vestibular input. These tests should be supplemented with clinical observations. Integrity of CNS processing of vestibular input can be observed during protecting, righting, and postural responses, equilibrium, muscle tone, co-contraction, and voluntary ocular control.<sup>13</sup> The vestibular nuclei and central vestibular connections are illustrated in Figure 2.3.<sup>33,45,47</sup>

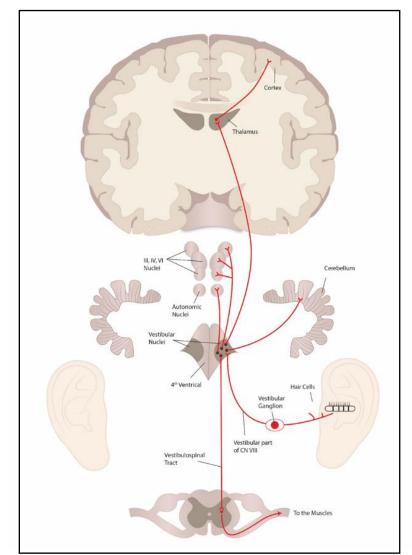


Figure 2.3 Illustration of the central vestibular connections (SimplySenseable©)

# (ii) A primary auditory pathway:

Afferents from the spiral ganglion enter the brain stem in the vestibular-cochlear nerve. The axons innervate the dorsal and ventral cochlear nuclei at the level of the medulla, ipsilateral to the cochlea where the axons originated.

The axons branch out to form synapses with neurons in both cochlear nuclei. From this point on, there are many parallel connections and more complicated pathways. One particular primary auditory pathway will be discussed from the cochlear nuclei to the auditory cortex. Refer to Figure 2.4 for an illustration of a primary auditory pathway (shown from one side of the head).

Cells in the ventral cochlear nucleus, project axons to the superior olive on both sides of the brain. A collection of olivary axons ascends in the lateral lemniscus and innervate the inferior colliculus of the midbrain. Efferents of the dorsal ventral cochlear nucleus follow a similar route to the ventral cochlear nucleus, but bypasses the superior olive.<sup>33</sup> Most of the lateral lemniscal fibres terminate in the inferior colliculus in the midbrain.<sup>46</sup> The neurons in the inferior colliculus send axons to the medial geniculate nucleus (MGN) of the thalamus, and project from there to the auditory cortex. In addition to the MGN, the inferior colliculus also project axons to the superior colliculus and cerebellum.

Cochlear nuclei receive input from just the one ear n the ipsilateral side. All other auditory nuclei in the brain stem receive input from both ears. Auditory and visual information is integrated at the superior colliculus (e.g. sound localisation) where cells receive input from cochlear nuclei on both sides of the brain stem.<sup>33</sup> Spiral ganglion cells receive input from a single hair cell at a particular location on the basilar membrane. Each portion of the membrane is maximally sensitive to a particular frequency. As a result, action potential is fired only in response to a particular frequency range.

In typical hearing individuals, there is a diverse stream of auditory information from conversations and traffic noises to electrical sounds and noises from inside our bodies the brain can either ignore, or choose to pay attention to the important sounds. Most sounds have certain features in common such as location, frequency and intensity. Each of these features are represented differently in the auditory pathways.<sup>33</sup>

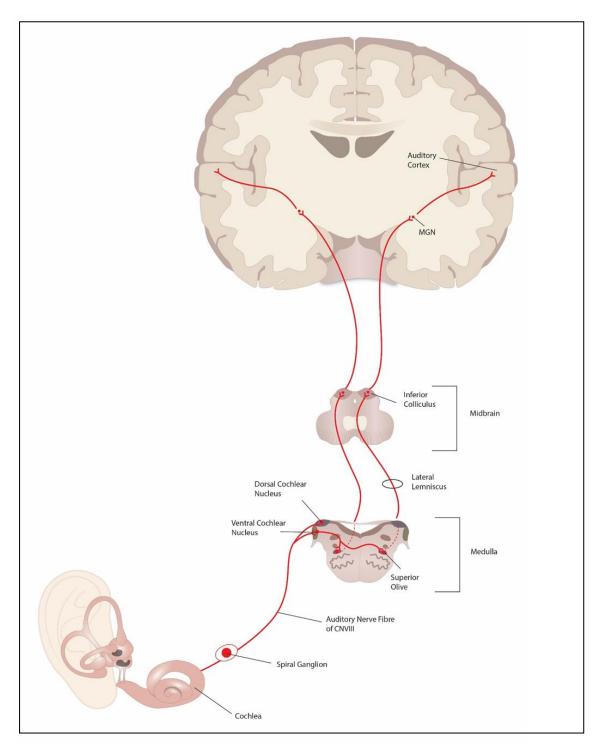


Figure 2.4 Illustration of a primary auditory pathway (SimplySenseable©)

# 2.4 AYRES SENSORY INTEGRATION® AS THEORETICAL FRAMEWORK

#### 2.4.1 History and background

Sensory integration is a neuro-behavioural theory.<sup>11</sup> The research, assessment tools, as well as intervention strategies and equipment were originated by Dr A. Jean Ayres. She was described by her scholars as a visionary occupational therapist and educational psychologist.<sup>3</sup> Schaaf and Davies (2010) stated that Ayres Sensory Integration (ASI®) is one of the most used and researched approaches within the field of occupational therapy. Occupational therapists using ASI® frame their clinical reasoning when working with individuals whose participation in occupations appear to be related to difficulty with processing and integrating sensory information from the body and environment.<sup>18</sup>

Typical sensory integrative abilities provide a foundation for meaningful and purposeful participation in a full range of daily occupations.<sup>4</sup> The process of sensory integration can be described as the central nervous system's ability to translate information into action. Ayres defined sensory integration as the "organization of sensory input for use".<sup>11</sup>

ASI® can be **applied across age spans and diagnostic categories** with implications for theory and practice, ranging from assessment to intervention.<sup>3,42</sup> From the publication "Applying SI to diverse populations" it is evident that occupational therapists using ASI® can be an effective approach for diagnoses such as fragile X syndrome, cerebral palsy, high-risk infants, visual impairment, environmental deprivation and autism. Although there is limited research for hearing impaired children, the adaptable and evolving nature of ASI® makes it possible to apply assessment procedures and intervention strategies to children with cochlear implants. Ayres proposed when a sensory rich environment is created in the context of play, it is possible to tap into an individual's inner drive to engage in just-right challenges. Active participation in purposeful, fun and challenging sensory-motor activities facilitate adaptive responses and self-direction so that a child can be more willing to tackle every day challenges. Improved sensory integration leads to more complex somato-motor adaptive responses, that facilitate adaptive behaviour in occupations and well-being.<sup>3,18</sup>

A unique feature of ASI® theory is **adaptive responses** that are the catalyst for change.<sup>9</sup> Adaptive responses are defined as an appropriate action in which an individual respond successfully or make an adjustment to some environmental demand.<sup>1,4,9,11</sup> There are different types of adaptive responses. Adaptive behaviours include, but are not restricted to, motor or action-orientated responses. A physical adaptive response might be evident in improved postural control, or motor output. An adaptive response might be a more organized autonomic nervous system response that is not easily observable such as improved respiration, heart rate, digestive functions, or sleep-wake cycles. An affective adaptive response can be observed as increased emotional stability under stressful circumstances such as the absence of a primary care-giver or dealing with an unfamiliar transition (e.g. unexpected change in routine). Adaptive responses can also be observed in more organized spatial-temporal responses to a given routine such as better rhythm and more fluid sequencing when running and kicking a moving a ball. Adaptive responses are a measure of an individual's ability to cope with and successfully meet environmental challenges.<sup>4</sup>

The **underlying assumptions of Ayres's sensory integration theory** are related to the neural and behavioural processes that are involved in typical development. These underlying assumptions are the core concepts and guiding principles of the ASI® theory include the following:<sup>1,3,4,9,11,43</sup>

- i) Sensory information provides an important foundation for learning and behaviour.<sup>9</sup>
- Sensory integration promotes neuroplasticity. Although Ayres indicated the critical period for the development of sensory integration is between the ages of 3 to 7 years, assessment and intervention procedures are not restricted to that age group. Older children and adults still have the potential for significant changes.<sup>1,11</sup>
- Sensory integration is a developmental process: it develops as behaviours at each stage in the developmental sequences provides a basis for more complex behaviours.<sup>9</sup>
- iv) Ayres based the theory of sensory integration on the proposition that behaviour is linked to neurological processes and that brain-stem level processing enables higher cortical centers to develop and specialize. She proposed that disorganized neuronal processes may lead to disorganised behaviours.<sup>3</sup> Although the brain functions as a whole, Ayres used hierarchical concepts to facilitate communication of difficult ideas and as a guide for intervention. For example: the development and optimal functional of higher-order cortical structures were partly dependent on the development and optimal functioning of lower order structures. However, Ayres emphasized the holistic interactive hierarchy of the nervous system as different systems interact with each other, and both cortical and sub-cortical structures contribute to sensory integration.<sup>43</sup>
- v) Adaptive interactions are critical to sensory integration: Active movements provide vestibular and proprioceptive sensory feedback from the body that form the basis of memories (neuronal models) of "how it felt". The performance of increasingly more complex movements indicates that new neuronal models have formed.

Active participation is therefore a critical component of learning from previous experience.<sup>43</sup> Successful integration of sensory information results in and is further developed by adaptive responses.<sup>3,9</sup>

vi) Children have an innate drive to seek meaningful experiences from their environment. Their inner-drive and self-direction develops through participation in sensory-motor activities that are presented as "just-right challenges". A "just-right" challenge requires the child to exert some degree of effort in a challenge that is not too easy or too difficult for the child to achieve. This implies that the therapist alters the activities and modifies the environment so that the child can achieve success, and perform something a little more difficult than before.<sup>1,3,9,11,34</sup>

#### 2.4.2 Neuroplasticity and ASI®

Neuroplasticity is at the heart of the ASI® theory. It can be defined as the nervous system's ability to change in response to environmental input and demands. Neuroplasticity can be enhanced by modifying sensory conditions in the environment and by facilitating active motor participation. This has a significant implication for ASI® intervention. By providing a sensory rich environment, successful participation in activities of daily living can be promoted. However, when providing ASI® intervention, the environment is enriched, structured and manipulated in such a way as to match the individual's needs by providing a "just-right challenge" according to the individual's level of performance. Changes can be seen very quickly in adaptive responses and can be long-lasting, depending on the individual. It is noted that stimulus pairing can be an effective intervention tool, and used when needed. Sensory input is therefore an important mediator for neuroplasticity. Motor activity, interest in the task and cognitive demands also appear to be significant contributors for enhanced neuroplasticity that will support the individual's adaptability.<sup>2</sup> Ayres (1972) noted that due to the young child's brain that is capable of modifying its function by means of organism-environmental interaction, it is possible for therapeutic intervention to change the brain's organisation so that it is better able to perceive and learn.4,11

#### 2.4.3 Identification of sensory integrative dysfunction

Sensory integrative dysfunction occurs when there is a disruption in the organization of sensory input. Ayres described it *"When the flow of sensation is disorganised, life can be like a rush-hour traffic jam"*.<sup>11</sup> Children who are unable to process and use the sensory input they receive often have a sensory integrative disorder. They have difficulty organising information and performing the complex tasks necessary for learning and functioning in the world. Dysfunction can occur within a specific sensory system, or in any combination of systems.

Possible causes include the following: a difference in neurological wiring (too much or too little pruning that happens in-utero), a genetic predisposition, prematurity, birth trauma and/or hospitalisation, adopted children, heavy metals (e.g. lead or mercury). Ayres proposed that sensory integrative dysfunctions do not reflect frank neurological damage, but rather deficits in the central processing of information. Sensory integrative dysfunctions may however coexist with other conditions such as developmental delay, high risk infants, food intolerances, autistic spectrum disorders, attention deficit disorders, foetal alcohol syndrome, visual impairment, hearing impairment, cerebral palsy, Down's syndrome.<sup>1,3,11,48</sup>

The ASI® approach encompasses the use of reliable assessments that measure specific sensory and motor performance areas that may be related to sensory integrative functions, assessment data that can guide intervention and document meaningful outcomes.<sup>19</sup> The Sensory Integration and Praxis Tests (SIPT) serve primarily as a standardised diagnostic and descriptive tool to identify patterns of sensory integration dysfunction.<sup>12</sup> The SIPT measures sensory perception, practic abilities, balance, motor coordination and major behavioural manifestations of deficits in integration of different sensory systems for children between 4 years and 8 years 11 month of age.<sup>13</sup> The SIPT is currently considered as the golden measure to identify patterns of sensory integration dysfunction.<sup>12</sup> Other assessment instruments include caregiver interviews, sensory questionnaires and observational tools. Since the 1950's, Ayres consistently found specific patterns of sensory integrative dysfunction over many years of research. Scholars and researchers continued to expand on her original work and confirmed these patterns of sensory integrative dysfunction.<sup>12,18,19,42</sup> The large body of literature provides a solid foundation for understanding the associations between sensory and motor functions. Familiarity with the patterns of sensory integrative dysfunction and the associated sensorymotor abilities assist with the interpretation process and provides the basis for developing a hypothesis regarding the underlying sensory issues that may affect a child's participation in occupations.<sup>9</sup> The patterns of sensory integrative dysfunction are: Visuo- and somatodyspraxia, Vestibular and proprioceptive bilateral integration and sequencing deficit, poor sensory perception, and difficulty with sensory reactivity.<sup>12</sup>

Dr Annamarie van Jaarsveld et al. (2012) investigated the equivalency between the US normative data and a sample of 775 typically developing children in South Africa. Results indicated that the SIPT is a fair and reliable test to use on children in South Africa. Although 12 out of the 17 tests can be scored against the normative data of the US population, the South African children scored significantly better on five tests.

The standard deviation (SD) scores of those five tests need to be adapted with -0.5 for children 6 years and older to ensure that possible sensory integrative dysfunctions do not go undetected in South African children.<sup>14</sup>

#### 2.4.4 Description of patterns of sensory integrative dysfunction (SID)

a) *Visuo and somadyspraxia*: Dyspraxia is a word used for poor praxis or poor motor planning. Praxis refers to the ability conceptualise, plan and sequence a new or different activity. Motor planning is a component of praxis and refers to the ability to conceive, organize and carry out a sequence of unfamiliar actions.<sup>1</sup> Most children with visuo-dyspraxia also have somatodyspraxia, but is not always the case. When reporting visuo- or somatodyspraxia, it is helpful to identify the specific areas of sensory processing difficulty by means of using the SIPT. It is characterized by high loadings on the tests of visual perception and visuopraxis functions, including scores related to perception of body position and imitation of postures.<sup>12,13</sup>

b) Vestibular and proprioceptive bilateral integration and sequencing deficit (VPBIS): Bilateral integration functions are associated with vestibular and proprioceptive functions. All of the SIPT scores related to this pattern of dysfunction were noted to involve bilateral and sequential actions. Vestibular and bilateral functions needed for the coordination of eye, head, and hand movements; postural adjustments; and crossing of body midline are compromised in this group. Additional clinical observations in this group include poor extensor tone, righting reactions and equilibrium responses.<sup>12,13,49</sup>

c) *Difficulties with Sensory perception*: Children in this group have difficulty with perceiving information related to the tactile and visual sensory systems, without SIPT scores indicating difficulties with praxis, or bilateral and/or postural measures.<sup>12</sup>

d) *Sensory modulation disorders and difficulties with sensory reactivity*: Children who overreact to sensory input, can have a reaction to any one or combination of sensations. Typical disorders in this group include tactile defensiveness and gravitational insecurity.<sup>1,9,11</sup>

# 2.4.5 The impact of sensory modulation disorders and sensory over-reactivity on a child's behaviour and participation

Unusual under- or over-responsiveness / reactivity is often called a sensory modulation disorder. For the sake of consistent use of terminology, sensory over-reactivity will be used to describe the child's behaviour that is out of proportion to environmental sensory input. Sensory over-reactivity may occur in any one or combination of sensory systems, including but not limited to the tactile, auditory and vestibular systems.

There are two main types of sensory modulation disorders namely tactile defensiveness and gravitational insecurity. Some children may have under- or over-reactivity in many types of sensations, or to one specific type of input. If the child's brain cannot inhibit the effect of the sensory input, the sensation(s) will bother the child and cause disruptive behaviours. Careful observation is needed to establish when the child is reacting to these sensations, or to something else that is happening at the same time.<sup>1,3,9,11</sup>

Difficulties related to sensory over-reactivity may also interfere significantly with everyday functioning and speech development.<sup>1,9</sup> Sensory over-reactivity seems to have a direct impact on playfulness and learning new skills in all occupations.<sup>50</sup> Occupational therapists using ASI® has been proven to be an effective approach for improving difficulties of children with sensory over-reactivity and sensory modulation disorders.<sup>1,51</sup>

Ayres identified *tactile defensiveness* in 1965 and described it as an unusual heightened sensitivity to touch. Children with tactile defensiveness may respond negatively and emotionally to touch sensations, often have high activity levels and are easily distractible. The negative emotions and behaviours associated with tactile defensiveness can interfere with everyday self-care tasks such as dressing, eating, bathing as well learning and social situations.<sup>1,9,11</sup>

When an individual is not able to inhibit or modulate vestibular input that is not useful, they may overreact to activities involving movement or a change of head position. Sensory over-reactivity in the vestibular system is called gravitational insecurity. This is described as an excessive emotional overreaction i.e. the reaction is out of proportion to the input when there is no actual danger of falling. The child with gravitational insecurity feels a primal threat in the pull of gravity and feel fear, anxiety or distress when their head is out of the vertical plane, or when moving into backward space. They worry about falling and want their feet firmly on the ground. They may be reluctant to jump and are afraid of walking up or down stairs, or climb on/ride moving things such as swings or animals. They are uncomfortable with being upside down and may avoid somersaults. This overreaction is not rational, and is as a result of an overreaction in the gravity receptors (otolith organs). A child with gravitational insecurity tends to avoid exploring vigorous movement activities with their friends such as climbing on jungle gyms, or riding their bicycles. This negatively impacts the development of their balance and motor skills, and may impact on their social skills and play. Our relationship with gravity is our most important source of security. According to Ayres (1979) "our relationship with gravity is more essential to our well-being than our relationship with our mother". When a child is not gravitationally secure, all other relationships are apt to be less than optimal. Gravitational insecurity may therefore affect every aspect of a person's life.<sup>1,9,43</sup>

Atypical reactivity to the ordinary sensations of daily life can be so unpleasant and may significantly impact the quality of life for these children and their families by limiting their participation in home, school and community activity. Children with disturbances in sensory modulation have demonstrated the following challenges<sup>21</sup>:

- decreased skills development, social participation and participation in play,
- disturbance in self-confidence and self-esteem,
- difficulties with daily life skills and at school, and
- emotional experiences related to anxiety, disturbances in attention and ability to regulate reactions to others,

#### 2.4.6 The role of the central nervous system on sensory modulation and reactivity

The *brain stem* forms the stalk from which the cerebrum and cerebellum sprout. It consists of the diencephalon, midbrain, pons and medulla oblongata. It is a complex network of fibres that relay information from the cerebrum to the spinal cord and cerebellum, and vice versa. The brain stem is also considered the most primitive part of the brain and is responsible for regulating the arousal of the nervous system as a whole. It is the site where vital functions (such as breathing, consciousness and body temperature) are regulated. It also assists with regulating the excitability of sensory information.<sup>1,33</sup>

The *reticular formation* is a network of fibres that runs through the midbrain to the medulla in the brain stem. It sends projections to the thalamus and is involved in many functions. Every sensory system sends impulses via the reticular formation to the rest of the brain. It is involved in regulating sleep and wakeful cycles, and is responsible for controlling of body posture and locomotion. It can be considered as a transitional link for all parts of the nervous system and assumes an extensive integrative role by organising sensory input through inhibition, facilitation, augmentation and synthesis to assist in the interpretation of the sensory world. The significance to occupational therapy is based on the survival value of sensory input; it may differ from moment to moment and is specific to each individual's perception of the sensory input.<sup>1,11,33</sup>

The *hypothalamus* forms part of the ventral part of the diencephalon and is involved in the control of the autonomic nervous system.<sup>33</sup>

The *autonomic nervous system* regulates an individual's ability to adapt to changes in the environment through modulation of sensory, motor, visceral and neuroendocrine functions. The autonomic system consists of the sympathetic and parasympathetic branches. These branches function together to promote adaptation and self-regulation in response to internal and external

environmental sensory demands. The sympathetic branch modulates immediate phasic responses to events such as increased heart rate and the fight-or-flight reaction. The parasympathetic branch modulates visceral and neuroendocrine systems to maintain homeostasis and self-regulation to recover from stressful sensory events. Children with sensory modulation disorders who have disturbance in severe over- or under-reactivity to sensory input, may have difficulty to restore homeostasis or implement self-regulation strategies to recover from a stressful event. It is therefore deducted that children with sensory modulation disorders and severe sensory over-reactivity to everyday sensations may have disturbances in their autonomic nervous system that influence their ability to participate in activities. Reactions that are beyond voluntary control, such as "butterflies in the stomach" or blushing, are mediated by the autonomic nervous system.<sup>21,33</sup>

# 2.4.7 Fidelity in ASI® intervention

Intervention based on the theory of ASI® is widely used among occupational therapists working with children with developmental, learning, and behavioural problems. In the context of effectiveness studies, fidelity refers to the extent to which an intervention is faithful to its underlying theoretical and clinical guidelines. Fidelity can therefore be considered as an aspect of research validity as it addresses whether study findings reflect the underlying purpose of the study. More specifically, it may be viewed as a kind of construct validity as it addresses the fit between the philosophy and principles of ASI® theory, and the way the intervention procedures are implemented. The availability of a well-developed fidelity tool enables researchers to accurately deliver effectiveness results pertaining to ASI® intervention.<sup>52</sup>

This fidelity instrument not only allows the researcher to verify that the therapeutic strategies used in the study represent the defined intervention but also makes the study replicable.<sup>52</sup> It became crucial to differentiate ASI® intervention from other approaches that merely use sensory stimulation as an applied input, or as a reward for positive behaviours.<sup>18</sup> The *Ayres Sensory Integration Fidelity Measure* addresses the key structural and process elements of ASI® intervention Research Collaborative.<sup>34,52</sup>

This sensory integration fidelity measure provides a tool for "ensuring that intervention called sensory integration is replicable and consistently adheres to the principles of Ayres' sensory integration frame of reference". The Ayres Sensory Integration Fidelity Measure consists of structural and process elements that are considered essential to the provision of ASI® intervention.<sup>34,52</sup> The Ayres Sensory Integration Fidelity Measure provides a valid measure of ASI® intervention for use in effectiveness studies on an international standard.

Adherence to the structural and process elements will increase the likelihood that interventions called "sensory integration" and provided by qualified therapists are faithful to ASI principles, not only in research but also in education and practice. The *structural elements* include the therapist's qualifications and training, records and detailed assessment results, requirements pertaining to the physical space and equipment, as well as parent-therapist collaboration in goal-setting.

The *process elements* are the key therapeutic strategies involved in providing ASI® intervention. In order to adhere to the ASI® fidelity requirements, the therapist has to intentionally implement these process elements in a 1:1 intervention session<sup>34</sup>:

- 1. Ensures physical safety
- 2. Presents sensory opportunities
- 3. Helps the child to attain and maintain appropriate levels of alertness
- 4. Challenges postural, ocular, oral, or bilateral motor control
- 5. Challenges praxis and organization of behaviour
- 6. Collaborates in activity choice
- 7. Tailors activity to present just-right challenge
- 8. Ensures that activities are successful
- 9. Supports child's intrinsic motivation to play
- 10. Establishes a therapeutic alliance

# 2.4.8 Intervention guidelines for children with vestibular and proprioceptive bilateral integration and sequencing (VPBIS) pattern of sensory integration dysfunction (SID)

Although the occupational therapist using the ASI® approach has to adhere to all the fidelity requirements in intervention, some of the key elements will be noted here to specifically address in the VPBIS group<sup>3,4,9,34,52</sup>:

It is key that children receiving ASI® intervention are <u>safe</u> and that the occupational therapist is in control of the environment. The therapist may anticipate physical hazards and attempts to ensure that the child is physically safe through manipulation of protective and therapeutic equipment and/or the therapist's physical proximity and actions. The therapist anticipates that the child will move, play vigorously, take physical risks or enjoy crashing e.g. through foam blocks or into pillow pits. The occupational therapist provides a variety of <u>sensory opportunities</u> (specifically including vestibular, proprioceptive and tactile experiences) with varying intensities, qualities, speed, and duration to improve sensory perception and sustain an adequate arousal state for sustained engagement during the course of the session. Movement experiences to tap into the vestibular system may involve linear, orbital, or rotary head movement, rocking, rolling, swinging, somersaults, jumping from a height, and wholebody movement through space. The therapist may use suspended (such as swings) or nonsuspended moving equipment (such as balance beams). The therapist will also provide experiences to tap into the proprioceptive system in which muscle tension and stretch sensations are the dominant input. Typical examples include pulling, pushing, carrying heavy objects, hanging on to equipment.

In order for a child to remain <u>regulated</u> throughout the session, the occupational therapist modifies sensory conditions, challenges and supports that help the child to attain and maintain appropriate levels of arousal and alertness, as well as an affective state and activity level that supports engagement in activities. The therapist may initiate changes to the environment, activity, social interaction, or sensory input to support the child's levels of alertness and to avoid a sensory overload.

For children with the VPBIS pattern of SID, it is crucial that the therapist <u>supports and</u> <u>challenges postural control, ocular control, or bilateral development</u>. The therapist challenges the child to engage in sensory motor activities that build strength, dexterity, speed and agility in static and dynamic postural control and fine and gross motor skills. The aim is to improve under-reactivity to vestibular and proprioceptive input. Specific examples of such activities are provided in Chapter 5.

The occupational therapist will also provide the intervention in a child-directed manner to ensure active participation in the context play. "Just-right" challenges will be provided in a graded manner to ensure success and to promote self-esteem. The occupational therapist will promote and establish a connection with the child that conveys a sense of working together towards one or more goals in a mutually enjoyable partnership.<sup>34</sup>

#### 2.5 COCHLEAR IMPLANTS

#### 2.5.1 Definition and background

Cochlear implants (CIs) are electronic medical protheses for individuals with profound sensorineural hearing loss. CIs provide access to sound and language so they can enjoy life to their fullest potential. CIs treat profound hearing loss by providing direct electrical stimulation to auditory nerve endings. An electrode is surgically inserted into the cochlea through the round window or an adjacent cochleostomy.<sup>5</sup> The devices pick up sound and digitise it, convert that digitised sound into electrical signals, and transmit those signals to electrodes embedded in the cochlea. The electrodes electrically stimulate the cochlear nerve, causing it to send sound signals to the brain.<sup>53</sup>

CIs were approved for adults in the early 1980's in Australia and subsequently, children worldwide are using CI for more than 20 years. More than 80 000 children worldwide have received CIs.<sup>26</sup> In South Africa, the first adult received a CI in 1986 and the first child in 1988.<sup>54,55</sup> There are currently nine independent CI programs across South Africa. Accurate statistics about the number of children in South Africa with CIs are difficult to obtain in published literature.<sup>16</sup> However, according to the South African Cochlear Implant Group (SACIG) 1060 children between 0 – 18 years across South Africa have been received CI implants since 1988 until 2016.<sup>56</sup>

The benefit from CIs is often not immediate. Improvements occur over a period of months or years and is linked to the age of a child at the time of implantation, the cause of hearing loss, and family involvement.<sup>6</sup> In adult CI recipients, the prognosis for health related quality of life outcomes is better when there is no history of tinnitus prior to the CI procedure, when they receive bilateral CIs, and when they attended mainstream schooling with a normal hearing educational setting.<sup>55</sup> In children, bilateral implantation is a good predictor for better auditory performance and speech production. Better outcomes also strongly relate to an oral communication mode and mainstream education.<sup>54</sup>

#### 2.5.2 Complications and side-effects of cochlear implants

After a successful cochlear implantation, delayed failures may occur and may be categorized as either a "hard failure" or as a "soft failure". "Hard failures" refer to malfunctions where the speech processor fails to lock with the internal device. "Soft failures" refer to a suspected but not proven device malfunction. The characteristic symptoms in such cases may include shocking sensations, popping sounds, intermittency or an unexplained progressive decrement in performance.

Foreign body or hypersensitivity granuloma is described as a delayed hypersensitivity response after cochlear implantation, and may be a possible cause for "soft failures".<sup>57</sup> It is interesting to note that the child developed localised granuloma annulare (inflamed skin condition with circular reddish bumps) on her scalp in the area of the device and coil.<sup>58</sup>

Up to one-third of people experience disequilibrium (a loss or lack of equilibrium or stability, especially in relation to supply, demand, and prices), vertigo (a sensation of whirling and loss of balance, associated particularly with looking down from a great height, or caused by disease affecting the inner ear or the vestibular nerve), or vestibular weakness lasting more than 1 week after the procedure and generally resolve over weeks to months.<sup>6</sup>

Postoperative vertigo is a well-known complaint after cochlear implantation in adults. Soundinduced vertigo can occur in adults with cochlear implants. Unspecific post-operative vertigo seems to be primarily caused by electrical co-stimulation of the sacculus as part of the otolith organs of the vestibular system in the inner ear (See Figure 2.1). This occurrence is referred to as Tullio's phenomenon, which is a sound induced vertigo caused by environmental noise that corresponds clinically with dizziness, nystagmus, and vestibulospinal disorders.<sup>22</sup> It was noted that this phenomenon was identified in adults who were able to compare and describe their pre- and post-operative experiences. Coordes et al (2012) concluded that sound-induced vertigo by environmental noise after cochlear implantation in adults occurred in about one fifth of cases.<sup>22</sup> Although there are not many child cases reported with Tullio's phenomenon, it is hypothesized whether or not the child in this case study may have suffered from this condition, seeing that her behaviours were outside of the normal expectations.

In the child's case, the question arose whether sound induced vertigo by environmental noise could interfere with experiences of environmental sensory input which can lead to negative behavioural responses and disorganized functional performance. Another question arose what the impact was of the granuloma annulare in the area of the device and coil in terms of possible irritation to the skin and increased sensitivity. The child did not have the verbal skills to communicate and compare pre- and post-operative experiences. She could not verbalise her discomfort, nor did she have the vocabulary or understanding of the invasion and assault on the sensory system. Therefore, the child may have reacted with challenging or acting out behaviours. It might be a possibility that her behaviour was the most effective way she could indicate discomfort and/or distorted sensory information.

In addition to the surgical trauma of inserting the electrode array, indirect electrical stimulation of the vestibular nerve may also cause vestibular deficits in children with cochlear implants.<sup>16</sup>

Previous assumptions indicated that implant activation had a slight advantage in accomplishing balance tasks.<sup>59,60</sup> However, more recent research findings indicated that it did not appear if auditory stimulation obtained from the CI had a positive effect on motor development and balance performance.<sup>16</sup> Therefore, despite more auditory information that the cochlear implant provides, the balance skills of children with CI were poorer than the non-implant group.

Vestibular deficits may be more prevalent in deaf children and cochlear implant candidate than in children with lesser degrees of hearing loss is likely to result in balance deficits. In addition, vestibular dysfunction is reported to be one of the predictors of this Tullio's phenomenon vestibular dysfunction.<sup>16,22</sup>

# 2.6 THE LINK BETWEEN COCHLEAR IMPLANTS AND SENSORY INTEGRATION 2.6.1 Patterns of SID with CIs: US sample vs SA sample

Koester et.al. (2014) conducted a study to investigate the pattern of sensory integrative dysfunction in children with cochlear implants in the US. Their study consisted of 49 children with hearing impairments and cochlear implants of which 18 participants were tested with the SIPT. All children assessed had at least one cochlear implant. It is noted that from the 18 children that were tested with the SIPT, six had bilateral cochlear implants. The SIPT results indicated that children with cochlear implants scored significantly lower on the tests of Motor Accuracy, Sequencing Praxis, Bilateral Motor Coordination, Standing and Walking Balance, Manual Form Perception, and Postrotary Nystagmus. Of the 18 children with cochlear implants who were tested with the SIPT, 15 had depressed PRN scores with at least 1 standard deviation below the mean. The above-mentioned tests are associated with the vestibular and proprioceptive bilateral integration and sequencing pattern of sensory integrative dysfunction. Their results therefore indicated that children with cochlear implants share similar characteristics and present with the vestibular and proprioceptive bilateral integration and sequencing pattern of sensory integrative dysfunction. It is further noted that children with cochlear implants are at risk for decreased vestibular functioning and have functional motor related difficulties related to standing and walking balance, postural, ocular, bilateral integration, and sequencing tasks.7,13

Kruger et.al. (unpublished, Presented at WFOT 2018) *A Pilot Study to Identify Sensory Integrative Dysfunction in Children with Bilateral Cochlear Implants in South Africa* indicated that children in South Africa with bilateral cochlear implants also presented with the vestibular and proprioceptive bilateral integration and sequencing pattern of sensory integrative dysfunction. SIPT results from 9 children from Gauteng province were statistically analysed and compared to the US findings. There were significant similarities between the US and SA findings e.g. low scores on standing and walking balance, bilateral motor coordination, sequencing praxis, oral praxis, kinesthesia and postrotary nystagmus.<sup>61</sup>

#### 2.6.2 The link between the vestibular system and cochlear implants:

The close proximity and neurological connections between the vestibular and auditory systems are evident as illustrated in Figure 2.1 (The sense organs of the inner ear) and Figure 2.2 (The vestibular cochlear nerve). Ayres recognised the of sensory systems, in particular the tactile, proprioceptive and vestibular senses in explaining function and dysfunction.<sup>42</sup> Seeing that the vestibular system is recognised as one of the crucial body-centered senses in the context of ASI®, it is critical to investigate the link between as well as the impact of the vestibular system on audition and cochlear implants.

Many hearing children with speech- and language difficulties show signs of inefficient vestibular sensory processing, especially evidenced by a shortened duration of postrotary nystagmus (PRN). This can be related to ineffective processing of vestibular input from the semi-circular canals as one of the vestibular receptors, and may result in perceiving less detailed information about the body in relation to gravity and 3D space.<sup>1,13</sup> Increased vocalisation is often seen when a child with a speech disorder participates in a variety of movement activities. Children with hearing loss experience vestibular dysfunction.<sup>7</sup> Children with CIs presented with the vestibular proprioceptive bilateral integration and sequencing (VPBIS) pattern of sensory integration dysfunction. It was concluded that the VPBIS pattern of dysfunction has significant implications for occupational performance. Occupational therapists have an essential role to play in identifying challenges related to participation in occupations that have not been routinely addressed in children with CIs.<sup>7</sup>

Hearing loss due to an inner ear impairment may cause vestibular dysfunction.<sup>16</sup> Both the auditory and vestibular input is received by the vestibular nuclei coordinate the two kinds of input.<sup>1</sup> The vestibulocochlear nerve (CN VIII) transmits sound and balance information from the inner ear to the brain. It has associated nuclei in the brainstem; and has interconnecting fibres with many other parts of the brain.<sup>33</sup>

Children with CIs are at risk for motor and balance deficits. Vestibular and motor evaluations, as well as interventions to improve balance and motor skills, should be prioritized for this population.<sup>16</sup> Occupational therapists using ASI® may assist with speech and language development by fostering efficiency of lower level functioning on a brain stem level.<sup>1</sup>

Increased vocalisation is often seen when a child with a speech disorder participates in a variety of movement activities.<sup>1</sup>

# 2.7 THE IMPACT ON PARTICIPATION IN CHILDHOOD OCCUPATIONS

Participation in social aspects of daily life is crucial to children's development. Children with disabilities are often isolated from social events as a result of either the nature of the disability, or the practices that limit their access to typically developing peers. This includes opportunities to participate in social activities at home, school and in the community.<sup>62</sup>

Deaf children do not have the same exposure to sensory and learning opportunities as their typical peers with normal hearing. They often resort to compensatory measures to develop their skills. Deaf children are often isolated from social events as a result of their disability. This includes opportunities to participate in activities at home, school and in the community.<sup>62</sup> Furthermore, deficits in sensory processing interfere with the ability to interact with people and objects. This negatively impacts their ability to explore, form new ideas, build vocabulary and learn new skills.<sup>50</sup>

In this particular case study the child had difficulty in all areas of occupational performance including activities of daily living (e.g. eating and dressing), play (e.g. stereotyped behaviours such as sorting similar objects and packing things in a line), social participation (e.g. ability to develop interpersonal skills and relationships limited to non-verbal cues and some vocalisations, isolating herself) and education (had not been attending a school, mainly at home, and medical centers to deal with the medical issues related to her CI's and speech rehabilitation).<sup>20</sup>

# 2.8 THE IMPACT OF COCHLEAR IMPLANTS ON THE FAMILY UNIT

There has been an increase in studies on family stress caused by children with hearing impairments, specifically on challenges related to the cochlear implant process. The parents are exposed to stressful situations that relate to authorising the expensive implant procedure in a condition that is not life threatening and play a vital role in post-operative rehabilitation. Other challenges may involve the difference between parents' expectations and the child's experiences of the CIs impacting on long-term communicative, educational and social outcomes.<sup>63</sup>

In conclusion, there is evidence in other parts of the world to guide clinical processes for children with CIs which focus on motor control, language development, and to some degree the emotional impact on the child and the family.

However, there is a lack in available evidence to guide occupational therapists working with children with CIs, and more so in the South African context. Therefore, international references will be applied and adapted to inform and guide this case study.

# 2.9 CONCLUSION TO THE LITERATURE REVIEW

The information from this literature review will be used to support and interpret research results and assist with coming to a reasonable conclusion about this case study.

# **CHAPTER 3: METHODS**

# **3.1 INTRODUCTION**

Schaaf et. al. (2014) recommended that both quantitative and qualitative methods should be used with regard to outcome measurements of occupational therapy using Ayres' sensory integration (ASI®).<sup>19</sup> In another single case report, an occupational therapist used ASI® for a child with autism and the efficacy of ASI® intervention was measured. Although that case report formed part of a larger study, the child with autism showed an improvement in sensory processing, as measured by the Sensory Integration and Praxis Tests (SIPT), as well as enhanced participation in home, school, and family activities, as indicated on parent-rated goal attainment scales.<sup>64</sup>

In this single case study, ASI® was also selected by the occupational therapist as the theoretical framework for the child with cochlear implants (See Chapter 1 Section 1.12). In Chapter 1 Section 1.7 the child was defined as a unique, extreme and unusual case whose participation and behaviour fell outside of the typical expectations. However, due to the child's level of participation and behavioural disorganisation, it was not possible for the first two years of occupational therapy to administer a standardised test such as the SIPT. It was therefore warranted to develop another measurement tool to identify challenges related to sensory processing and participation in order to establish a measurable starting point, articulate realistic goals to direct the intervention and to establish the impact of ASI® on the occupational performance of the child with bilateral cochlear implants (CIs) over a period of time. This was the motivation for developing the <u>Occupational Therapy (OT) Paediatric (P) Intervention outcomes (I) for Cochlear Implants (C) using Sensory-based (S) activities (OT-PICS) as an observation tool.<sup>19</sup> The OT-PICS observation tool also assisted with documenting small changes in the child's behaviour and to reflect on the efficacy of ASI® intervention over a period of 45 months or approximately 4 years.</u>

Multiple sources were used to collect both quantitative and qualitative data to gather evidence and obtain in-depth knowledge of this case study.<sup>27</sup> Qualitative data helped to explain and build on quantitative results which provided a more holistic overview and context to statistical findings, seeing that the child was not isolated, but living within her family unit and formed part of the cochlear team.<sup>28,30</sup> This case study included findings from previous reports, clinical observations, assessments and intervention procedures. The cause-and-effect relationship between variables was established by means of comparing the outcomes of the respective measurement instruments namely OT-PICS and SIPT, before and after a period of intervention.<sup>27,30</sup> As presented in Figure 3.1, the points in time when the OT-PICS was used across the 45 month period are indicated by A1, A2, A4 and A6. A3 and A5 indicate the first and second SIPT assessments respectively, 19 months apart.

# 3.2 RESEARCH DESIGN

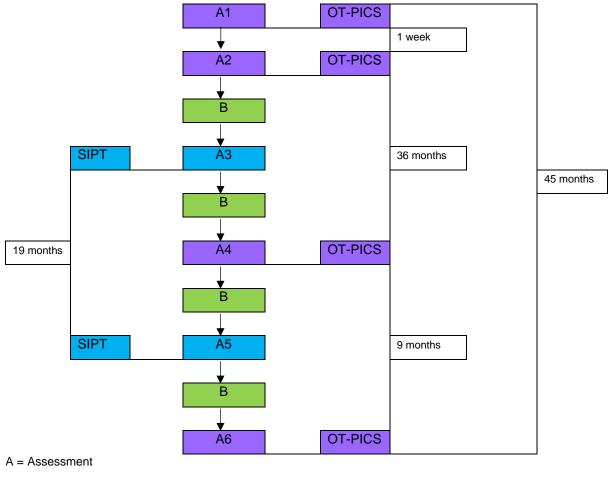
A retrospective, longitudinal, experimental holistic single case study design.<sup>27,28,29</sup>

Retrospective: In this retrospective case study, the outcome of interest has already occurred at the time the study was initiated. The researcher was able to formulate ideas about possible associations and investigated potential relationships between the variables by means of analysing existing material. This included video recordings of the child's intervention sessions that were conducted by the clinical occupational therapist between 2013 and 2017, as well as the two sets of SIPT results during that period (also administered by the child's occupational therapist). Existing material that was used as evidence also included clinical notes, medical records and reports, as well as parent questionnaires (including the Sensory Profile<sup>10</sup>) that were completed prior to the start of the research investigation. The child's behaviour due to exposure to the CI was assessed by looking back in time.<sup>65,66</sup> The researcher was also the child's clinical occupational therapist who is a trained ASI® practitioner and conducted all the clinical procedures such as the intervention and the two SIPT assessments. Refer to Section 3.3. Selection of participants for more detailed information. As part of the case study research, the scientific basis of the outcomes to determine possible associations between variables was investigated by comparing the results with existing, up to date and relevant literature. The OT-PICS (as discussed in Section 3.4.2 Data collection tools) was used on existing video material between 2013 and 2017 to determine the possible scientific basis and associations between dependent (e.g. the child's behaviour) and independent variables (e.g. ASI® intervention).

*Longitudinal:* The child received occupational therapy from the age of 3 years 6 months (May 2013) to 7 years 3 (February 2017) months, for a duration of 45 months (approximately four years). During this period, regular video recordings were made which were used for assessment purposes to indicate small changes in her behaviour and acquisition of skills.

*Experimental:* This single case study aimed to show that the dependent variables (e.g. the child's sensory-motor skills and participation in occupations) changed over time when the independent variable, namely the ASI® intervention, was implemented. Refer to Sections 2.4 and 5.5 for more detailed information about ASI® intervention and adaptations specifically for this child.

For the purpose of the case study research, the OT pics observation tool was developed to determine small changes in her sensory-motor and functional skills across the period 45 months by means of watching the videos as discussed above. The video recordings guided clinical reasoning processes when it was not possible to obtain reliable test scores. The Sensory Integration and Praxis Tests (SIPT) was used as to as a standardised test to identify a pattern of sensory integrative dysfunction (SID) and determine changes in her underlying sensory processes over 19 months. Refer to Figure 3. 1 below for a schematic representation of the research design over a period of 45 months indicating the assessment and intervention intervals:



B = Intervention

Figure 3.1 Schematic representation of the case study research design

# **3.3. SELECTION OF PARTICIPANTS**

An extreme, unusual and unique case was identified to investigate a particular phenomenon that fell outside the typical expectations of a child with bilateral cochlear implants (CIs).<sup>31</sup> Please refer to Chapter 1 Section 1.7 for Defining the case in more detail. The other participants in this study were selected and described in the sections to follow.

#### 3.3.1 Quantitative procedures

All clinical procedures conducted on the child, including assessments and intervention, were done by the child's clinical occupational therapist who was also the researcher for this case study. The researcher completed all aspects of training in ASI® which implies that she is a qualified SIPT administrator and her intervention adheres to the ASI® fidelity measure© as certified by die South African Institute for Sensory Integration (SAISI). See Annexure C for certificates. The OT-PICS observation tool was developed as part of the case study research, and used this measurement instrument to score behaviours of the child by watching existing video material that was recorded prior to the start of the study.

A statistician from the University of Pretoria was involved in analyzing the data.

Three (3) experienced occupational therapists who have completed their post-graduate training in Ayres Sensory Integration (ASI®) were purposefully selected to assist with the development of the OT-PICS observation tool. They participated in the capacity of experts that were included in verifying the usability of the OT-PICS by means of reviewing the items and rationale for the inclusion of each item, as well as the inter-rater reliability process. The Oxford definition of an expert is someone with "expert knowledge or skill in a particular subject, activity or job".<sup>67</sup>

# 3.3.2 Qualitative procedures

The child's parents and the cochlear team were purposefully selected as participants to obtain perspective about the child from various contexts. The child's parents participated in a *semi-structured interview* at their home which lasted about 30 minutes. An *on-line questionnaire* was sent to the child's cochlear team via Google forms to obtain insights about their experience of referring the child they were concerned about to the occupational therapist for ASI® intervention. The cochlear team consisted of the ear, nose and throat surgeon, the audiologist and the speech and language pathologist who oversaw the initial cochlear implantation and switch-on.

The questionnaire was also sent to the child's second speech and language pathologist who took over when the long drive in the car was impacting the child's ability to optimally participate in regular therapy sessions at the initial speech and language pathologist. Upon recommendation of the occupational therapist, the parents changed to someone closer to their home to reduce travelling a long distance and spending at least 45min to an hour in the car to get to the cochlear implant centre for sessions 1-2 times per week. Each member of the cochlear team had at least 10 years' experience in their field.

According to adherence to the ethical requirements of this case study research, all of the abovementioned participants provided written informed consent (Annexure D 1 and 3). The child that was selected for this case study research signed the Assent Consent form (included as Annexure D 2).

# 3.4 DATA COLLECTION

#### 3.4.1 Physical setting

Clinical procedures took place at a private paediatric practice in Gauteng, South Africa. Contact meetings were held via Skype, or in person on the premises of the University of Pretoria. A virtual platform was used for handling electronic data. The parent interview was conducted in the child's family home.

# 3.4.2 Data collection tools and methods

For the purpose of providing an orderly and logical approach to describe the various methods, data collection instruments and analysis procedures, information is organised and presented under the respective objectives. Objective 1 - 5 consisted of quantitative tools, methods and statistical measures. Objective 6 consisted of qualitative tools, methods and descriptions.

# 3.4.2.1 <u>Objective 1:</u> To develop a measurement instrument that can identify and describe sensory-motor factors and functional participation challenges in occupations for children with cochlear implants (CIs).

The OT-PICS observation tool was developed to assist with recording and measuring small changes in a child' behaviour, by means of scoring observable behaviours while watching a video recording of ASI® intervention sessions. This observation tool was developed according to the following steps<sup>68</sup>:

#### Step 1: Application of principles from ASI® literature and clinical experience:

The OT-PICS observation tool was designed by means of integrating ASI® theoretical principles from the literature and insights from clinical experience. The OT-PICS observation tool can be used by occupational therapists working with young children with cochlear implants who are trained in ASI®, especially during the early intervention phase before children are able to participate in formal testing procedures such as the SIPT.

The application of ASI® principles to other diagnostic groups was used as a guideline to bridge the gap in the literature pertaining to occupational therapists using the ASI® approach for children with cochlear implants.<sup>3</sup>

In "Sensory integration: applying clinical reasoning to practice with diverse populations" by Schaaf and Roley (2006)<sup>3</sup>, guiding principles for intervention were discussed to assist practitioners working with other diagnostic groups such as high risk infants, cerebral palsy, autism spectrum, visual impairments, fragile X syndrome and environmental deprivation. Principles had to be adapted and applied where relevant and appropriate for the child with bilateral cochlear implants. In the "Clinician's guide for implementing Ayres Sensory Integration®: promoting participation in children with autism" by Schaaf and Mailloux (2015)<sup>9</sup>, the concepts of ASI® theory were operationalized as a systematic framework called '*data driven decision making*' (DDDM). Although the DDDM was presented in autism literature, the principles were adaptable and applicable to the child with cochlear implants.

The DDDM framework is a step-by-step model that can direct practitioners to use assessment data as a guide for designing an individualised intervention map and to articulate and document outcomes of intervention specifically for each child.

The DDDM consists of the following steps<sup>9</sup>:

- 1. Identifying child's strengths and concerns/challenges
- 2. Conducting a comprehensive assessment
- 3. Generating hypothesis (identifying possible diagnosis / area of dysfunction)
- 4. Developing and scaling goals (goal setting for each specific child, consider wishes and needs of caretakers)
- 5. Identifying outcome measures: what is the end result we are striving for, what clients can achieve as a result of OT intervention
- 6. Setting the stage for intervention
- 7. Conducting intervention
- 8. Measure outcomes and monitor progress

According to this model, outcomes include improvements in sensory-motor skills (proximal outcomes) and in functional skills and participation in daily activities (distal outcomes). The DDDM assists practitioners to understand and address a child's sensory integrative difficulties related to their challenges in participation in daily activities. The DDDM also ensures that practitioners maintain systematic reasoning that include the articulation of participation goals, and constant monitoring of outcomes. A key area of distinction between ASI® and other sensory-based approaches is the emphasis on how sensory-motor factors affect participation in occupations.<sup>8</sup>

The SIPT manual, together with other original work from Dr Ayres, also provided information about the underlying sensory systems and the impact on performance in terms of linking certain sensory systems with certain motor skills or behaviours.<sup>1,11,13</sup>

Occupational therapists working in the field of Ayres' sensory integration (ASI®) have to adhere to structural and process elements as stipulated in the ASI® fidelity measure© during intervention.<sup>34,52</sup> The ASI® fidelity measure© allows for the application of knowledge and skills to assist children with various difficulties and diagnostic groups while adhering to the fidelity requirements of ASI® intervention.

The use of this fidelity instrument not only allowed the researcher to verify that the therapeutic strategies used in the study represent the defined intervention but also made the study replicable. The researcher was able to draw on previously gained clinical knowledge and skills in over 20 years of working with various diagnostic groups including the autism spectrum, genetic disorders, premature births, and development delays. This includes ten other children with cochlear implants in the past 15 years. This period of clinical experience provided a platform for the integration of theoretical concepts to clinical practice, and to link assessment findings with underlying sensory processing difficulties with participation challenges. Clinical experience also provided insights into the impact on the family, and that the parents should be considered part of their child's therapeutic team.

# Step 2: Identifying developmental domains and sections:

The OT-PICS observation tool is divided into two developmental domains namely: sensorymotor factors (proximal outcomes) and functional participation factors (distal outcomes) as presented in the DDDM.<sup>9</sup> Each domain consists of three different sections. Each section consists of different items to identify and describe children's responses to sensory input. Items were further divided under *Favourable* and *Unfavourable* outcomes. The *Favourable* outcomes refer to responses that are appropriate and desirable for a child with Cls (e.g. engaging in movement experiences while wearing the Cls), whereas the *Unfavourable* outcomes refer to the responses that are not appropriate and undesirable for a child with Cls (e.g. W-sitting or removing the Cls). The items are further discussed in Step 3.

Sensory-motor factors are described as the clinical aspects identified after assessment that require intervention. These include the following categories: sensory perception, motor related functions and sensory reactivity. If the goal-attainment scale (GAS) is to be used, this section will assist with defining the proximal outcomes.<sup>9</sup>

Functional participation factors are described as the skills, abilities and behaviours expected to change in response to the intervention that impact participation in occupations. These include the following categories: speech, language and communication skills, play and cochlear usage. If the goal-attainment scale (GAS) is to be used, this section will assist with defining the distal outcomes.<sup>9</sup>

The developmental domains and the categories are presented in table 3.1 below:

Developmental Domain:	Section:
Sensory motor factors	1 Sensory perception
	2 Motor related skills
	3 Sensory reactivity
Functional participation factors	4. Speech, language and communication
	5. Play
	6. Cochlear usage

Table 3.1 Developmental domains and categories for the OT-PICS observation tool

# Step 3: Designing the observation tool

The OT-PICS observation tool was designed to promote cost and time-efficiency in clinical practice, and to be as clear and user friendly as possible. No additional test materials need be acquired. The occupational therapist can print the document to be used when scoring the video recording of the child's ASI® intervention session after the child has left the OT room. An electronic copy of the OT-PICS observation tool can also be used. This implies that the occupational therapist is trained in ASI® and adheres to the structural and process fidelity requirements in ASI® intervention©, or working under supervision in ASI® certified therapist.<sup>34</sup>

The document consists of four pages that contains the personal information about the child, the complexity of the session and specific items under each of the categories. The items are the scorable aspect of the OT-PICS observation tool and identify observable and measurable behaviours in children with cochlear implants. A theoretical rationale was used to support and justify the inclusion for each of the item under each of the categories. See Annexure E for the rationale for including each item. The items were divided into *Favourable* and *Unfavourable* outcomes due to certain behaviours that might be observed often, but are not favourable for children with CIs (such as avoiding movement activities or removing the CIs). The items under each of the categories are shown in table 3.2 below:

Table 3.2 OT-PICS developmental domains, sections and items under Favourable andUnfavourable outcomes

	Unfavourable outcomes Developmental Domain: Sensory-Motor Factors (Proximal Outcomes)			
	Section Description of the child's responses to sensory input			
1.	Sensory perception:	Favourable Outcomes (FO):		
	ability to identify,	1.1 Participates in heavy work activities with whole body		
1	discriminate and	1.2 Participates in movement activities e.g. rotation, acceleration		
1	interpret sensory	1.3 In-hand identification of objects without vision		
1	input from various	1.4 Orientates towards natural sounds in environment		
1	sensory systems	Unfavourable Outcomes (UO):		
1		1.5 Participates in sedentary activities		
1				
1		1.6 Bumps into objects / appears clumsy		
1		1.7. Looks at body or limbs while performing a motor task		
	NA-1	1.8 Uses excessive force		
2.	Motor related	Favourable Outcomes (FO):		
1	functions: postural	2.1 Able to maintain balance on a stable surface		
1	control, balance and	2.2 Able to maintain balance on a moving surface		
1	equilibrium, bilateral	2.3 Uses arms together in a coordinated manner		
	coordination	2.4 Performs a sequential movement pattern (arms and legs)		
1		2.5 Able to get on / off equipment independently		
1		2.6 Uses preferred hand		
1		2.7 Uses trunk rotation to cross body midline		
1		Unfavourable Outcomes (UO):		
1		2.8 W-sitting		
1		2.9 Toe walking		
3.	Sensory reactivity:	Favourable Outcomes (FO):		
	hyper- or hypo-	3.1 Participates in tactile experiences		
	reactivity to typical	3.2 Tolerates changes in head position		
1	levels of sensation	3.3 Indicates discomfort or requests to stop		
1	(emotional and/or	Unfavourable Outcomes (UO):		
ļ	behavioural	3.4 Preference for certain sensory experiences		
	behavioural responses)	3.4 Preference for certain sensory experiences 3.5 Avoids certain sensory experiences		
		3.5 Avoids certain sensory experiences		
		<ul><li>3.5 Avoids certain sensory experiences</li><li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short</li></ul>		
		<ul> <li>3.5 Avoids certain sensory experiences</li> <li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game</li> </ul>		
		<ul> <li>3.5 Avoids certain sensory experiences</li> <li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game</li> <li>3.7 "Muting" of surfaces to reduce noise</li> </ul>		
	responses)	<ul> <li>3.5 Avoids certain sensory experiences</li> <li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game</li> <li>3.7 "Muting" of surfaces to reduce noise</li> <li>3.8 Makes use of quiet spaces e.g. tent / box</li> </ul>		
	responses) Developmen	<ul> <li>3.5 Avoids certain sensory experiences</li> <li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game</li> <li>3.7 "Muting" of surfaces to reduce noise</li> <li>3.8 Makes use of quiet spaces e.g. tent / box</li> <li>Intal Domain: Functional Participation Factors (Distal Outcomes)</li> </ul>		
	responses) Developmen Section	3.5 Avoids certain sensory experiences         3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game         3.7 "Muting" of surfaces to reduce noise         3.8 Makes use of quiet spaces e.g. tent / box         tal Domain: Functional Participation Factors (Distal Outcomes)         Description of child's responses to sensory input		
	responses)           Development           4.         Speech,	3.5 Avoids certain sensory experiences         3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game         3.7 "Muting" of surfaces to reduce noise         3.8 Makes use of quiet spaces e.g. tent / box         tal Domain: Functional Participation Factors (Distal Outcomes)         Description of child's responses to sensory input         Favourable Outcomes (FO):		
	responses)           Development           Section           4.         Speech, language and	3.5 Avoids certain sensory experiences         3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game         3.7 "Muting" of surfaces to reduce noise         3.8 Makes use of quiet spaces e.g. tent / box         tal Domain: Functional Participation Factors (Distal Outcomes)         Description of child's responses to sensory input         Favourable Outcomes (FO):         4.1 Makes eye contact		
	responses)	3.5 Avoids certain sensory experiences         3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game         3.7 "Muting" of surfaces to reduce noise         3.8 Makes use of quiet spaces e.g. tent / box         tal Domain: Functional Participation Factors (Distal Outcomes)         Description of child's responses to sensory input         Favourable Outcomes (FO):         4.1 Makes eye contact         4.2 Responds when name is called		
	responses)           Development           Section           4.         Speech, language and	3.5 Avoids certain sensory experiences         3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game         3.7 "Muting" of surfaces to reduce noise         3.8 Makes use of quiet spaces e.g. tent / box <b>ntal Domain: Functional Participation Factors (Distal Outcomes) Description of child's responses to sensory input</b> Favourable Outcomes (FO):         4.1 Makes eye contact         4.2 Responds when name is called         4.3 Uses single words to describe an action or make a request		
	responses)           Development           Section           4.         Speech, language and communication	3.5 Avoids certain sensory experiences         3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game         3.7 "Muting" of surfaces to reduce noise         3.8 Makes use of quiet spaces e.g. tent / box <b>ntal Domain: Functional Participation Factors (Distal Outcomes) Description of child's responses to sensory input</b> Favourable Outcomes (FO):         4.1 Makes eye contact         4.2 Responds when name is called         4.3 Uses single words to describe an action or make a request         4.4 Makes use of 2 to 3-word sentences		
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	responses)           Development           Section           4.         Speech, language and communication	<ul> <li>3.5 Avoids certain sensory experiences</li> <li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game</li> <li>3.7 "Muting" of surfaces to reduce noise</li> <li>3.8 Makes use of quiet spaces e.g. tent / box</li> <li>1.8 Makes use of quiet spaces e.g. tent / box</li> <li>1.9 Description of child's responses to sensory input</li> <li>1.1 Makes eye contact</li> <li>4.2 Responds when name is called</li> <li>4.3 Uses single words to describe an action or make a request</li> <li>4.4 Makes use of 2 to 3-word sentences</li> <li>4.5 Makes use of sentences with 4 words or more</li> <li>4.6 Follows verbal commands</li> <li>1.0 Unfavourable Outcomes (UO):</li> <li>4.7 Makes noisy / unclear vocalisations</li> <li>4.8 Uses gestures as a means to communicate</li> <li>4.9 Uses visual aids e.g. demonstration, lipreading or pictures to assist with an</li> </ul>		
	responses) Development Section 4. Speech, language and communication skills	<ul> <li>3.5 Avoids certain sensory experiences</li> <li>3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of time at an activity before moving onto next game</li> <li>3.7 "Muting" of surfaces to reduce noise</li> <li>3.8 Makes use of quiet spaces e.g. tent / box</li> <li>atal Domain: Functional Participation Factors (Distal Outcomes)</li> <li>Description of child's responses to sensory input</li> <li>Favourable Outcomes (FO):</li> <li>4.1 Makes eye contact</li> <li>4.2 Responds when name is called</li> <li>4.3 Uses single words to describe an action or make a request</li> <li>4.4 Makes use of 2 to 3-word sentences</li> <li>4.5 Makes use of sentences with 4 words or more</li> <li>4.6 Follows verbal commands</li> <li>Unfavourable Outcomes (UO):</li> <li>4.7 Makes noisy / unclear vocalisations</li> <li>4.8 Uses gestures as a means to communicate</li> <li>4.9 Uses visual aids e.g. demonstration, lipreading or pictures to assist with an instruction / conversation</li> </ul>		
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	Unfavourable Outcomes (UO):	
	5.6 Rigid / prefers to play familiar games	
	5.7 Sorting or lining up similar looking toys	
	5.8 Withdraws from play environment	
	5.9 Repetitive and/or stereotyped behaviours	
6. Cochlear usage	Favourable Outcomes (FO)	
	6.1 Able to process sound and movement at the same time (wearing cochlear	
	apparatus during movement activities)	
	6.2 Able to put cochlear apparatus back on after taking a break?	
	How long was the break?:	
	Unfavourable Outcomes (UO)	
	6.3 Removes / hides one or both pieces of cochlear apparatus?	
	Time of cochlear usage before apparatus are removed:	

#### Step 4: Evaluation of OT-PICS observation tool:

In order to ensure that the OT-PICS observation tool was usable and the rationale for the inclusion of items were reliable, three (3) experts in the field of ASI® were consulted.

In this instance, the experts were selected by the researcher and adhered to the following inclusion criteria:

- Qualified occupational therapist with at least 20 years' working experience,
- Completed post-graduate training in the field of ASI®,
- Post-graduate lecturer and mentor for the South African Institute for Sensory Integration (SAISI), and
- Qualified ASI® fidelity measure© rater implying that the expert has experience in rating of videoed intervention sessions.

Electronic documents were sent to the ASI® experts to obtain feedback regarding the overall usability of the OT-PICS observation tool. These documents included the theoretical rationale for the inclusion of each item as well as the scoring mechanism for the observation tool (See Annexure F). The following questions had to be answered by the experts:

- Does each item identify and describe the child's responses to sensory input that link to sensory motor factors (proximal outcomes) and functional participation (distal outcomes)?
- Do you agree that the categories match the developmental domains?
- Does each rationale support the inclusion of the item?

Feedback from the ASI® experts indicated that the OT-PICS was usable and that they agreed with the rationale behind the inclusion of each item.

It became evident that the context in which the intervention session takes place also needed to be described, as a high score did not necessarily imply a high level of functioning if the activities were simple, or if the child was merely exploring between many activities, without engaging in a meaningful just-right challenge. A complexity rating was therefore developed to supplement the child's scores. This assisted with interpreting the child's performance in the context of the level of difficulty to establish adaptive behaviour in relation to just-right challenges, acquisition of skills and improved performance. See Annexure G for the complete OT-PICS observation tool.

The final OT-PICS observation tool is a four-page document that is to be scored while watching a video recording of an ASI® intervention session between 30 – 60min in duration.

The information is recorded as follows:

Page 1: The child's personal information, reason for referral and additional comments or observations.

*Page 2*: The complexity rating (Part 1) and the scale to score the child's responses (Part 2). *Page 3*: The developmental domain for *sensory-motor* factors is provided with its respective categories namely sensory perception, motor related functions and sensory reactivity, each containing its specific favourable and unfavourable items to be scored.

*Page 4*: The developmental domain for *functional participation* factors is provided with its respective categories namely speech, language and communication skills, play as childhood occupation and cochlear usage. The specific Favourable and Unfavourable items for scoring under each section are provided.

# Step 5: Reliability

(i) Intra-rater reliability

To statistically determine the internal consistency of the OT-PICS observation tool, four (4) videos were rated on two occasions approximately one month apart. The videos are indicated as A1, A2, A4 and A6 in Figure 3.1. The preferred measure of reliability for the intra-rater reliability was the percentage agreement. This method indicated the percentage of times that the scores, for each of the items in the checklist including the complexity rating, were exactly the same between the two different time points. The results were investigated for each section as well as across all sections. Cohen's Kappa was used as it is also a very highly used measure of reliability and was used to provide a more descriptive level of agreement.<sup>69</sup>

#### (ii) Inter-rater reliability

Three (3) expert occupational therapy clinicians participated to evaluate two (2) video recordings of occupational therapy sessions of the child on two separate occasions namely session A2 and A6 as indicated in Figure 3.1. The purpose of the statistical comparison was to evaluate if the scoring of the items in OT-PICS observation tool was consistent. Two statistical tests were used to measure the interrater reliability namely percentage agreement, and the Intraclass Correlation (ICC).<sup>70</sup> The percentage agreement displayed the number of times that the scores, for each of the items in the checklist, were exactly the same. This means that the statistical measure did not take into account how close the results were when they were not exactly the same and did not provide scope for smaller variations and differences in opinions e.g. differentiating between a score of 1 and 2, or 3 and 4.

The ICC was selected as the preferred statistical measurement of reliability as it took into account the differences in the means of the measures being considered between the raters. It therefore provided some flexibility for slight differences in opinion.<sup>70</sup>

The inter-rater reliability for the OT-PICS observation tool to was measured to compare reliability between items scored for the child's performance, as well as the complexity of the session. The consistency between the complexity scores reported by the inter-raters for the two videos (A2 and A6) was also measured by the ICC.<sup>70</sup> The results of the intra- and interrater reliability will be discussed in Chapter 4.

# 3.4.2.2 <u>Objective 2</u>: To identify challenges related to sensory-motor factors and functional participation in a child with bilateral CIs.

The OT-PICS observation tool was used to identify strengths and areas of concern in the child with bilateral cochlear implants. In addition, previous records were reviewed to support observations that were made throughout the child's intervention period, not only on the days that video recordings were made. Four (4) videos were selected across the four-year period. The OT-PICS observation tool was completed to record the level of the child's participation to identify sensory-motor factors and functional participation challenges. The complexity scores of the sessions were also recorded.

# 3.4.2.3 <u>Objective 3</u>: To determine changes in sensory-motor factors and functional participation in a child with bilateral CIs across a four-year period of ASI® intervention.

In order to investigate if there was a positive growth that occurred over the four-year period, information from the OT-PICS observation tool was considered to provide a score for child's responses and participation, as well as the complexity of the sessions in which they occurred. Scores were compared to establish if favourable behaviours increased, and unfavourable behaviours decreased. Descriptive statistics and the Spearman's correlation were used to establish meaningful relationships between the Favourable and Unfavourable outcomes.<sup>71</sup> Results are presented with the aid of visual graphs and tables in Chapter 4. Results of the OT-PICS observation tool assisted with the identification of trends and changes in sensory-motor factors and functional participation challenges in a child with bilateral CIs.

# 3.4.2.4 <u>Objective 4:</u> To determine the pattern of sensory integration dysfunction in a child with bilateral CIs by means of using the Sensory Integration and Praxis Tests (SIPT).

The first time the child had adequate work habits and was able to participate in standardized testing, was after two years of ASI® intervention when she was 5 years and 4 months old. The first SIPT assessment is indicated as A3 in Figure 3.1 above. The assessment was conducted over two days.

The tactile section consists of five (5) tests with vision occluded by means of using a cardboard shield to cover the child's hands. Seeing that the tactile section is the last section of the SIPT, the tactile tests were done on another day to obtain the most reliable results possible, to avoiding a cumulative effect through the build-up of sensory input in the SIPT.<sup>13</sup>

# 3.4.2.5 <u>Objective 5</u>: To compare the pre- and post-intervention SIPT results of a child with bilateral CIs to determine changes in sensory integrative functions.

The parametric paired t-test was used to compare the two sets of SIPT scores where each of the items of the first test was compared to each of the items of the second test. The non-parametric Wilcoxon Signed Rank test was also used to evaluate if the conclusion is the same for this small sample size i.e. one child.<sup>72</sup>

# 3.4.2.6 <u>Objective 6</u>: To obtain perspectives of the cochlear team and parents regarding changes in the child's behaviour and participation in occupations.

A semi-structured interview (Annexure A) was conducted with both parents at their home for approximately 30min. It was recorded and transcribed verbatim into a MS Word format. A theme analysis was done according to the six steps of Braun and Clarke to identify emerging themes and categories. Supporting quotes were provided to support each statement.<sup>73</sup> Refer to Section 4.3.1 for the detailed theme analysis

An electronic questionnaire was sent to the child's cochlear team via Google Forms. (Refer to Section 1. For inclusion of participants). Rich descriptions were used to discuss feedback from the electronic questionnaires that were completed by the cochlear team.<sup>28,74</sup> (See Annexure B)

# 3.5 DATA MANAGEMENT: STORAGE AND ACCESS

The child's clinical files were stored in a fire-proof and locked filing cabinet at the occupational therapist's private practice. All electronic data for the case study was stored in specifically allocated files on the researcher's password protected computer, as well as on a folder in Google Drive as electronic back-up.<sup>40</sup> (See Annexure H)

# 3.6 DATA ANALYSIS

The following table provides the different statistical procedures used to analyse the data:

Objective	Data analysis procedure
1	Percentage agreement and Kohen's Kappa
2	Intraclass correlation (ICC)
3	Descriptive statistics
4	Factor and cluster analysis
5	Paired t-test and Willcoxon Signed Rank
6	Theme analysis and rich descriptions

Table: 3.3 Summary of data analysis for each objective

# 3.7 ENSURING QUALITY OF THE STUDY 3.7.1 Reliability and validity of quantitative data:

#### (i) OT-PICS observation tool

The intra- and interrater reliability of the OT-PICS observation tool is discussed in Chapter 4.

# (ii) Sensory Integration and Praxis Tests (SIPT)<sup>13</sup>

Test validity refers to the ability to draw a meaningful inference from test scores to meet an intended purpose. The primary purpose of the SIPT is to assess sensory integrative and practic status of children with suspected difficulties to detect, describe and explain current dysfunction. The secondary purpose of the SIPT is to provide a basis for ASI® intervention. In the SIPT manual (Ayres 1989), three types of validity were discussed namely construct validity, criterion-related validity and content validity. Construct validity explained the extent to which the test assesses the relevant theoretical constructs. Criterion-related validity explained the extent to which the test on related tasks. Content validity explained the extent to which the test items provide a representative sampling of performance on important aspects.<sup>13</sup>

The test-retest reliability of the SIPT was also discussed and explained the extent to which test scores for an individual are consistent across different assessments over time. The constructs assessed by the SIPT have been fairly stable over time, and a good measure of these constructs should have a fairly high test-retest reliability. In terms of interrater reliability of the SIPT, statistical correlations indicated that different examiners trained in the use of the SIPT will obtain similar results from the SIPT instrument.<sup>13</sup>

In this case study research, the SIPT was used as the preferred "golden" measurement instrument to identify the pattern of sensory integrative dysfunction in the child with cochlear implants.<sup>12</sup> Internal validity will depend on the adherence to standardized procedures.<sup>7,12,13,27</sup>

The SIPT was also used to measure improvement by means of re-testing the case after a period of 60 intervention sessions (over a period of approximately 19 months). During this period of time, the child showed changed in sensory processing by means of carry-over of sensory-motor skills for more refined use. The re-assessment was administered at a time when the child was healthy and actively participating in daily tasks in a positive manner. Sessions occurred weekly and lasted between 45 – 60min in duration.<sup>9</sup> The SIPT re-assessment is indicated as A5 in Figure 3.1 above.

The SIPT is a reliable measurement tool which can be used with various conditions and within various contexts, as long as the occupational therapists have completed their training and adhere to the SIPT manual.<sup>13,28,30</sup>

In more recent publications (2011 and 2012), it is noted that the SIPT has a high test-retest reliability as a diagnostic measurement tool internationally and in South Africa.<sup>12,14</sup> In a study that was published in 2015, the SIPT was used as the preferred assessment instrument to identify the pattern of sensory integrative dysfunction in children with cochlear implants in the United States of America.<sup>7</sup> The occupational therapist who conducted the SIPT for this case study is trained in using the SIPT as a standardised measurement tool and adhered to requirements and stardardised procedures to ensure reliable scores. (See Annexure C)

External validity in a case study refers to the extent to which the findings can be analytically generalized to other situations that were not part of the original case.<sup>27</sup> Although only one child was used in this case study, the findings will provide valuable insights to occupational therapists with training in ASI® to follow similar clinical processes in working with children with CIs. It may therefore be possible to generalise the findings of this case study, to other children with CIs with similar challenges.

The clinician adhered to standardised procedures, such as administering and scoring the SIPT, as well as presenting the intervention according to the ASI® fidelity requirements.<sup>13,34,52</sup>

# 3.7.2 Ensuring trustworthiness of qualitative data

*(i) Credibility*: Data was obtained from various sources to describe the observed phenomenon as accurately as possible.<sup>40</sup> Participants were selected on grounds of their direct involvement in the case and to convey an accurate opinion about the phenomenon based on their expertise so that this case study would have measured what was intended.

*(ii) Confirmability*: The data reflects the perspectives of the participants and is congruent in terms of accuracy, relevance and meaning. In order to eliminate bias, multiple sources for data collection were used to supplement feedback from the parents and cochlear team e.g. previous reports, therapy notes, and review of video recordings.<sup>28,30</sup>

*(iii) Transferability:* This case study defined observations within the context they occurred. Theme analysis and thick descriptions may assist other occupational therapists to apply the findings in other contexts or with other similar cases. Detailed descriptions of data and

processes were reported in such a manner to assist occupational therapists to apply related clinical processes to similar cases.<sup>28,30</sup>

*(iv) Authenticity*: A range of realities from the various participants were indicated in a fair and faithful manner to convey the feelings and experiences of the participants as they were lived. The knowledge about this case was based on a true and authentic clinical profile by means of compiling thick descriptions.<sup>30</sup>

(*v*) *Dependability*: Existing videos of treatment sessions were reviewed and analysed by SAISI to ensure that the occupational therapist adhered to the ASI® fidelity requirements©.<sup>34,75</sup> Evidence is provided in such a manner to allow the application of procedures with some careful adjustments to a similar case in a similar situation with similar outcomes.<sup>40</sup> (See Annexure C).

(*vi*) *Eliminating bias*: Objective reviewers were included to obtain an outsider's perspective of videos that were being analysed. Bias was monitored by means of using the same observation tool between the researcher and objective reviewers.

# 3.8 ETHICAL CONSIDERATIONS AND CONFIDENTIALITY

Ethical principles guided the researcher's manner of conduct and management of procedures.<sup>28</sup> The researcher took special care and sensitivity to protect the interest of the case and related parties.<sup>27</sup> The researcher obtained approval from the Ethics Committee of the Faculty of Health Sciences of the University of Pretoria. (See Annexure J).

# 3.8.1 Principle of respect for others

Participation was completely voluntary. This right was be respected by means of allowing the child and/or her parents, or any member of the cochlear team, to withdraw from the study at any point. The researcher avoided using any form of coercion or penalty.

Informed written consent was obtained from the parents, including assent from the child (See Annexure D 1).<sup>27,28,30</sup> The child and the parents provided written consent (See Annexure D 2). Consent from each member of the cochlear team was obtained to review their relevant documents and to include their feedback from the electronic questionnaires (See Annexure D 3).

#### 3.8.2 Principle of beneficence

The researcher ensured the well-being of the participants who had the right to be protected from discomfort and harm of any kind. The child fell within a vulnerable population and the researcher kept her best interests at heart at all times. The child was not exposed to any form of invasive or harmful procedures such as purposeful exposure to noxious sensory input that would elicit an over-reaction. The parents were comfortable during the semi-structured interview and it was not necessary to discontinue the interview.<sup>27,28,30</sup> (See Annexure I)

#### 3.8.3 Principle of justice

The case was selected for reasons directly related to the research problem. All participants had the right to privacy. All data obtained was handled confidentially. Names were removed from all records included in this study. No names of people or places were included in the report or presentation of these findings.<sup>27,28,30</sup>

# 3.8.4 Protection of human rights

Verbal and written information about the scope and extent of the research was provided to obtain informed consent, most importantly from the child herself, as well as the child's parents. Considering the child's age, she was informed about why the researcher would like to tell her story, and that she must give consent that the researcher may share her story with relevant others to help other children like her and their families. (See Annexure I) The assent form was done in a way that is understandable to the child. Confidentiality was maintained throughout by means of removing names of people and places.<sup>30</sup>

# **3.9 LIMITATIONS**

It may be argued that case studies lack rigour, could be prone to bias, lack generalization ability, and could take too long. Case studies often result in very long documents.<sup>31</sup> It may further be argued that a case study is not representative of a group. However, the single case study was an effective way to define a problem and intervention clearly in determining changes in behaviour and performance of a child with CIs. Depth in this case study was obtained by means of collecting data from various sources to compensate for the small sample size, being only one case.<sup>28</sup> By means of using standardized procedures and assessments to obtain measurable data over a four-year period, this study contributed to evidence-based research.<sup>31</sup>

## 3.10 CONCLUSION TO CHAPTER 3: METHODS

In order to obtain depth and robust but reliable evidence for this single case study research, both qualitative and quantitative methods and sources have been included. This was warranted to come to a reliable and informative conclusion about the impact of ASI® on the occupational performance of a child with bilateral CIs.<sup>19</sup>

## **CHAPTER 4: RESULTS**

### **4.1 INTRODUCTION**

This chapter provides results from both the quantitative and qualitative components to describe, analyse, and interpret the particular phenomenon within this case study. The case was investigated across a four-year period through a process of detailed data collection. Multiple sources of information were utilised to gain an in-depth understanding of this case in various contexts. In order to present the results in a logical manner, the results are discussed under each objective. Objectives 1 - 5 are included under the quantitative components. Objective 6 is included under the qualitative components.

### 4.2 QUANTITATIVE COMPONENTS

## <u>4.2.1 Objective 1: To develop a measurement instrument that can identify and describe</u> <u>sensory-motor factors and functional participation challenges in occupations for</u> <u>children with cochlear implants (CIs).</u>

The OT-PICS observation tool was developed according to the steps as described in Chapter 3. In order to establish whether this observation tool is a reliable instrument, the intra- and interrater reliability was statistically measured. To measure the intra-rater reliability, four (4) videos were used between May 2013 and February 2017, illustrated as A1, A2, A4 and A6 in Figure 3.1. To measure the inter-rater reliability only two (2) videos between May 2013 (A2) and February 2017 (A6) were used to reduce time constraints on the inter-raters as their expert opinions were greatly valued. For the sake of clarity, the dates of the videos were included and indicated in separate colours so that the same videos could be compared for the interrater reliability.

### 4.2.1.1 Intra-rater reliability

The percentage agreement was investigated for each section as well as across sections combined overall. As illustrated in Table 4.1, the percentage agreement between the four (4) videos was consistently within the 80% range.

	Video 1 (A1) 20 May 2013	Video 2 (A2) 27 May 2013	Video 3 (A4) 30 May 2016	Video 4 (A6) 17 Feb 2017	4 Videos Combined
Combined					
sections overall	86,96	89,13	89,13	80,43	86,41

Table 4.1 Percentage agreement to determine OT-PICS intra-rater reliability

The Cohen's Kappa is also a very highly used measure of reliability.<sup>69,70</sup> The following results were calculated using IBM SPSS Statistics 25, once again for each section as well as overall for all sections combined. The table illustrates the overall result per video:

Table 4.2 Cohen's Kappa to determine OT-PICS intra-rater-reliability

	Video 1 (A1)	Video 2 (A2)	Video 3 (A4)	Video 4 (A6)
Combined	0.000	0.054	0.054	0.704
sections overall	0.822	0.851	0.851	0.734

The following guideline can be used to evaluate the Cohen's Kappa and intraclass correlation (ICC) results<sup>69,70</sup>:

- Less than 0.40—poor / minimal
- Between 0.40 and 0.59—fair
- Between 0.60 and 0.79— good
- Between 0.75 and 1.00—excellent

Both the percentage agreement as well as the Cohen's Kappa results showed that there was an excellent intra-rater correlation between the four videos for sections combined overall.

## 4.2.1.2 Inter-rater reliability

The inter-rater reliability of the OT-PICS observation tool was measured to compare reliability between items scored for the child's performance, as well as the complexity of the session. For reliable measures, an ICC value close to 1 is required.

## (i) The child's performance

During the development of the OT-PICS observation tool as described in Chapter 3, the child's performance is divided into two developmental domains namely sensory motor factors and functional participation factors. Under sensory motor factors, the child's responses are recorded under three sections namely sensory perception, motor related functions and sensory reactivity. Under the functional participation factors, the child's responses are recorded under three sections namely sensory perception, motor related functions and sensory reactivity.

Under each section, the items are divided into Favourable and Unfavourable outcomes in order to record which behaviours have changed, and if progress can be indicated over time i.e. an increase in favourable responses and a decrease in unfavourable responses.

	Video 2 (A2)	Video 4 (A6)
	27 May 2013	17 Feb 2017
Sensory Motor Factors:		
Section 1: Sensory perception	0.584	0.478
Section 2: Motor related functions	0.748	0.739
Section 3: Sensory reactivity	0.649	0.711
Functional Participation Factors:		
Section 4: Speech, language and communication	0.706	0.444
Section 5: Play as childhood occupation	0.189	0.668
Section 6: Cochlear usage	0.417	0.882
Overall score for six sections combined	0.59	0.64
TOTAL ICC RESULT FOR ALL VIDEOS:	DS: 0.610	

Table 4.3 OT-PICS inter-rater comparison of the ICC results

Considering the ICC comparison between the different sections of each of the two videos as illustrated in Table 4.3 above, it is evident that the majority of scores for the inter-rater reliability is ranging between fair and excellent, with 5 /14 items rated Fair, 7/17 items rated Good and 1/14 items rated Excellent. Only one item namely "Play as childhood occupation" in Video 2 (A2) had a poor inter-rater correlation with an ICC result of 0.189, possibly due to the different opinions of the level and/or quality of play of the young child when she started with occupational therapy intervention.

It is however interesting to note that the inter-rater correlation in the same section for video 4 (A6) indicated a good correlation with an ICC result of 0.668. Furthermore, it is interesting to note that the inter-raters had a Fair agreement in Video 1 for Cochlear Usage, and in Video 2 they had an Excellent inter-rater agreement for Cochlear Usage. When considering the overall score of all six sections combined, the ICC results were 0.59 for Video 2 (A2) and 0.64 for Video 4 (A6), indicating a fair to good reliability. The total ICC result of all videos combined was 0.610 and indicated a good inter-rater reliability overall.

## (ii) Complexity of the session

The complexity score was included in the OT-PICS observation tool after feedback from the experts was received to assist with determining the therapeutic context of the intervention sessions in which the child's behaviour is observed.

The complexity score assists with determining if sessions became increasingly more advanced over time, indicating graded and more complex "just-right" challenges to facilitate graded and more complex adaptive responses.<sup>1,11</sup> As seen in Figure 4.1, the complexity score consisted of the following items: number of activities, steps of activity, number of equipment, and variety of sensory input. In addition to the child's performance, the complexity rating is scored as follows:

Description of complexity	1	2	3	Item Score
items	Low level	Medium	High	
		level	level	
1.1 Number of activities	1 - 2	3 – 5	6 or more	
1.2 Steps of activity	1 -2 step	3 – 5 steps	6 or more	
1.3 Number of Equipment	1 – 2 pieces	3 – 5 pieces	6 or more	
1.4. Variety of Sensory input	Single	Combined 2	Combined	
	system		various	
	тс	TAL COMPLE		

### **DESCRIPTION OF COMPLEXITY RATING:**

TOTAL SCORE	DESCRIPTION
10 - 12	High level
6 - 9	Medium level
5 and lower	Low level

Figure 4. 1 OT-PICS observation tool Complexity rating

As illustrated in Table 4.4 below, video 2 (A2) indicated a poor correlation with an ICC score of 0.212, while A6 indicated a good correlation with an ICC score of 0.714, and the combined ICC score for all the videos was 0.671, indicating a good correlation overall.

Table 4.4 OT-PICS inter-rater ICC results for the Complexity Scores

	A2 27 May 2013	A6 17 Feb 2017	Combined
Overall complexity			
scores	0.212	0.714	0.671

Due to the good overall ICC results for the different sections and the complexity scores, it can therefore be concluded that, despite some minor differences in opinion between the inter-raters, the OT-PICS observation tool is a reliable tool for utilisation by a qualified occupational therapist, trained in Ayres Sensory Integration®.

# 4.2.2 Objective 2: To identify challenges related to sensory-motor factors and functional participation in a child with bilateral CIs.

Based on low scores (items achieving a score of 1 or 2) on the OT-PICS observation tool for video 1 (A1) and video 2 (A2) in combination with written notes, specific strengths and areas of concern could be identified. The child's performance can be described as follows:

### 4.2.2.1 Strengths

From the additional observations and comments that were made on the first page on OT-PICS observation tool, it was indicated that the child appeared friendly and sociable as she made appropriate eye contact and was animated in her facial expressions and non-verbal gestures.

### 4.2.2.2 Concerns and challenges observed

### (i) Additional comments recorded:

The child preferred sedentary visual perceptual activities. Although she participated by imitation, she was not able to follow verbal instructions and was dependent on visual cues or demonstrations to negotiate and facilitate alterative activities. Although it could be considered as a strength too, the child was visually orientated and guided by visual order. This however had a negative impact on her play repertoire as she preferred familiar activities and preferred the way things were the previous time (e.g. when equipment was moved).

## (ii) Section 1: Sensory Perception:

The child had limited participation in movement activities and was not able to identify objects in her hands without vision (e.g. shapes in a "feely box"). It was also difficult for her to say the words of the items in her hand but was able to visually match them once the shape was taken out of the box. The child often used visual compensation, excessive force or deliberate movements e.g. looking at her feet when walking up the ramp with big heavy footsteps.

## (iii) Section 2: Motor related skills:

The child was dependent on assistance to get on and off equipment, especially to stabilise moving equipment.

The child had difficulty with maintaining her balance on unstable surfaces, but was often observed in a W-sitting position on stable surfaces or on the carpet. W-sitting is not a recommended sitting position for a developing child. Children who are frequent W-sitters often rely on this position for added trunk and hip stability to provide more freedom for their arms e.g. to play. They appear "fixed" through the trunk which limits trunk rotation and lateral weight shifts e.g. twisting and turning to reach toys on either side of her body. Trunk rotation and weight shifts are important for the development and maintenance of balance e.g. running outside or playing on the playground.<sup>76</sup> These skills are also important for the development of crossing the midline and performing rhythmical movement patterns.<sup>1,11</sup> Observations of coordinated movements were limited due to limited participation in movement activities.

### (iv) Section 3: Sensory reactivity:

The child had difficulty tolerating changes in her head position in relation to gravity and preferred to keep her head in an upright position. She participated in limited movement activities, and often used quiet spaces such as a tent or box-house to play a sedentary or visual perceptual game. She appeared to have a low tolerance for movement as her participation was short in duration, and then escaped to quiet spaces afterwards. External noise was often muted e.g. by putting a blanket on the wooden ramp, or the child putting her hoody over her head during a movement activity. The child was somewhat sensitive to light touch input such as shaving cream, but was able to continue with the activity if she was able to clean her hands in between, or "allowed" to avoid direct contact e.g. by means of using a paint brush instead of getting her hands dirty by working directly with the shaving cream.

### (v) Section 4: Speech, language and communication skills

This was an obvious area of difficulty for the child. Her vocalisations were unclear and she was unable to use words to express herself. She made use of hand gestures, eye and facial expressions to communicate. She was good at lipreading and relied on vision for context.

## (vi) Section 5: Play as childhood occupation

The child preferred visual perceptual games with some kind of order where she could sort similar looking items. She preferred familiar games, but showed some symbolic and imaginative play when presented with familiar toys e.g. feeding a doll, pretending to sleep and wake-up. She showed enjoyment by laughing and jumping up and down. It was observed that she withdrew from the play environment when she participated in either a movement or sound activity.

### (vii) Section 6: Cochlear usage

The child did not seem comfortable wearing her CIs during the few movement activities she participated in and had difficulty processing sound and movement input together. She preferred sedentary games while wearing her CIs. She was able to process approximately 30 seconds of combined auditory and movement input where after she removed her CIs and hid them away. The child's mother was able to put the CIs back on after a short break of a few minutes.

# 4.2.3 Objective 3: To determine changes in sensory-motor factors and functional participation in a child with bilateral CIs across a four-year period of ASI® intervention.

### 4.2.3.1 Changes in the child

Table 4.5 below illustrates the total scores for Favourable and Unfavourable outcomes of each of the four (4) videos (A1, A2, A4 and A6). It is noted that the scores for the Favourable items increased across the videos while the Unfavourable scores showed an initial increase followed by a significant decrease over the period of 45 months. Statistical tests could not be performed for these results as this meant that one overall score would be compared per video against another.

Video Favourable		Unfavourable
1	59	51
2	70	54
3	96	32
4	93	28

Table 4.5 Comparison of total favourable and unfavourable scores over four videos:

In order to determine if ASI® intervention had an impact on the child's Favourable and Unfavourable scores, the following comparisons were made:

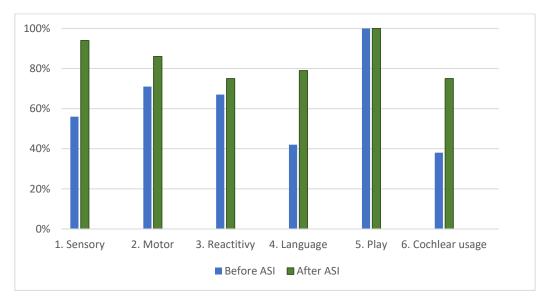


Figure 4.2 Illustration of changes noted in total scores for Favourable Outcomes in OT-PICS

In Figure 4.2 above, the scores indicated in green, after ASI® intervention, are significantly higher than the scores indicated in blue, before ASI® intervention, for all the sections, except section 5: Play. This indicates that the scores for Favourable behaviours observed in sensory perception, motor related skills, sensory reactivity, language and cochlear usage were higher after occupational therapy intervention using the ASI® approach. Examples of Favourable outcomes include participation in whole-body and movement activities, maintaining balance, tolerating changes in head position, using words/ sentences to communication, trying new equipment, and the child's ability to process sound and movement together, implying the she wore her CIs while participating in movement activities. It appeared if the child's positive aspects of play were consistent over the 45-month period.

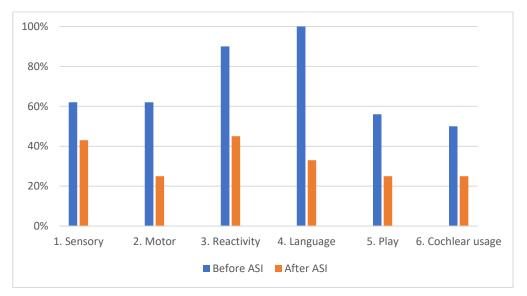


Figure 4.3 Illustration of changes noted in total scores for Unfavourable Outcomes in OT-PICS

In Figure 4.3 above, the changes noted in Unfavourable outcomes before and after the child received occupational therapy using the ASI® approach are visually presented. Examples of unfavourable outcomes include clumsiness, using excessive force, visual compensation, W-sitting postures, avoidance of certain sensory experiences, high activity levels, disorganised behaviour, muting of surfaces, using gestures, noisy / unclear vocalisations, rigidity in play, removing and hiding of CIs.

From Figure 4.2 above it is evident that there exists a general upward trend in the Favourable scores as the videos progressed from A2 (video 1 from 2013) to A6 (video 4 from 2017). When evaluating the Spearman's correlation<sup>71</sup>, it is noted that the p-value is not less than 0.05 which means the null hypothesis will not be rejected. Therefor no significant relationship exists. The general upward trend indicates an increase in the Favourable scores, indicating an increase in the child's level of performance across the 45-month period.

From Figure 4.3 it is also evident that there exists a general downward trend in the Unfavourable scores as the videos progressed from A1 (video 1 2013) to A6 (video 4 2017). When evaluating the Spearman's correlation, it is evident that the p-value is not less than 0.05 which means the null hypothesis will not be rejected. Therefor no significant relationship exists. The general downward trend indicates a decrease in the Unfavourable scores, indicating that the child was showing less Unfavourable behaviours across the 45-month period.

The increase in scores for Favourable outcomes, and the decrease in scores for Unfavourable outcomes, indicate that the ASI® intervention presented by the occupational therapist had a positive impact on the child's overall performance. This is further discussed in Chapter 5.

### 4.2.3.2 Changes in the complexity of sessions across the 45-month period:

In order to determine if the occupational therapist consistently provided the child with graded challenges throughout the 45-month intervention period between 2013 and 2017, and ensured that the child participated in activities that presented the "just-right-challenge"<sup>34</sup>, the complexity rating of each of the videos was considered.

This will determine if the increase in favourable scores, and the decrease in unfavourable scores occurred in the therapeutic context of intervention sessions with increased levels of complexity to challenge the child's adaptive responses.

TOTAL COMPLEXITY	A2	A6	DESCRIPTION
SCORE	27 May 2013	17 Feb 2017	
10 - 12		10, 10, 11, 11	High level
6-9	6,6,7,7		Medium level
5 and lower			Low level

Table 4.6 Interrater total complexity scores for A2 (2013) and A6 (2017)

As illustrated in Table 4.4, it was noted that the ICC results for the complexity scores were higher for A6 than for A2, and that overall the inter-rater reliability indicated a good statistical correlation. It is possible that the differences in opinion for the individual items (e.g. regarding Play) could have impacted the score. It is also possible that the raters were more familiar with the OT-PICS the second time and felt more confident in how to observe and score the complexity items. When considering the scores and descriptions, the total complexity scores by each of the raters are presented in Table 4.6 above and illustrate that they were in agreement in terms of the <u>description of the complexity</u> of each session. For the session on A2 (27 May 2013), two of the inter-raters scored the total complexity rating as a 6, and the other two scored the total complexity rating a 7. Despite minor differences in opinion about the total scores being 6 or 7, it is evident the total complexity rating of the session on A2 (27 May 2013) received the <u>description</u> of *medium level* of complexity by all four of the raters. This showed they were in agreement regarding the description of the level of complexity of this session for clinical purposes.

For the session on A6 (17 February 2017), two of the inter-raters scored the total complexity rating as 10, and the other two scored the total complexity rating 11. Despite the individual differences in opinion for the individual items scored, the raters were once again in agreement that the total complexity rating of the session on A6 (17 February 2017) received the description of *high level* of complexity.

The complexity rating therefore indicated that the level of difficulty increased over time, and that the child's improvement as seen by an increase in Favourable outcomes, and a decrease in Unfavourable outcomes, occurred in the context of an increasingly higher level of complexity i.e. "just-right-challenges". The OT-PICS was able to show that the occupational therapist using ASI® was able to facilitate increased levels of adaptive responses across the 45-month period. This is discussed in more detail in Chapter 5.

The OT-PICS observation tool is not norm-based and therefore compared the child's own performance to her previous performance at a different point in time.

The OT-PICS observation tool was therefore an effective measurement instrument to determine changes in the child, as well as complexity of the intervention sessions despite some minor individual differences in opinion between the raters.

# 4.2.4 Objective 4: To determine the pattern of sensory integration dysfunction in a child with bilateral CIs by means of using the Sensory Integration and Praxis Tests

The child's initial Sensory Integration and Praxis Tests (SIPT) results (shown as A3 in Figure 3.1) are indicated in Figure 4.4 below:

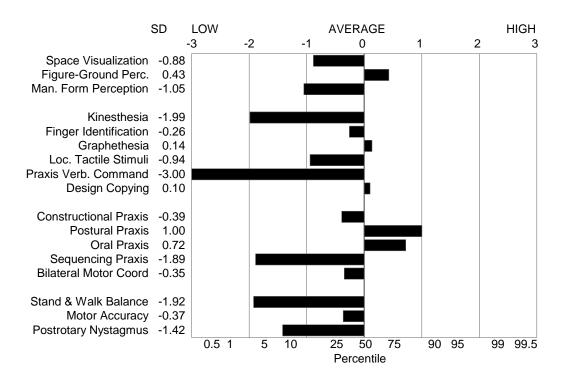


Figure 4.4 Summary graph of the child's initial SIPT results

When a child's raw scores are entered into the computer, the SIPT program compiles a complete computer generated SIPT report and the graph is shown in Figure 4.5. The following is relevant for the interpretation of the scores as part of general everyday practice: *The graph shows the major scores for the 17 tests in the SIPT. The standard deviation (SD) scores shown correspond to a metric usually associated with the normal curve, and are also known as z-scores. In a normal distribution, SD scores have an average or mean value of 0 and a standard deviation of 1. The SD score ranges for the SIPT can be interpreted as follows: a score of -3.0 to -2.5 indicates severe dysfunction; a score of -2.5 to -2.0 indicates definite dysfunction; a score of -2.0 to -1.0 indicates mild dysfunction or mild difficulty; a score of -1.0 to +1.0 indicates functioning typical for the child's age; a score of +1.0 to +2.0 indicates above average functioning; and a score of +2.0 to +3.0 indicates advanced functioning.* 

Test scores above 3.00 SD are reported as 3.00 and scores below -3.00 are reported as -3.00. The percentile scores shown on the bottom of this graph indicate the percentage of children of this age in the general population who would be expected to score at or below a given value. For example, an SD score of 0 corresponds to the 50th percentile, which means that half of the children would be expected to obtain SD scores at or below 0.<sup>13</sup>

As discussed in Chapter 2, the SIPT is a reliable test to use on South African children.<sup>14</sup> The patterns of sensory integrative dysfunction in children from America and South Africa are similar.<sup>49</sup> From the SIPT manual as well as more recent research by Mailloux et al (2011), Koester et al (2014) and Van Jaarsveld et al (2014) it is evident that the child with cochlear implants had significant high loading scores that are characteristics of the Vestibular and Proprioceptive Bilateral Integration and sequencing (VPBIS) pattern of sensory integrative dysfunction as originally identified by Dr Jean Ayres, associating bilateral integration and sequencing deficits to the vestibular and proprioceptive systems.<sup>7,12,13,49</sup>

These scores include the following:

- Kinesthesia (KIN) (-1.99)
- Standing Walking Balance (SWB) (-1.92)
- Sequencing Praxis (SPr) (-1.89)
- Post Rotary Nystagmus (PRN) (-1.42)
- Manual Form Perception (MFP) (-1.05)

The child's findings are however consistent with the results of available literature and are characteristic of the VPBIS pattern of sensory integrative dysfunction. It is also expected that the child would have difficulty with following verbal instructions which is evident in the score for Praxis on Verbal Command of -3.00 as shown in Figure 4.4, which fell in the severely dysfunctional range as described above.

# 4.2.5 Objective 5: To compare the pre- and post-intervention SIPT results of a child with bilateral CIs to determine changes in sensory integrative functions.

The following results were based on the child's two sets of SIPT scores (shown as A3 and A5 in Figure 3.1) and are compared below:

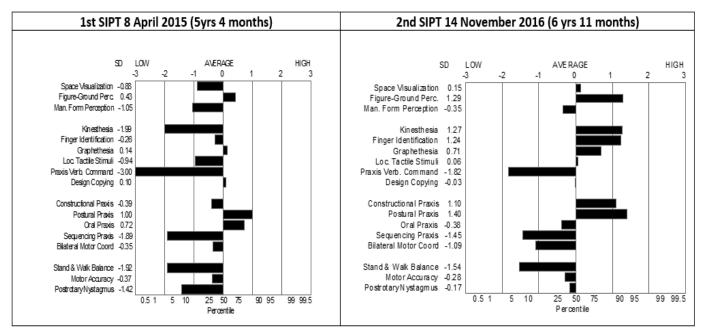


Figure 4.5 SIPT graph comparison (A3 is on the left, and A5 is on the right)

The two sets of SIPT results above have been combined in the graph below to visually illustrate an overview of the child's changes in sensory processing skills between A3 (first SIPT indicated in blue) and A5 (second SIPT indicated in orange):

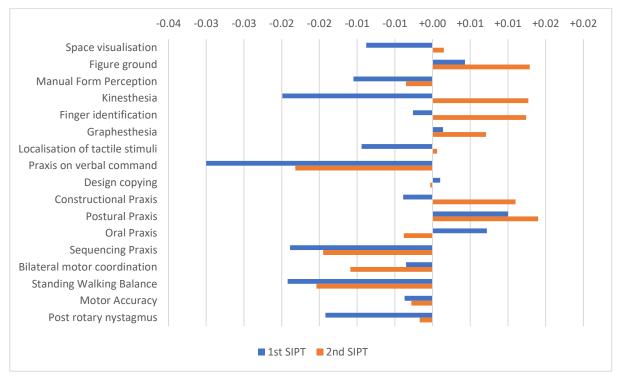


Figure 4.6 Visual comparison of differences between pre and post intervention SIPT results

The following table contains the descriptive results of the two sets of SIPT scores. The table summarises the general results when considering all 17 items in each of the SIPT tests:

**•**•••••

Statistics			
		SIPT1	SIPT2
Ν	Valid	17	17
	Missing	0	0
Mean		7100	.0065
Median		3900	0300
Std. Deviation		1.07929	1.05664
Minimum		-3.00	-1.82
Maximum		1.00	1.40
Percentiles	25	-1.6550	7350
	50	3900	0300
	75	.1200	1.1700

Table 4.7 Descriptive results of two complete sets of SIPT scores

When considering the results above, it is evident that the results of the second set of SIPT scores (A5) are higher than the first set (A3).

The parametric paired t-test was used to compare the two sets of SIPT scores where each of the items of the first test was compared to each of the items of the second test.<sup>72</sup> The corresponding p-value = 0.008 which is lower than 0.05 implies that the means between the two sets of scores are significantly different. The results of SIPT 2 (A5) are significantly higher than the results of SIPT 1 (A3).<sup>72</sup>

The non-parametric Wilcoxon Signed Rank test was also used to evaluate if the conclusion is the same for this small sample size i.e. one child. The corresponding p-value of the test statistics is 0.0079 which is smaller than 0.05. The null hypothesis is rejected at a significance level of 5% indicating that the paired difference means differs significantly from zero and there is a significant difference between the first set (A3) and second set of SIPT results (A5). This indicates that there was a significant improvement in the scores from SIPT 1 (A3) to SIPT 2 (A5).<sup>72</sup>

Results from both these statistical measures indicated a significant difference between the two sets of SIPT scores when considering the overall results. Both the statistical measures indicate that the results for SIPT 2 were significantly higher than the results of SIPT 1.

Higher scores for SIPT 2 indicate a better performance of the child the second time the SIPT was administered after a period of 19 months. Therefore, it can be concluded that the child with CIs showed a <u>significant improvement</u> in performance and underlying sensory processing skills after a period of 19 months of ASI® intervention presented by the occupational therapist.

In order to compare the individual tests, the first and second scores for each test is specified in Table 4.8 below. The difference between the two sets of scores is indicated in the third column. In the instance where the child improved with 1.0 SD or more, the score is highlighted in green. In the instance where the child's score improved from a lower average range (at risk) to a functional range, the test item is highlighted in green. In the instance where the child was at risk in a specific test (lower average range), the score is highlighted in orange. In the instance where the child's scores remained in the dysfunctional range, the test item is highlighted in red (the key is indicated below the table):

Name of SIPT test	1 <sup>st</sup> SIPT	2 <sup>nd</sup> SIPT	Difference
Space visualization	-0.88	+0.15	+1.03
Figure ground	+0.43	+1.29	+0.86
Manual Form Perception	-1.05	-0.35	+0.70
Kinesthesia	-1.99	+1.27	+3.26
Finger identification	-0.26	+1.24	+1.50
Graphesthesia	+0.14	+0.71	+0.57
Localisation of tactile stimuli	-0.94	+0.06	+1.00
Praxis on verbal command	-3.00	-1.82	+1.18
Design copying	+0.10	-0.03	-0.13
Constructional Praxis	-0.39	+1.10	+1.49
Postural Praxis	+1.00	+1.40	+0.40
Oral Praxis	+0.72	-0.38	-1.10
Sequencing Praxis	-1.89	-1.45	+0.44
Bilateral motor coordination	-0.35	-1.09	-0.74
Standing Walking Balance	-1.92	-1.54	+0.38
Motor Accuracy	-0.37	-0.28	+0.09
Post rotary nystagmus	-1.42	-0.17	+1.25

#### Table 4.8 SIPT comparison with differences in scores

Key to colours used in table above:

- Score Improved with 1.0 SD or more
- Score improved from a lower average range (at
- risk) to a functional range
- Child's score fell in lower average range (at risk)
- Child's score fell in dysfunctional range

The results of seven (7) out of the 17 tests showed an improvement of 1 SD or more.

The biggest improvements were noted in the tests of Kinesthesia (somatic perception of arm position and movement), Manual Form Perception (recognition/visualisation of forms held in hands) and Post-rotary nystagmus (central nervous system processing of vestibular (cupular) input) where the child's scores improved from a dysfunctional to a functional range for her age.<sup>13</sup>

The results of two tests that were at risk have shown some improvement and it is noted that the second score fell within the functional range for her age. It is interesting to note that although Oral Praxis (imitating tongue\ lip\ jaw movements; somatopraxis) showed a decrease of 1 SD, the child's score still fell within the typical functional range for her age.

The results of three out of the 17 tests remained in the dysfunctional range namely Praxis on Verbal Command (following verbal directions without demonstration), Sequencing Praxis (performing a rhythmical sequential movement pattern by imitation) and Standing and Walking Balance (considering muscle and joint stability in relation to gravity with eyes open and closed).<sup>13</sup>

It is interesting to note that the child's score for Bilateral Motor Coordination (functional integration of the two sides of body) went from a functional to a dysfunctional range.<sup>13</sup> This is further discussed in Chapter 5.

It is significant to note that the scores of the first SIPT assessment showed six (6) out of 17 test items fell in the dysfunctional range, and two at risk. Scores of the second SIPT assessment showed only four (4) out of the 17 items fell in the dysfunctional range, and none at risk.

The quantitative results can be summarised as follows:

- <u>Objective 1 and 2</u>: The OT-PICS observation tool was developed as a reliable and useable measure for occupational therapists using ASI® to identify and describe challenges related to sensory-motor factors and functional participation challenges in a child with CIs.
- <u>Objective 3</u>: The OT-PICS observation tool showed changes in sensory-motor factors and functional participation in a child with CIs. Improvement in the child's functioning was indicated by an increase in Favourable Outcomes, a decrease in Unfavourable outcomes, and an increase in the complexity scores over the 45-month period.
- <u>Objective 4</u>: The SIPT was able to identify a pattern of SI dysfunction, namely VPBIS, in a child with CIs, which was consistent with available literature.

• <u>Objective 5</u>: The SIPT test-re-test results showed a significant improvement in the child's underlying sensory processing skills after a period of 19 months of occupational therapy intervention using the ASI® approach (with an average of three to four sessions per month).

### **4.3 QUALITATIVE COMPONENTS**

# 4.3.1 Objective 6: To obtain perspectives of the cochlear team and parents regarding changes in the child's behaviour and participation in occupations.

### 4.3.1.1 A semi-structured parent interview

By means of following the steps of Braun and Clarke for the theme analysis, the emerging themes and categories are summarised as follows<sup>73</sup>:

Themes	Categories
1. Cochlear usage	1.1 Sensory triggers impacting tolerance of the cochlear devices
	1.2 Parent wishes
	1.3 The cochlear team referral.
2. Child's participation	2.1 Strengths
	2.2 Challenges
	2.3 The impact of challenges on the family unit.
3. Impact of	3.1 Cochlear usage
occupational therapy	3.2 Language development
using the ASI®	3.3 Family unit
approach (OT-SI)	3.4 The child
	3.5 Cochlear team
4. Message of hope	4.1 To other parents

Table 4.9 Summary of themes and categories of parent interview

The following table includes specific quotes to support the categories that were identified under each theme:

Table 4.10 Themes, categories and supporting statements from parent interview

	Theme 1: Cochlear Usage		
Category	Supporting statements		
1.1 Sensory	Sound: "constant rain over a period of a day or two"; "The sound of birds,		
triggers	lawnmowers and weed-eaters, still now"; " immediately when we were in the		
impacting	car she would take them off the sshh-sound of the tyres that took very long		
tolerance of	for her to actually start wearing her cochlears in the car"; "Could be the vibration		
the cochlear	or movement, don't know, we were focussed on all the sounds".		
device			

	Textures: "She couldn't tolerate ponies, or little hair clips, or an Alice-band. She
	didn't want to wear anything wool; she refused to wear if you just mess
	something on her, a drop of water or sand, she'd want to change her clothes".
1.2 Parent	"that she would just tolerate her cochlears so she could start verbalising our
wishes	biggest wish for her was just to be an oral speaking child"; "same opportunities
	as other children", "to have a normal life"; "We were told it was a possibility
	that through OT she could tolerate the cochlears on her head for a longer period
	of time"
1.3 Cochlear	"She was hiding her cochlears"; "she wasn't tolerating the devices on her
team referral	head that is why she was referred: because of her behaviour"; "We didn't
	know it was over-stimulation at the time. OT was a totally unknown"
	"it wasn't the norm, so it wasn't something that they were used to"; "She
	needed to hear the language before she could speak the language".
	Theme 2: Child's participation
2.1 Strengths	"Very innovativecleverhappy child"; "she was differentgentle soul but she
	had a lot of determination"; "there was something special about her", "… could
	gesture from very early We knew exactly" "She would touch people's lives
	the people at Sparthe security guardsbig heart really caring"
2.2	"Hiding her cochlears"; "she didn't like certain textures"; "she liked familiarity
Challenges	to follow a specific routine, that's why people made the suggestion that there
	might be a bit of autism thereshe just liked to do things her way"; "We actually
	withdrew from society for about two years because she was very busy, it was
	difficult to take her somewhere and do stuff She was comfortable at home and
	we were comfortable having people over because it's her own environment";
	"separation anxiety extremely clingy, just mommy"
2.3 Impact of	"We were stagnant in the beginning we were very angry"; "We withdrew from
challenges	our support structure it makes your world very small. And when your world
on family unit	becomes smaller your problems just seem so much bigger"; "We neglected
	ourselves"; "We should have done more normal family things to go out, mix
	with other people. It was very difficult you know. We tried from day to day. We
	didn't know where we were going. We knew where we wanted to go. We just
	didn't know how to get there. And just to get through one day was tough".
	1

	Theme 3: Impact of OT-SI
3.1 Cochlear	"We went from next to zero use, or maybe having 10% use per day, to, in the early
usage	days went from that, to a couple of hours. To the whole day. I mean it made a huge
	impact. And I don't think, if we didn't discover OT, we might have gone to sign.
	Because that's where we were being pushed towards".
3.2	"She really didn't enjoy the cochlears or the access to sound in the beginning";
Language	"she still had that deaf tone"; "one-word sentences, was so hard for hershe
development	would go "cooooommmee". I think that was part of tolerating her cochlears" and also
	then the motor planning"; "with her tolerating the cochlears more, she got more
	access to sound that was the breakthrough that we really needed"; "In the
	beginning it was very slow progress. Phenomenal where we've come from"; "that's
	what's amazing to us now, is with this access to soundher language is developing
	just from listening to other children"; "good speech role models at school big
	abstract wordsshe can pick up spontaneously: I <u>literally</u> cut open my knee"
3.3 Family	"It changed our whole life"; "Such a change, almost immediately with our child's
unit	behaviour. You know, small things. And then it went from small things to big things";
	"the coping mechanisms we learnt, she got to tolerate things a bit more, her
	behaviour changedthat separation anxietyEven that got better".
3.4 The child	"She is enjoying sound now and she has learnt how to tolerate, or how to regulate
	herself"; "she doesn't even want to take her cochlears off. Never".
3.5 Cochlear	"Everybody learnt from it it was a big stepping stone, because it wasn't something
team	they were accustomed to. And I think a lot of their other patients, had they known,
	could have benefited from OT. They realised what kind of an impact it can have, a
	very positive one"; "It changed the whole team's perspective of how to handle things,
	to share resources and to help each other."
	Theme 4: Message of hope
4.1 To other	"Don't be like us. We put a lot of pressure on ourselves and our marriage by
parents	excluding ourselves, pulling ourselves away from everybody else. Don't withdraw.
	You're gonna need that support structure of friends. Even if they don't understand.
	They will eventually come around. Educate them. We were angry wanted to blame
	someone for it. It is something that's happened. It's something you just need to deal
	with and work through. Trying to blame someone is not going to change it. The big
	step came to us when we decided to focus on solutionsand not to find fault";
	"Every story is different, but you are not alone, there are other people out there in
	the same boat as you"; "You just have to persevere in the challenges you are faced
	with."

Findings from the parent interview indicated that they experienced positive changes in the child's behaviour, cochlear usage and language development as a result of occupational therapy using ASI® intervention (OT-SI). It was apparent that both the child's father and mother felt that their wishes were fulfilled with occupational therapy using ASI® intervention and commented *"most definitely"* and *"beyond our expectations"* respectively, and that OT-SI had a significant impact on the overall quality of life of the family unit.

### 4.3.1.2 An electronic questionnaire (See Annexure B)

Four responses were obtained. All four (4) responses from the cochlear team unanimously agreed that this child benefited from occupational therapy using ASI® intervention (OT/SI). They had consensus that they will refer more children with cochlear implants to OT/SI. The following table provides a summary of their comments in response to the impact of OT/SI on this child:

Keywords of	Quotes
question	
Positive	• "Definitely made a difference to her tolerance of the processor
changes	physically and to the additional auditory stimulation"
observed	• "She suddenly Clicked and progressed quicker than usual"
	• "Change in general behaviour pattern - calmer, more willing to
	engage socially, more accepting of the device, less 'fearful',
	progress in learning to listen and access spoken language"
	• "More willing to wear CIs regularly"
Contribution	• "Makes tremendous difference to child tolerating the device on the
of OT/SI to	head and helps with acceptance of new auditory stimulation. This
add value to	helps the audiologist to reach optimal levels of stimulation more
the cochlear	quickly".
team	• "Should be an integral member in cases where acceptance of the
	CI device is problematic - and possibly routine post-op evaluation
	of whether SI issues exist (for the benefit of team members who do
	not recognize or have worked with children displaying SI issues)".
	• "The OT can help the child and parent to understand sensory
	processing and regulation".

Table 4.11 Cochlear team responses regarding outcomes of OT/SI
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All three (3) the original cochlear team members indicated that they had never come across other similar cases in terms of extreme and unusual behaviours in response to adapting and using the cochlear apparatus. Concerning the rarity of this case being investigated, they indicated that the child was probably 1 out of 50 - 100 children that cochlear teams might encounter. Feedback from the cochlear team therefore indicated that OT/SI was able to make a valuable contribution to the team, the child and the parents.

## 4.4 CONCLUSION TO CHAPTER 4: RESULTS

Upon consideration of quantitative results as measured by the OT-PICS observation tool as well as the SIPT, it is evident that the child showed a significant improvement in her level of her sensory-motor skills, underlying sensory processing skills and functional performance in the context of increasingly more complex ASI® intervention sessions presented by the occupational therapist.

When considering the qualitative findings from the parent interview and cochlear team, it is evident that the parents as well as the cochlear team had seen positive changes in the child's performance such as wearing her CIs consistently, showed "better" behaviour, using spoken language and interacting with others. The parents' wishes were fulfilled and the cochlear team felt satisfied about their referral, and will refer more children with CIs to the occupational therapist using ASI® in the future.

These findings will be further discussed in Chapter 5.

## **CHAPTER 5: DISCUSSION**

### **5.1 INTRODUCTION**

In order to determine the outcome of ASI® intervention on the occupational performance in a child with bilateral cochlear implants (CIs), both quantitative and qualitative methods have been used. To obtain an in-depth knowledge and understanding about this single case, clinical notes and other reports have been used to supplement the results. The case study research covered 45 months or approximately a four-year period of occupational therapy using ASI® as the preferred approach to guide assessment measures and application of intervention strategies for a young child with CIs with unique and unusual difficulties. In this chapter, the results of each objective as put forward in Chapter 4, are integrated so that the information is organized in a manner that can provide perspective of the child's journey and to answer the research question: What is the impact of Ayres Sensory Integration (ASI®) on occupational performance in a child with bilateral cochlear implants within the first four years after implantation?

### 5.2 INITIAL CHALLENGES AND CONCERNS

The child was initially identified by her cochlear team as a challenging case due to behavioural and acceptance difficulties pertaining to the CI device, which resulted in minimal speech progress. The unique and unusual behaviours (as discussed in Chapter 1) were challenging to manage and interfered with her development and progress. The child was referred to occupational therapy using ASI® to investigate and address the possible underlying sensory issues to facilitate optimal cochlear usage, speech development and participation in everyday life.

ASI® is not only an approach for treating and describing dysfunction, but also a way of considering individual differences, which makes us all unique. Unlike the objective physical nature of the sensory stimulus, sensation is variable and influenced by many individual factors such as task demands, motivation, previous experience, state of arousal and emotions. Sensation can be viewed as a dynamic property. It was therefore necessary to evaluate both the child who perceived the sensation as well as the changing context (i.e. source of sensory stimulus). It was also a reminder to acknowledge that each of us is different and will experience sensory input according to our perspective, especially for this child who had to adapt to the sensory awakening of sound as well as the possible impact of the cochlear device itself. Differences in sensory processing become problematic when it interferes with our ability to participate in everyday activities and occupations.<sup>1,11,33,77</sup> Evidently for this child, her ability to participate in everyday activities and occupations were compromised by various factors.

As discussed in Chapter 1, the child in this case study had significant challenges that interfered with her ability to respond to sensation appropriately which impacted on her development and progress, and in turn on her participation in occupations and enjoyment in life. For this child with CIs, it became evident that there were three dependent variables which had to be investigated and included the following:

- The child's behaviour towards the constant presence of the <u>CI device</u> itself,
- <u>The child's</u> perception of and ability to integrate multi-sensory input, and
- The ever-changing external multi-sensory environment.

With the above perspective in mind, it opened up the possibility that not all children with CIs should be treated the same according to a predetermined protocol or set recipe simply they fall in the same diagnostic group.

It is known from the literature that children with hearing loss and CIs may have specific difficulties such as motor challenges related to vestibular deficits (e.g. compromised balance).<sup>5,16,78</sup> However, it is critical to consider each child's individual neurological wiring when it comes to the perception of sensation and the impact on behaviour and development, especially with the addition of an electronic device that was inserted into the child's inner ear, and permanently attached to the child's head with a magnet and is constantly providing new electrical sound impulses from her body and the environment.<sup>7,66</sup>

For children to optimally learn and to actively engage in everyday activities and enjoy life, sensory input has to be organized. Effective integration of sensory input (including proprioceptive, vestibular, tactile, visual, auditory, taste, and olfactory input), allows children to participate to their full potential in learning and active, adaptive engagement in childhood occupations.<sup>7</sup> It was therefore imperative to consider the child's perception and experiences of her sensory environment in totality, and not just focusing on the vestibular system and compromised motor related skills as is the case with the majority of currently available CI research.

The mismatch between the child's reactions and the sensory input from her environment created a platform for scientific investigation to determine possible associations and relationships between variables by means of examining existing material in a reflective manner (as discussed in Section 3.2 Research design).

Individual factors pertaining to her underlying sensory-motor challenges, that made her react differently to other young children who received CIs, were investigated to determine the possible interference with her participation in childhood occupations and enjoyment of life.

## **5.3 ASSESSMENT INSTRUMENTS**

As previously mentioned, the child in this case study was not able to participate in formal testing when she was initially referred, despite the recommendation that early intervention is provided for the best possible outcome after cochlear implantation.<sup>17,79</sup> This created a dilemma as the child was already between two to three years behind her hearing peers in terms of listening and language skills development and she was not responding to and using her CIs to develop language as expected. As discussed in Chapter 3 it was therefore warranted to develop another strategy or measurement tool to identify challenges related to sensory processing and participation in occupations to establish a measurable starting point, articulate realistic goals to direct the intervention and to establish the impact of ASI® on her day-to-day functioning. Her intervention had to be targeted to avoid losing out on the window of opportunity of early intervention.<sup>16</sup> It was important to pin-point her specific challenges and to predict the possible underlying sensory triggers that caused behavioural disorganization, in order to effectively manage and regulate her alertness and the environment to prevent the removal of her CIs. Without some kind of concrete evidence, the approach to her intervention would not only be trial-and-error, as her behaviour was contradicting to what was known from the literature and typical expectations, but possibly contributing to disorganized behaviours and even less cochlear usage at the detriment of the child's progress.

In order to document how the child responded to activities and sensory input, her sessions were recorded on video for objective viewing afterwards, starting with her second appointment (as indicated by A1 in Figure 3.1). The video recordings enabled the occupational therapist to be more mindful and move freely with the child without disrupting the flow of the session or losing the young child's interest during an activity while writing down observations, as opposed to scoring the child's responses and observations in the moment.

Mindfulness is defined by the Oxford dictionary as a "*mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations*".<sup>67</sup> As occupational therapists, we have to calmly accept and be mindful of the child's experience and work from moment to moment in each session with what we know. This insight into each session provided a more holistic perspective of the therapeutic journey of this child.

### 5.3.1 The OT-PICS observation tool

The OT-PICS observation tool was developed as an objective measurement instrument to obtain information about the three variable that had to be investigated namely the child's response to sensory input, the possible impact of the CI device, and the changing sensory environment.

The OT-PICS observation tool was used to determine challenges related to sensory-motor skills and functional participation as an initial level of performance (indicated by A1 and A2 in Figure 3.1), as well as measuring progress during the course of her therapeutic process over the four-year period (as indicated by A4 and A6 in Figure 3.1). The OT-PICS observation tool was used to record observations about the child's sensory-motor and functional participation components in the context of an ASI® intervention session where play was used as the medium to actively engage the child in "just-right" challenges.<sup>34</sup>

As discussed in Chapter 4, the intra- and interrater reliability results indicated that despite some differences in opinion, the OT-PICS observation tool can be regarded as a usable and reliable measurement instrument to obtain information about the child as well as the complexity of the sessions in an objective and systematical manner.

When considering the three variables as mentioned above, the scorable items provided information about the child and her cochlear device, while the complexity of the session provided some context of the session in terms of the sensory environment. The complexity score took into account the number and steps of activities, number of equipment and variety of sensory input. The OT-PICS observation tool therefore provided perspective of the child's functioning and a measurable framework to assist with the clinical reasoning process e.g. to identify possible triggers for sensory or behavioural over-reactions and what could have caused the possible "mismatch" between the child's responses to the multi-sensory environment input.

### 5.3.2 The Sensory Integration and Praxis Tests (SIPT)

The SIPT is internationally recognized as the golden measure to assess sensory integrative functions for children.<sup>12</sup> It was therefore a suitable test to use for the child with CIs in this case study, once she was ready to participate (indicated as A3 in Figure 3.1). The SIPT evaluated her abilities associated with sensory perception, praxis, and related motor functions such as bilateral integration and balance.<sup>7,13</sup> The SIPT has also been proven to be a reliable test to use on children in South Africa.<sup>14,49</sup> However, as discussed in Chapter 2, there are a limited resources available pertaining to occupational therapy and children with CIs, especially regarding possible sensory integrative dysfunctions and the impact on occupations.

The constructs assessed by the SIPT are assumed to be fairly stable over time. The SIPT is also a reliable test-retest measure with a period of at least one to two weeks inbetween.<sup>13</sup> The SIPT was re-administered (indicated as A5 in Figure 3.1) after a period of approximately 19 months after the first SIPT assessment (indicated as A3 in Figure 3.1) which therefore indicate that the SIPT results can be viewed as reliable.

## **5.4 ASSESSMENT RESULTS**

### 5.4.1 OT-PICS observation tool

The OT-PICS observation tool was used to review the first two recorded sessions (refer to A1 and A2 in Figure 3.1) to determine the child's strengths and areas of concern over two sessions, one week apart. Refer to section 4.2.2 for the discussion of strengths and concerns under each of the sections of OT-PICS.

### Strengths:

The child's strengths included that she appeared friendly and animated in her non-verbal gestures, she seemed to enjoy visual order, was good at lip-reading, and enjoyed familiar toys and games (e.g. playing a hospital game with a doll). She also appeared to be compensating and depending on visual input when she was not able to rely on her body or sound. The child made appropriate eye contact and was actively participating in the session.

### The child's challenges are discussed as follows:

(i) Sensory over-reactivity and the interplay between sound (auditory input) and movement (vestibular input)

As discussed in Section 4.2.2 (iv) Sensory Reactivity, the child had difficulty tolerating changes in her head position in relation to gravity and preferred to keep her head in an upright position. The child had limited participation in movement activities, especially when her feet were not touching the ground (e.g. on suspended equipment such as a swing) or when she was not in control of the movement (e.g. stable equipment on the floor or activities that compromised her balance such as a ramp or bridge). These symptoms are associated with *gravitational insecurity* which is a sensory modulation disorder due to the extreme emotional over-reaction to otolith input in the vestibular system (as described in Chapter 2). It was further noted that sound and movement input is processed by the vestibular-cochlear nerve (CN VIII as illustrated by Figure 2.2 in Chapter 2) and that it is possible that the one my influence the other due to heightened activity in their respective nerve fibres.<sup>33</sup> The central vestibular connections are illustrated by Figure 2.3 in Chapter 2.

As discussed in Section 4.2.2, the child appeared to be having difficulty tolerating movement input while wearing her CIs as it appeared that sound and movement amplified each other. From the video it was observed that she was prepared to slide down the ramp on her bottom while wearing her CIs, she put a dark, soft blanket over her head and covered her whole body to eliminate vision (her strength as mentioned in Section 4.2.2.1) when having to process sound and movement input together. This behaviour further supported the reasoning that she could have a sensitivity to input detected by otolith organs such as changes in the child's head position in relation to gravity.

The child seemed to be coping with the movement experience while wearing her CIs and reducing the multi-sensory input of her environment by narrowing her visual field. Shortly after the movement experience, she removed her CIs, and went into the tent to play a quiet visual-perceptual game. She reduced the input from the external environment by limiting visual input, and getting into a smaller space where there were no sound and movement challenges she had to deal with. In retrospect, removing the CIs and herself from the situation seems like an understandable and effective self-regulation strategy, however at the time, it was frustrating to the parents and cochlear team as it was not clear why she kept on removing her CIs and hiding away. The parents also reported that the child sometimes have a delayed response after a sensory event, which can vary between a few hours to a few days, depending on the intensity. There were still many unanswered questions and further investigation was needed.

The possibility of appearing more sensitive to movement may appeared somewhat contradictive to research findings that mentioned the vestibular system was hypo-responsive / hypo-reactive (less sensitive to movement) at the time.<sup>7,10,16</sup> However, the sense organs of the inner ear are complex, with the cochlea, and by implication the cochlear implant itself, is within close proximity and connected to the vestibular system as illustrated Figure 2.1 in Chapter 2. It was therefore necessary to consider the different vestibular receptors namely the otolith organs and the semicircular canals as well as the possible impact of each of the different vestibular receptors on her behaviour and performance.

The information discussed above clearly indicate a sensitivity in the child's otolith organs (i.e. gravitational insecurity). The neurological projections to the reticular formation could explain the behavioural over-reactivity.<sup>1,33</sup> The powerful effect of the vestibular system on the autonomic nervous system pertaining to the regulation of alertness and activity levels was clearly contributing to the child's challenges and participation in everyday activities.

This clinical reasoning is supported by findings as discussed in Chapter 2: when the functioning of the vestibular system is disrupted, the results can include unpleasant feelings associated with motion sickness, vertigo, or nausea as well as a sense of disequilibrium, and uncontrollable eye movements, similar to the symptoms experienced by adults with Tullio's phenomenon.<sup>22,33</sup>

Sound was a new experience to the child, and a degree of sensory disorganisation could be expected. However, the impact of the cochlear device itself providing an electrical signal representing sound could not be ignored. It is possible that the child suffered from a degree of over-reactivity to sound or *auditory defensiveness*. She presented with some symptoms that are characteristic of *auditory over-reactivity* or *auditory defensiveness* such as difficulty adapting to the CIs, as well as removing and hiding the CIs and a loss of appetite when feeling overwhelmed by sounds from her environment.<sup>1,9</sup>

It was clear that it was difficult for the child to effectively filter and process the sound input in order to respond appropriately to her environment. The possible impact of the cochlear device is further discussed below.

### (ii) Sensory over-reactivity to tactile input

The child appeared somewhat sensitive to light input to her skin (e.g. textures and temperatures), but was able to tolerate playing with shaving cream while building a girl's body with foam blocks on the mirror as discussed in Section 4.2.2 (iv) Sensory Reactivity. She responded well to "sensory breaks" e.g. having a towel near-by to wipe her hands when the feeling of the shaving cream felt sticky as it was drying on her hands. She did not abandon the game and proceeded until it was finished. The "sensory breaks" helped her to regulate her alertness, as she did not become overstimulated or disorganised. She was able to adapt to the small, manageable amounts of touch input on her skin in order to stay in the situation while wearing her CIs. When considering supporting evidence from her background as mentioned in Chapter 1, certain behaviours were noted, such as: refusing to eat certain textures, not being able to tolerate anything on her head like hair clips, or wet clothing on her skin, changing her clothes up to eight times per day, becoming distressed when having her toe nails cut and taking a bath up to three times per day. It was also noted from her background history and sensory questionnaire that the child had a tendency to chew on her hair brush when she was feeling angry or frustrated, and that the brush had to be replaced almost every second week in times of stress. This evidence contributed to the clinical reasoning that the child was sensitive to light touch and overly reacting to light touch input. Furthermore, the child was diagnosed with granuloma annulare (skin condition resulting in inflamed reddish bumps on her scalp) after her first CI.58

This was localized in the area of the device and coil and could have contributed to the child's heightened sensitivity to light input to her head and face.<sup>1,11</sup> It is evident that the child's symptoms are characteristic of a *mild tactile defensiveness*, another type of sensory modulation disorder as described in Chapter 2.<sup>1,11</sup>

### (iii) Sensory over-reactivity and the possible impact of the cochlear device

The possible impact of the cochlear device itself and the possible complications that might have compromised her ability to adapt to and tolerate the CIs was questioned. Tullio's phenomenon (sound-induced vertigo) was considered to be a possible contributing factor that interfered with the child's perception of input from the gravity receptors in the vestibular system (otolith organs), due to electrical co-stimulation from the CI device on the saccule (structure in the otolith organs).<sup>22</sup>

As discussed in Chapter 2, the child's gravity receptors (otolith organs in her vestibular system) appeared overly sensitive and presented with *gravitational insecurity*. It was possible that sound induced vertigo (Tullio's phenomenon) contributed to her distorted perception of her head position in relation to gravity, as well as her body in relation to her environment with the added input of the electrical device, literally inside her head. Seeing that the expectation was to wear her CIs for the whole day (except when sleeping), it was clear that her behaviour would become disorganized if she was not allowed to regulate her alertness by taking short sensory breaks such as removing the CIs for a few minutes at a time. As discussed in section 4.2.2 (vii) Cochlear Usage, it was mentioned that the child was only able to tolerate about 30 seconds of combined auditory and vestibular input before removing her CIs. Findings from the parent interview as presented in Table 4.10 Theme 2 Child's participation, there was a query about the possibility of a diagnosis of autism as she could become very active and disorganised in times of sensory overload and behavioural disorganisation. This allowed her brain and body to adapt to the bombardment of multi-sensory input and to have less extreme over-reactions to sensory input.

In the words of Dr Ayers: "when the flow of sensation is disorganized, life is like a rush-hour traffic jam".<sup>1,11</sup> The child's neurological system was disorganized at a brain stem level, which prevented access to higher centers in the brain such as engaging in play, dealing with motor demands, being able to listen, or learning language.<sup>1,33</sup>

As discussed in Chapter 2, Ayres recognized the link between the brain and behaviour.<sup>1,3,4,11</sup>

It was therefore crucial to address the child's sensory over-reactivity to sound, movement and light touch input and to prevent a state of sensory overload in intervention by means of including more proprioceptive input which she enjoyed and needed more of to organize her brain and behaviour. More organized behaviour will allow the child to be more adaptable, and open to "just-right" challenges to develop her skills and participate in childhood occupation more comfortably. This is adding value as a reflective case study design as discussed in Chapter 3, as the exposure to the device could significantly impact her behaviour and participation in occupations, to the point where autism was questioned.<sup>65,80</sup>

The child's sensory preferences were not investigated prior to the first CI, which made it difficult to determine which symptoms were already present prior to the surgery, and which symptoms may have been triggered or amplified due to the surgical trauma to the child's inner ear and bombardment to her neurological system. When considering the complications and possible impact on the child's ability to effectively process sensory input, it became clearer why her behavioural reactions were out of proportion to the sensory stimulus from her environment alone. It could have been possible that the child was struggling to process additional input from the cochlear device itself, causing a mismatch between the external and internal sensory messages her brain was receiving. The CI device itself could have contributed to feelings of discomfort or dizziness by means of sound induced vertigo as discussed in Chapter 2.<sup>22</sup>

Although she was not able to express her experience in words, it was clear that either the movement itself, or the combination of sound with the movement, made her feel uncomfortable to the point of removing her CIs and removing herself from the situation. It appeared as if sound and movement amplified each other and that she was not able to tolerate the multi-sensory experience. She needed some quiet time, or a "sensory break" from sound and movement (e.g. retreating into a tent or pretend box-house as mentioned in section 4.2.2), before proceeding with activities and putting the CIs back on. These behaviours together with reported high activity levels and slow speech progress, were what leaded to questioning the possibility of autism.<sup>80</sup>

### (iv) Proprioceptive input and body scheme

As discussed under section 4.2.2, the child often used visual compensation and excessive force during play, indicating inadequate proprioceptive feedback from her body. This impacted on her body scheme as the instinctive "map" of her body did not provide a clear message to establish where she was in relation to objects in her environment and how to grade her movements appropriately. The child's inability to tolerate and integrate sound and movement input also contributed to a distorted perception of her body in relation to the 3D space in her environment.

This further compromised her body scheme and contributed to her tendency to compensate on a visual level.<sup>1,3,4,9</sup> As discussed in Chapter 2, the vestibular connections with the visual, tactile and proprioceptive systems enables the child's brain to combine vestibular information with the motor system and other sensory modalities such as touch and joint perception for optimal engagement in sensory-motor tasks.<sup>33</sup>

In typical developing children, the echo of one's own voice, the sound of footsteps, or the distance of falling objects in the three-dimensional (3D) space, contribute to the child's perception of his/her environment and contributes to the development of body scheme and spatial awareness. The auditory system is vital for survival (i.e. early warning signs of danger), communication (language development and social interaction) as well as education.<sup>11,33,44</sup> The child's early listening experiences were limited due to her profound hearing impairment. The role of the auditory system in the development of body scheme should therefore be considered in the experience of 3D visual space. This will be further discussed in the sections to follow.

### (v) Compromised motor related skills

The child's results as described in Section 4.2.2 (iii) Motor related skills were consistent with research findings pertaining to the motor and balance deficits in children with cochlear implants e.g. having difficulty with balance and motor coordination. It was observed that she was often sitting in a w-sitting position which was also evident of insufficient trunk control and stability.<sup>7,16</sup>

Results from the OT-PICS showed that the CI itself, the child's sensory perception, motor skills development and sensory reactivity, not only had an impact on her emotional well-being and behaviour, but also her enjoyment of life and participation in occupations as a young child.

### 5.4.2 Sensory Integration and Praxis Tests (SIPT)

After approximately two years of intervention, the child was ready to do the SIPT for the first time. At the time of the first SIPT assessment, the child was 5 years and 4 months old, and "hearing" for 16 months. As discussed in Chapter 4, the child's first SIPT results (refer to A3 in Figure 3.1) were indicative of the vestibular and proprioceptive bilateral integration and sequencing pattern (VPBIS) of sensory integrative dysfunction.

As shown in Figure 4.4, the child's SIPT results specifically indicated vulnerabilities in the vestibular and proprioceptive systems as seen in low scores for kinesthesia (KIN) and post-rotary nystagmus (PRN) with respective SD scores of -1.99 and -1.42, indicating a mild dysfunction.<sup>13</sup>

The information from the SIPT supports vestibular hypo-responsivity / hypo-reactivity of the semi-circular canals in a child with cochlear implants which was evident by the low post-rotary nystagmus (PRN) score of SD -1.42.<sup>7,13</sup> As discussed in Chapter 2, the PRN is an example of a vestibular-ocular-response (VOR) contributing the child's ability to sustain a stable visual field during movement.

A considerable amount of integration of information about movements of the body, the eyes and the visual scene in our three-dimensional (3D) space occurs at a cortical level. The vestibular system is therefore responsible for continually maintaining a representation of body position, awareness of and orientation in space, which is essential for the child's perception of equilibrium and for planning and executing complex coordinated movements.<sup>33,43,47</sup>

In Figure 4.4 it is interesting to note that the child obtained an SD score of -0.88 for space visualisation (SV) which did not fall below the norm for her age. However, it might contribute to the clinical reasoning that the child's depth perception was at risk due to lack of 3D auditory input to support the visual 3D space perception.<sup>11,13,33</sup>

The child also showed related compromised motor skills such as poor balance and sequencing skills as seen in the low standing and walking balance score (SWB) of SD -1.92 and sequencing praxis (SPr) with a SD of -1.89 as shown in Figure 4.4.<sup>12,13</sup> The child's results were consistent with a study by Koester et al (2014) who used the SIPT on six children with bilateral cochlear implants in the USA (who formed part of a larger study with 48 participants with hearing impairment and cochlear implants), indicating children with CIs reflected the VPBIS pattern of SI dysfunction.<sup>7</sup>

The child scored within the typical range for her age in the following tests that are also associated with the Vestibular and Proprioceptive Bilateral Integration and Sequencing (VPBIS) pattern of sensory integrative dysfunction: Bilateral Motor Coordination (-0.35), Oral Praxis (+0.72), and Graphesthesia (+0.14). A possible interpretation for achieving age-appropriate scores in these tests could be that the child had two years of occupational and speech therapy intervention, and the she benefited from the intervention up until the point in time where the SIPT could be administered.

Another hypothesis by Koester et. al. could be that facial imitation and tactile perception may be more highly developed in a child who is compensating for the loss of other sensory input, such as hearing.<sup>7</sup>

It is however relevant to note that despite the two years of ASI® intervention prior to the first SIPT assessment, there are still strong clinical indicators suggestive of a pattern of sensory integrative dysfunction when considering the low PRN (-1.42) and standing Walking Balance (-1.92) scores as seen in the first set of SIPT results shown in Figure 4.4.

Ebrahimi et al (2016) used the Bruininks-Oseretsky test of Motor Proficiency (BOTMP) on 85 children with hearing impairment (35 of which with unilateral CIs) to compare static and dynamic balance of deaf children with and without CIs. Although their study did not consider underlying sensory processing impacting the children's motor performance and did not include children with bilateral CIs, results still showed that the total balance score of the hearing loss group was lower than that of the hearing group.

Because the cochlea and vestibular end organs are closely related (as illustrated in Figure 2.1 The sense organs of the inner ear), hearing loss due to an inner ear impairment may cause vestibular dysfunction and is likely to result in balance deficits. It is also valuable to note that children with hearing impairment are more dependent upon visual cues when it comes to balance and postural control, in comparison to children with normal hearing.<sup>16</sup> Upon perusal of the complete listing of SIPT scores on page 4 and 5 of the full SIPT report (Annexure K), it is interesting to note that the child's scores for standing and walking balance with eyes open (SD -1.80) and eyes closed (SD -1.72) were equally low. This implies that vision (balancing with eyes open to provide additional visual input) did not assist the child in this test to have a better performance in balance. When considering the involvement of the otolith organs in maintaining static postures and balance, it should be taken into account that the child had gravitational insecurity, and the CI device itself might have impacted on the child's perception of gravity input which both indicate vulnerabilities in the otolith organs.<sup>1,13,22</sup> Vision alone was therefore not sufficient to support the child with better balance during her participation during the balance test in the SIPT.

The child's first SIPT results as shown in Figure 4.4 indicated motor difficulties related to the VPBIS pattern of sensory integrative dysfunction such as poor balance, postural control, and crossing of the body midline as shown by the low scores in PRN, KIN and standing walking balance and sequencing praxis.<sup>12,13</sup> The child's motor performance was therefore consistent with the recent studies pertaining to the VPBIS pattern of sensory integrative dysfunction in children with CIs, including vestibular-cochlear and motor deficits.<sup>7,16</sup>

In summary, the child had an <u>over-reaction to input from her otolith organs</u> (as noted from the OT-PICS results presented in Section 4.2.2).

Clinical evidence indicated an irrational fear or over-reaction which is described as gravitational insecurity (as discussed in Chapter 2). This could have been enhanced by sound-induced vertigo due to the interconnectedness of the CN VIII (as discussed in Chapter 2) and contributing to anxiety or avoidance behaviours (such as hiding in a quiet place or removing her CIs). Input from the otolith organs traveled to the reticular formation which impacted her behaviour and alertness. Furthermore, as noted in the low PRN score (Figure 4.4), the child had an under-reaction to, or poor registration of rotation input which comes from the semicircular canals in the vestibular system. The input from the semicircular canals traveled to the spine and cerebellum, which impacted her postural control, balance and grading of movements. It is evident that the child with CIs had different kinds of vestibular deficits which can be understood due to the different receptor cells and ascending and descending tracts to the brain and body (as discussed in Chapter 2). The otolith organs appeared overly sensitive and overly reactive, while the semi-circular canals appeared to be under-reactive to input which would have impacted the child's experience of her body in relation to gravity, and changes in her head position, as well as not developing appropriate motor skills. This contrasting experiences to different types of movement input was significant with specific implications for her intervention, and are discussed in the sections to follow.

The other assessment opportunities as illustrated as A4, A5, and A6 in Figure 3.1, provided valuable data in terms of progress and changes noted in the child after a period of ASI® intervention. This will assist with determining the impact of ASI® on the occupational performance of a child with bilateral CIs and will be further discussed in the sections to follow. Before changes in the dependent variables can be discussed (as mentioned in Section 3.2), it is necessary to discuss the independent variable, namely the ASI® intervention that would have facilitated the observable changes.

### 5.5 APPLICATION OF ASI® INTERVENTION PRINCIPLES AND STRATEGIES

The underlying principles of the ASI® theory and intervention (as discussed in Section 2.3 Chapter 2), formed the foundation that guided the child's intervention, with neuroplasticity at the core. The child's intervention consisted of sensory-motor activities that were presented in the context of play to tap into the child's inner drive and active participation, and created "just-right" challenges that could facilitate adaptive responses for improved participation in daily life.<sup>1,9,11,34</sup> The occupational therapist adhered to the fidelity requirements© of ASI® intervention (see Annexure C).<sup>34</sup>

### 5.5.1 Preparing for the intervention or "Setting the stage"

Before the intervention commenced, additional steps were considered to "set the stage" for intervention, as described by the Data Driven Decision Making (DDDM) model.<sup>9</sup> Setting the stage appropriately will assist with creating the optimal therapeutic environment to present ASI® intervention, and will create context in which the child's behaviours are observed by the OT-PICS. This therapeutic context is the aspect that is scored by the Complexity rating in the OT-PICS (as discussed in Chapter 3 and 4). These steps ensured that, before the child entered the room, the therapist checked that the environment was safe and equipment was adjustable for the child's proportions e.g. suspension points and hooks were strong and good, ropes were not worn out, no sharp corners or nails, no broken equipment, sufficient matrasses in case the child should fall. The sensory environment should consist of sensory opportunities that include the child's strengths (e.g. visual compensation such as a mirror), as well as opportunities that can tap into the child's vulnerable systems being vestibular, proprioceptive, tactile and auditory systems, that can be carefully balanced and tailored not to cause a sensory overload and disorganized behaviour. As shown in Table 4.6, the child's complexity score described a medium level of complexity in 2013, whereas an increase in the complexity score for her session in 2017 indicated a high level of complexity, therefore implying a more advanced justright challenges to facilitate adaptive responses.

Part of the preparation was to consider why the child was referred by the cochlear team (e.g. what were their concerns), as well as the parents needs and wishes for their child in order to formulate the outcomes of intervention. The therapist and the parents had to reach an agreement about how often the child needed to attend occupational therapy sessions (*dosage*), and how they could be involved to support the therapeutic process.

### 5.5.2 Conducting the intervention

### (i) Modulation disorders and sensory reactivity

In order to address the challenges related to the child's over-reactivity to input discussed in Chapter 4, activities had to be carefully selected and graded to match the therapeutic context as described above. It was also crucial to promote optimal sensory processing and integration of multi-sensory input, and not contribute to sensory overload and behavioural disorganisation. Results from the OT-PICS (as discussed in section 4.2.2) indicated that vestibular, auditory and light touch input had an alerting and disorganizing effect on the child's nervous system and behaviour. Whereas results from the SIPT confirmed motor related challenges due to inadequate feedback from her semi-circular canals (i.e. low PRN score as seen in Figure 4.4).

As discussed in Chapter 2, Ayres proposed that behaviour is linked to neurological processes and that brain-stem level processing enables higher cortical centers to develop and specialize. She proposed that disorganized neural processes at a brain stem level may lead to disorganized behaviours.<sup>3</sup> When the concept is flipped around, more organized neural processes at a brain stem level may lead to more organized behaviours and access to higher cortical structures and processes, to promote optimal flow of sensation and facilitate sensory integration for use. In order to facilitate more appropriate responses to sensory input for this child with Cls, principles for addressing *gravitational insecurity, tactile defensiveness* and *auditory defensiveness* were included in such a way to promote more appropriate responses to her environment, e.g. lowering swings so that her feet can touch the floor, and she has control over when to stop or start the movement, and to empower the parents to implement regulation strategies at home. It was crucial to respect the child's experiences and not to force any type of input that made her feel threatened or uncomfortable that would compromise active participation and success.<sup>1,3,4,9,11</sup>

Sensory breaks where she could remove her CIs for 5 – 30min at a time during the course of the session were helpful to facilitate the child's ability to adapt to multi-sensory input by means of being exposed to one or two sensory modalities, before combining the input. The parents were actively involved in the therapy process and could see the value of short breaks, and how the child benefited from experiencing new movements without sound first, before putting her CIs back on to combine the sound with the movement once she was familiar with what it "felt" like so she could trust her body.

The child was *allowed to "retreat"* to a tent or another quiet space where she could reduce the amount of visual input from her environment (e.g. cardboard box or pretend house) for recovering after an intense sensory experience and to avoid a sensory overload. It was also noted that when she child had to go down the ramp, and covered her head and body with the blanket, she might have had difficulty with the depth perception of going down the ramp (e.g. how steep it really was as she could not trust her body).

From the video material is was noted that there were two contradicting colours and textures at the bottom of the ramp (e.g. wood vs carpet) that might have created the sense of fear or anxiety as she was not sure how to judge the speed at which she was visually approaching the end of the ramp. This reasoning is supported by her borderline score for space visualization (SV presented in Figure 4.4) in the first SIPT (A3 in Figure 3.1) that provided grounds for the reasoning that depth perception was challenging for her.

When the child was involved in a controlled movement experience, proprioceptive feedback was increased be means of providing heavy-work activities against resistance to assist with counter-balancing the effect of the movement input on her neurological system. It is known that vestibular input can be used to either increase or decrease alertness which can be observed e.g. in the organisation of behaviour, quality of motor output, eye contact or vocalisation.<sup>1,13,33,47</sup>

When considering results from both the OT-PICS and SIPT (as discussed in Chapter 4), for this child with CIs, vestibular input was presented with extreme caution. The inconsistencies in her perception of vestibular input, and vulnerabilities in the vestibular receptors itself i.e. the otolith organs being overly sensitive to input, and her semi-circular canals being under responsive to input provided some challenges, as the more sensitive input triggered a flight response when she needed more feedback from her body during a movement activity. Movement experiences were carefully graded e.g. where she started with slow linear movement on non-suspended equipment (such as the ramp without the scooter board, or jumping on a trampoline), to slow linear movements on suspended equipment (such as a bolster swing attached to two points), and when she was ready, to include equipment which provided faster movements, acceleration, deceleration and rotation (such as the flexion and "frog swings"). This approach assisted with balancing the two types of vestibular receptors for increased adaptability towards the different movement experiences.

### (ii) The multi-sensory development of body scheme

Observations such as visual compensation and using excessive force or deliberate movements e.g. walking up the ramp with heavy footsteps as identified by the OT-PICS and discussed in Section 4.2, support the low scores in PRN and KIN (as shown in the first set of SIPT results in Figure 4.4). The child did not have an accurate internal map of her body due to distorted and limited reliable feedback from her body, which included vestibular, proprioceptive, tactile, and auditory input which negatively impacted the development of her body scheme.

Once the child was more comfortable to wear her CIs, she was able to start tolerating and understanding sound as a contribution to her body scheme in combination with the other senses. She could experience the impact of the echo of her voice, or footsteps on a tile floor. She was starting to orientate herself towards the 3D spatial aspect of sound (e.g. where is the sound coming from: in front, behind, underneath, above?).

She could also develop the perception of her own body in relation to other objects where the impact of her body made a sound and provided a temporal component e.g. the amount of time between her jumps on a trampoline e.g. the "squeaks" of her feet between jumps, stomping her feet hard when walking up a wooden ramp, or the time that elapsed when she was swinging before bumping onto a foam block tower or ball, or hitting a target with a bean bag. She had to learn how to attach meaning to sound in relation to other sensations by means of matching the feeling, the sound and the visual input of an experience, similar to the developmental process of a typical baby without hearing loss (as discussed in Chapter 2). Gentle and natural noisy toys were included e.g. hiding a small cat ball with a tiny bell inside, in a bean box to play "hide and seek" games with sound e.g. so that she could dig in the bean box until she found the noisy toy.

### (iii) Vestibular and proprioceptive bilateral integration and sequencing

As shown by Figure 4.4 and discussed in Section 4.2.4, the child's SIPT results identified the VPBIS pattern of SI dysfunction. However, before difficulties related to the pattern of SI dysfunction could be addressed, the sensory-over reactivity and modulation disorders had to be dealt with. Once the child's sensory input was more effectively organized on a brain stem level, it was possible to proceed to more complex activities to address the development of her motor skills.

In order to support and challenge postural control, ocular control, and bilateral development, the therapist challenged the child to engage in sensory motor activities that build strength, dexterity, speed and agility in static and dynamic postural control and fine and gross motor skills. Examples of such activities include:

- Resistive whole-body movements through space e.g. pulling/pushing on a swing while bumping into a foam block tower.
- Change of direction, stop-go and variation of speed are useful during games e.g. when using targets and moving equipment.
- Encourage pairing of movement with stronger system e.g. visual cues
- Ocular-motor challenges that require visual localization of objects during body movement will be incorporated, e.g., smoothly using both eyes together to cross midline, eye-hand responses toward a visual target
- Incorporating bilateral challenges such as holding a rope at midline with both hands, pumping a swing, pulling or pushing with both arms or legs in a rhythmical sequence are crucial.

More theoretical guidelines about ASI® intervention for children with VPBIS were provided in Chapter 2.

## 5.6 CHANGES AND IMPROVEMENT AS A RESULT OF ASI® INTERVENTION 5.6.1 OT-PICS results

As illustrated in Figure 4.1, the child showed an *increase in responses for Favourable outcomes* in four out of the five sections including sensory perception, sensory reactivity, motor related skills, language and cochlear usage. The scores for her play items remained consistent and appeared that her playfulness was maintained at a consistent level over the four-year period. This implies that the child's ability to learn new skills, consistently wear her CIs and adapt to environmental sensory input improved over time.

It was further positive to note that there was a *decline in Unfavourable outcomes* across all sections, including play, as illustrated in Figure 4.2.

As pointed out in Chapter 4, examples of Unfavourable outcomes included clumsiness, using excessive force, visual compensation, W-sitting postures, avoidance of certain sensory experiences, high activity levels, disorganised behaviour, muting of surfaces, using gestures, noisy / unclear vocalisations, rigidity in play, and removing and hiding her CIs.

The *complexity* rating of sessions at the beginning of the four-year period was rated as a medium level of complexity. The complexity rating towards the end of the four-year period was scored as a high level of complexity. These results are presented in Table 4.5, and showed an *increase in the level of complexity* regarding the number and steps of activities, number of equipment, and variety of sensory input of activities the child participated in.

When considering the principles of neuroplasticity and adaptive responses in ASI® theory as discussed in Chapter 2, it is evident that the child was able to cope better in the therapeutic environment which provided a variety of sensory experiences e.g. not removing her CIs, able to tolerate sound and movement together without retreating to a quiet place afterwards, and was able to express herself verbally more clearly and in longer sentences.

The child was able to perform better on a motor level as seen in the higher level of complexity of sensory-motor activities that she participated in e.g. movement sequences with a combination of different types of suspended equipment. When considering results of the OT-PICS as discussed in Section 4.2.3, it is clear that there was a general trend for increased adaptive behaviour and better participation in childhood occupations for the child with CIs, as her behaviour was more organized and her responses were more appropriate in the context of an increasingly more complex and demanding environment.<sup>3,4,9</sup>

It is still speculative if this child was suffering from Tullio's phenomenon (sound-induced vertigo) as she was unable to communicate changes she experienced before and after the cochlear implantation in words, as an adult would be able to do.<sup>22</sup> However, when considering the positive changes in her behaviour, it can be deducted that if it was present, it was no longer present at the end of the four-year period. It is possible that occupational therapy using the ASI® approach had a positive impact on the child's ability to adapt to her cochlear devices, learn language, and participate in childhood occupations by reducing the impact of the CIs on her neurological organization.<sup>1,11,33</sup>

### 5.6.2 SIPT results

The SIPT was re-administered (as indicated by A5 in Figure 3.1) when the child was 6 years 11 months old, after a period of approximately 19 months after the first SIPT was administered (as indicated by A3 in Figure 3.1). According to research done on the use of the SIPT on South African children, five scores had to be adapted to prevent that more subtle sensory integration dysfunctions go unidentified by the SIPT. These scores are: design copying (DC), oral praxis (OPr), bilateral motor coordination (BMC), standing and walking balance (SWB) and motor accuracy (MAC).<sup>14,49</sup>

The statistical comparison (as discussed in Chapter 4) between the two sets of SIPT results indicated that there was a *significant improvement* in the child's underlying sensory processing skills. The two sets of SIPT results were combined and presented in Table 4.7.

As discussed in Chapter 4, seven (7) out of the 17 tests showed an improvement of one (1) standard deviation (SD) or more. The biggest improvements were noted in the tests of Kinesthesia (KIN), Manual Form Perception (MFP) and Post-rotary nystagmus (PRN) where the child's scores improved from a dysfunctional to a functional range for her age. These three scores are significant as it indicates an improvement in the child's ability to process proprioceptive and vestibular input, as well as the child's ability to use two hands together during a tactile matching task, which are the vulnerable areas for children with a vestibular and proprioceptive bilateral integration and sequencing (VPBIS) pattern of sensory integrative dysfunction.<sup>12,13,49</sup>

The two tests whose first scores were at risk namely Space Visualisation (SV) and Localisation of tactile stimuli (LTS), also showed an improvement of 1 SD implying that the scores fell within the functional range for her age after the second SIPT. This is a significant functional improvement considering the impact of improved depth perception on her participation in movement activities in her 3D space, as well as her ability to correctly perceive tactile input on her arms and hands.

Figure ground perception (FG), design copying (DC), constructional praxis (CPr), postural praxis (PPr) and motor accuracy (MAC) remained consistent between the two assessments as both sets of SIPT scores fell within the functional range for her age. It may be due to visual perception being her strength, and that she enjoyed participating in fine motor activities with an element of visual-motor integration such as tracing or building games. It may be her go-to activities when by implication she is avoiding the movement involved in gross motor activities. Her exposure to a pre-school environment also might have had a positive impact on her fine motor performance within the context of an education curriculum.

It is interesting to note that although Oral Praxis (OPr) showed a decrease of 1 SD, the child's score still fell within the typical range for her age and does not indicate difficulty with imitating tongue, jaw and lip movements. A possible consideration for the decrease in the OPr score might be the increase in age-related demands, and that the child still found it challenging to keep up with the developmental trend of her typical developing peers, even after intervention. On a functional level, this implies that her oral structures are able to imitate movements with the mouth, jaw and lips which are necessary for accurate speech production.<sup>1,11,13</sup>

Three out of the 17 tests remained in the dysfunctional range namely:

- Praxis on Verbal Command (PrVc): following verbal directions without demonstration
- Sequencing Praxis (SPr): performing a rhythmical sequential movement pattern by imitation, and
- Standing and Walking Balance (SWB): considering muscle and joint stability in relation to gravity with eyes open and closed.

Although some improvements were noted in all three of those tests, these areas still remained challenging for the child with CIs and VPBIS pattern of sensory integrative dysfunction. It was however evident when considering the child's raw scores for Praxis on Verbal Command, the child's score went from 0/24 (zero items correct in the first SIPT) to 17/24 (17 items correct in the second SIPT) which showed an improvement in her ability to follow verbal directions without visual cues, even though it might not be age appropriate yet and remains an area of difficulty for her.

It is interesting to note that the child's score for Bilateral Motor Coordination (BMC) went from a functional to a dysfunctional range, probably due to the higher expectations on the older age group and the adaptation of the BMC score with -0.5 for the South African children.<sup>14</sup> It is possible that this hearing-impaired child with CIs, did not play as robustly or participated in movement activities that developed her motor skill like her hearing peers during the early development years. This child with CIs found it difficult to keep up with the developmental trend of her typical developing South African peers in a vulnerable area of her development.

In summary, the second set of SIPT results as shown in Figure 4.5 indicated an improvement in specifically the child's ability to process vestibular (PRN score) and proprioceptive (KIN score) input which are the two crucial sensory systems involved in the vestibular and proprioceptive pattern of sensory integration dysfunction.<sup>7,12,13</sup> The child's PRN score improved with SD +1.25, and her KIN score improved with SD +3.26. As indicated in Table 4.8, both these scores improved from a dysfunctional range (SD below -1.0 to a functional range (SD above -1.0). The results also indicated that following verbal instructions, standing and walking balance, and the ability to perform bilateral and sequential movements remained challenging for the child with CIs, despite the progress that was noted.

## 5.7 IMPACT ON THE FAMILY

According to the theme analysis of the semi-structured parent interview (refer to Table 4.9), it was evident that insufficient cochlear usage had a significant impact on the child's participation and language development, and that occupational therapy using the ASI® approach had a positive impact, not only on the child, but also on the whole family unit. The parents described it as a "*huge impact*" that "*changed their whole lives*".

During the semi-structured parent interview, it was possible to identify sensory triggers that would result in the child feeling overstimulated and impacted the child's tolerance of her Cls. The two main sensory triggers were certain sounds (such as birds, or constant rain over a day or two, or the sound of the wheels while driving in a car) and textures (such as anything on her head like hair clips or pony tails, or certain textures in clothing e.g. wool). The child's behaviour initially after the second CI surgery was that she was clingy, liked familiarity and preferred certain routines. It was even considered that she might have a differential diagnosis such as autism, in combination with her high activity levels, slow speech progress and rigidity in play preferences.<sup>80</sup>

The parents felt angry in the beginning and withdrew from their social life and support system for about two years. They felt isolated with so many challenges to deal with alone. The child's mother resigned from her job to be with the children at home, one child being the child with the CI, and the other a new born baby of a few months. The father was working full-time to afford all the medical services, as well as the typical running expenses of a family household.

The parents noticed a change in her behaviour almost immediately after starting with occupational therapy. They had insight and appreciated changes in small things, and later in bigger things. After four sessions (about one month) of intervention, the mother noticed that the child wore both her CIs for just over 2 hours and she was trying her best to communicate. In that time the washing machine was on, she had been playing outside (running, jumping trampoline, riding scooter bike) and she was aware of background noise like cars passing by and birds singing as well as her little sister's voice. It was only when she was running and hit a speed wobble that she took them off. Her mother felt happy as that was progress for her daughter. The mother ended her message with *"Jump with joy!!"* 

The first few months of occupational therapy using ASI®, the child's CI usage gradually increased to the point where she was wearing her CIs the whole day, and the parents felt that was the breakthrough they needed. Where the child was only using her CIs for about 30 - 45min at a time in the early stages, at the end of the four-year period she was enjoying sound to the point where she does not want to remove her CIs. At the end of the four-year period, the child entered into a main stream school where she could enjoy the benefit of good language and communication models. She could even tolerate hair clips, pony tails and a cap for sport.

ASI® provided terminology and insight into the child's behaviour, regarding the concepts of sensory overload and self-regulation strategies. This knowledge was freeing the parents from the possible guilt of not disciplining their child for her "bad" behaviour, such as removing and hiding her CIs or hiding under tables. Alternative coping strategies were provided for different situations.

Examples of these coping strategies included the following: warning before a loud noise was going to happen such as switching on an electronic device or thunder; providing some sense of control over the child's environment e.g. being able to close a window if the birds or traffic were noisy, or switching the radio off if the input was too much to tolerate. The parents also had "permission" to remove the child's CIs to provide a sensory break that can help her adapt and process multi-sensory input more effectively e.g. to remove the CIs when driving long distances, or when in a noisy place like a shop, or after an intense sensory event such as a

birthday party. The child was empowered by means of having some sense of control over her environment e.g. by indicating if a specific noise was bothering her. This promoted communication between the child and her parents to promote a greater understanding as to her experiences of her environment and to ultimately have optimal CI usage for the full day.

The parents of this child had a similar experience to what was noted in the literature and discussed in Chapter 2. Specific links with the literature were evident in children with disabilities who are often isolated from social events as a result of either the nature of her disability which limited access to typically developing peers. This included opportunities to participate in social activities at home, school and in the community.<sup>62</sup> It was further noted that deaf children do not have the same exposure to sensory and learning opportunities as their typical peers and that they often resort to compensatory measures to develop their skills. Deaf children are often isolated from social events as a result of their disability, which was also true for this child with Cls.<sup>62</sup>

Furthermore, deficits in sensory processing interfered with the child's ability to interact with people and objects. This negatively impacted her ability to explore, form new ideas, build vocabulary and learn new skills like her typical developing peers.<sup>50</sup>

From Table 4.9 the parents had a message of hope to other parents of young children with CIs not to lose hope, and to persevere, as they also know how challenging it was to just get through one day: "We put a lot of pressure on ourselves and our marriage by excluding ourselves. Don't withdraw. You're going to need that support structure of friends. Even if they don't understand. They will eventually come around. Educate them. We were angry and wanted to blame someone for it. It is something that's happened. It's something you just need to deal with and work through. Trying to blame someone is not going to change it. The big step came to us when we decided to focus on solutions...and not to find fault... Every story is different, but you are not alone, there are other people out there in the same boat as you. You just have to persevere in the challenges you are faced with".

The parents' wishes for their child was to wear her CIs full time, to become an oral speaking child, and to have the same opportunities as other children, and for their family to have a "normal life". Both the parents felt that their wishes were fulfilled, and that occupational therapy using ASI® had an impact on their lives beyond expectations. The parents were of the opinion that everyone benefited from the ASI® perspective, including the cochlear team.

## 5.8 PERSPECTIVES FROM THE COCHLEAR TEAM

As reported in Chapter 4 and presented in Table 4.11, the cochlear team unanimously agreed that this child, who was a rare and unique case (about 1 in 50 – 100) benefited from occupational therapy using ASI® intervention. They experienced a difference in her behaviour such as being calmer, more willing to engage socially, more accepting of the device, and being less fearful. The child showed progress in learning to listen and access spoken language. The cochlear team did not consider the possibility of a differential diagnosis such as autism spectrum disorder anymore.

Upon reviewing previous records to support statements that were made on the electronic questionnaires, they noted a difference in the child's tolerance of CIs, that progress had been excellent. The child was wearing her CIs full-time and more accepting to new auditory stimulation which helped them to do their assessments and intervention e.g. to assist the child to reach optimal levels of stimulation more quickly. The cochlear team felt that the occupational therapist using ASI® supported the work of the cochlear team, and that they will refer more children with CIs in the future.

## **5.9 CONCLUSION TO CHAPTER 5: DISCUSSION**

In another single case report discussed in Chapter 3, an occupational therapist used ASI® for a child with autism and the efficacy of ASI® intervention was measured.<sup>64</sup> The child with autism showed an improvement in sensory processing, as measured by the Sensory Integration and Praxis Tests (SIPT), as well as enhanced participation in home, school, and family activities, as indicated on parent-rated goal attainment scales.<sup>64</sup> ASI® was also an effective approach for the occupational therapist to use for the child with CIs. The showed improvement in sensory processing as measured by the SIPT (shown in Figures 4.4, 4.5 and 4.6) as well as sensory-motor skills and functional participation as measured by the OT-PICS (shown in Table 4.5, and Figures 4.2 and 4.3).

It became evident that it was important to pay attention to the child's behaviour as it was a means to communicate that something was not right when she did not have the words to express herself. In this case, when she "misbehaved", examples of things that were not right included a faulty cochlear device which contributed to an intermittent signal, or granuloma annulare which contributed to tactile sensitivities and acceptance of the device.

Due to the adaptability and evolving nature of ASI®<sup>18,19</sup>, it was chosen as the preferred therapeutic approach for the child with cochlear implants as a diverse diagnosis that had not been previously included as extensively in diverse sensory integration literature such as autism

or visual impairment. The occupational therapist had to be adaptable to evolving technology and the sensory awakening of sound in the child with a cochlear implant.

The occupational therapist using the ASI® approach was able to adapt and apply known concepts to the unknown clinical aspects of this child with cochlear implants, such as being guided by the core theoretical principles, having a terminology to describe the child's behaviour, reliable assessment instruments and intervention strategies to guide the process.

A unique feature of ASI® theory is that **adaptive responses** (as described in Chapter 2) are the catalyst for change.<sup>1,4,9,11</sup> The child showed an increase in her adaptive responses pertaining to sensory-motor factors that could be seen in results from both the OT-PICS observation tool and SIPT (as presented in Figure 4.5). There was an increase in the child's Favourable outcomes (as shown in Figure 4.2) and a decrease in the child's Unfavourable outcomes (as shown in Figure 4.3) In addition to the child's skills and performance that improved, the complexity score also increased which implied more complex adaptive responses in a more challenging therapeutic environment (as presented in Table 4.6).

The parents (refer to Table 4.10) and cochlear team (refer to Table 4.11) indicated that her participation was overall better which created synchrony in her family life, as she was able to fully optimize the opportunity of having a CI that provided access to sound and language to the point where she could enter a mainstream school.

## **CHAPTER 6: CONCLUSION**

### 6.1 Reviewing research aim and objectives

The aim of this single case study was to determine the impact of ASI® on the occupational performance in a child with bilateral cochlear implants within the first four years after implantation.

A variety of methods were included to obtain quantitative and qualitative evidence so that the following objectives could be addressed:

1) To develop a measurement instrument that can identify and describe sensory-motor factors and functional participation challenges in occupations for children with cochlear implants (CIs).

2) To identify challenges related to sensory-motor factors and functional participation in a child with bilateral CIs.

3) To determine changes in sensory-motor factors and functional participation in a child with bilateral CIs across a four-year period of ASI® intervention.

4) To determine the pattern of sensory integration dysfunction in a child with bilateral CIs by means of using the Sensory Integration and Praxis Tests (SIPT).

5) To compare the pre- and post-intervention SIPT results of a child with bilateral CIs to determine changes in sensory integrative functions.

6) To obtain perspectives of the cochlear team and parents regarding changes in the child's behaviour and participation in occupations.

When considering the evidence available as discussed in Chapter 4 and 5 in light of available literature as discussed in Chapter 2, it can be concluded that the objectives in this case study have been achieved.

When considering the results and changes in the child as discussed in Chapter 4 and 5, it is clear that occupational therapy using ASI® had a life-changing positive impact and facilitated active involvement in occupations in the child with CIs, as well as the whole family unit. It can further be added that the occupational therapist using ASI® made a valuable contribution to the cochlear team.

When considering the Occupational Therapy Practice Framework<sup>8</sup>, impact on the following occupations have been noted for this child with CIs in Table 6.1 below:

Table 6 1 Summar	v of changes noted in	n occupations in a	child with CIs after OT/SI <sup>8</sup>
	y or changes noted ii	1 00000000113 111 a	

Occupation	Initial concerns	Changes noted after 4 years				
Activities of daily living (ADL): "Activities oriented toward taking care of one's own body						
which are fundamental to living in a social world; they enable basic survival and well-						
being".						
Bathing	Taking up to 8 baths per day to	Reduced to one bath per day,				
	regulate the child's alertness	unless during stressful times, adding				
		one more bath per day				
Dressing, feeding	Uncomfortable with textures	More adaptable with a variety of				
and grooming	such as wool, or in food; did	textures in food and clothing, not				
	not like wet fabric on her skin,	biting her brush anymore; able to				
	or hair bands/clips on her	tolerate hair clips/bands				
	head; disliked having her toe					
	nails cut. Biting her hair brush					
	in times of stress					
Personal device	Removing and hiding her CI	Wearing the CI device full time				
care	after 30 – 45 min of usage					
	ities needed for learning and part	icipating in the educational				
environment".		1				
Informal vs formal	At home with her mother,	Started attending pre-school at the				
	overwhelmed in noisy	age of 4 years. Entered into				
	environment or when under	mainstream primary school at the				
	pressure e.g. hiding under	age of 7 years.				
	tables					
	neous or organized activity that pro	ovides enjoyment, entertainment,				
amusement, or dive						
Play exploration	Had specific preferences,	Enjoying a variety of games and				
and play	specifically visual-perceptual	activities with multi-sensory				
participation	games; rigid routines, although	involvement				
	playful, not always open to					
	ideas from others besides her					
	mother					
	gatory activity that is intrinsically n					
	that is, time not committed to oblig	gatory occupations such as work, self-				
care, or sleep"						
Leisure	Family was in survival mode.	More balanced life, able to				
exploration and	Outings were dominated by	participate in leisure activities as a				
leisure	visits to medical professionals.	family e.g. going on holiday to the				
participation	Child not comfortable to drive	beach (including driving in the car				
	in car.	for a long distance).				
	on: "Engagement in community an ers and that support social interdep	nd family activities that involve social pendence"				
Family, peers,	Parents withdrew from society	Family integrated into society. Child				
friends,	for 2 years. Child had limited	has optimal access to social				
community	access.	situations				

It can therefore be concluded that the research question was answered and that this case study obtained valuable insights and implications for clinical practice.

### 6.2 Limitations of the study

- This study was conducted on only one child with cochlear implants
- Only four videos were used to determine the intra-rater reliability
- Only two videos were used to determine the inter-rater reliability

### 6.3 Contribution to the body of knowledge

- The OT-PICS observation tool can be used by other occupational therapists trained in ASI® to assess and measure progress in children with cochlear implants;
- Intervention strategies have been identified that can guide clinical practice for children with cochlear implants and sensory integrative challenges;
- Insights into the family unit and the parents' experience provided perspective for compassion, to work with them as part of the therapeutic team, not from a place of authority; and
- Identified roles of the occupational therapist can add value to the cochlear team
- By means of creating awareness, more children with cochlear implants can benefit from a holistic approach to increase participation in occupations and enjoyment in life.

### 6.4 Recommendations for future research

- To include a larger number of children with hearing impairment e.g. to determine the pattern of SI dysfunction in South Africa for this population;
- To differentiate between different groups e.g. children with hearing aids, and unilateral and bilateral cochlear implants;
- To review the items on the OT-PICS observation tool to take into consideration neurological maturation.
- To consider more Play items on the OT-PICS to increase test sensitivity for ageappropriate skills.
- To make the OT-PICS observation tool available for occupational therapists who are trained in ASI® to use in clinical practice, to continue to establish reliability and validity larger video bank to increase the number of videos for data collection
- To investigate the incidence and recovery rate of Tullio's phenomenon in children with cochlear implants.
- To publish a journal article reflecting the results to contribute to the body of knowledge of occupational therapists, as well as the rest of the cochlear team.

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## ANNEXURE A Parent Interview guidelines

### 1. Initial referral:

Why was your child referred for occupational therapy focusing on sensory integration?

- How did you feel at the time?
- In your opinion, what were your child's strengths at the time of the referral?
- In your opinion, what were your concerns / wishes for your child at the time of the referral?

### 2. Parents' hopes and wishes:

Can you tell me more... What did you hope to gain from occupational therapy focusing on sensory integration?

- Were your wishes fulfilled by bringing your child to occupational therapy?
- Did you receive support and guidance in terms of understanding sensory integration techniques and principles and how it applies to your child?

Transition: talk about behaviour (i) everyday behaviours, (ii) cochlear usage

### 3. <u>Application of sensory strategies regarding her behaviour and emotions in</u> <u>everyday activities:</u>

Were you able to apply the knowledge about self-regulation and coping strategies in areas of your life?

- Were you able to identify the possible triggers for eliciting disorganised behaviours e.g. removing CIs, changing clothes, taking more than one bath per day?
- Were you able to handle her behaviour more effectively? Could you see a positive change in her behaviour?
- Can you give some examples of her change in behaviours?
- At home?
- Going out e.g. to shops, birthday parties, church

# 4. In which way did occupational therapy contribute to more consistent cochlear <u>usage?</u>

- Increase in cochlear usage?
- Clearer vocalisations?
- Driving in car

### 5. What was the impact on the family unit?

- Sibling
- Other nearby family and friends
- Possible stressors on parents

## 6. What advice do have for other parents of young children with cochlear implants?

- Will you recommend to other parents of children with cochlear implants to go for occupational therapy focusing on sensory integration?
- In your opinion, in what way did the cochlear team benefit from having an occupational therapist focusing on sensory integration on board?

### Thank you

## ANNEXURE B Electronic questionnaire to the cochlear team:

### ENT, audiologist, speech therapists

- 1. How many years have you been part of a cochlear team?
  - 5+ years
  - 10+ years
  - 15+ years
  - 20+ years
- 2. Concerning the case under investigation, have you ever come across another similar case in terms of extreme and unusual behaviours in response to adapting and using the cochlear apparatus?
  - Yes
  - No
- 3. If your answer was yes in question 2, please indicate how often you have come across other similar cases:
  - 1 in 10 children
  - 1 in 50 children
  - 1 in 100 children
- 4. From your perspective, did the child benefit from occupational therapy focusing on sensory Integration?
  - Yes
  - no
- 5. If you answered yes in question 4, please indicate the positive changes you have observed:

- 6. Will you refer more children with cochlear implants for occupational therapy focusing on sensory integration in the future?
  - Yes
  - No
- If you answered yes in question 6, please specify from your perspective the contribution an occupation therapist focusing on sensory integration can make to add value within the cochlear team:

Thank you for taking the time to complete this questionnaire. Your contribution is greatly appreciated.

## ANNEXURE C SAISI Certification

	1 January 1 and 1
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	THE SOUTH AFRICAN INSTITUTE
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1 5 -02- 2018	THIS IS TO CERTIFY
NORN ENG DEPARTEMENT VAN ONDI TENG DEPARTMENT OF EDUC/ LAERSKOOL LYNNWOOD L' (012) 348-8894 FAKS/FAX: (012) 348- SEUS/P O BOX 74929, LYNNWOODRIF,	Stefanie Kruger
	(HPCSA NUMBER: OT0032514)
	(SAISI / OTASA MEMBERSHIP NUMBER: 4073)
HAS SUCCESSFULLY COM	PLETED ALL FOUR THE SAISI TRAINING COURSES IN SENSORY INTEGRATION, HAS
	NCE IN THE USE OF ASSESSMENT METHODS TO DETERMINE SENSORY INTEGRATION
	ULTIES IN CHILDREN INCLUSIVE OF THE SENSORY INTEGRATION AND PRAXIS TESTS
(SIPT) AND HAS ALSO DEMON	NSTRATED THE ABILITY TO IMPLEMENT THE KEY PROCESS ELEMENTS OF THE AYRES
SENSOR	RY INTEGRATION FIDELITY MEASURE DURING INTERVENTION
All -	- 11.1
	2 Round
CHAIRPERSON	
Dated at PRETORIA on: 2017	
Dated at FRETURIA on: 2017	

## ANNEXURE D 1 Informed consent parents

## Stefanie Kruger Occupational Therapist

stefanie@dreamnet.co.za • 082 820 1837

PR Nr 6617093	482 The Wishbone North
HPCSA Nr OT0032514	Lynnwood 0081

Date:

Dear parents,

### INVITATION TO BE PART OF A MASTERS DEGREE CASE STUDY RESEARCH

Introduction:

I am an occupational therapist working in private practice with a special interest in Ayres Sensory Integration (ASI<sup>®</sup>) and young children with cochlear implants.

Nature and purpose of this study:

Your child is a unique case who was referred to me for occupational therapy focusing on sensory integration. I have learnt a great deal from working with her, with you as supportive parents, and with other members of the cochlear team. It sparked a particular interest to do further research. I would like to gather information (in the form of reviewing documents and existing videos) to obtain in-depth knowledge and understanding in her behaviour (e.g. when she had to initially adapt to the cochlear implants in order to learn language), her skills development (as measured by the SIPT), her progress (e.g. to compare test-retest SIPT results), and treatment techniques, as well as your journey to determine the impact of sensory integration intervention on a child with cochlear implants. The intention is to reflect on assessment and intervention processes and to convey relevant information to other occupational therapists and interested team members, to build onto the existing body of knowledge and to expand the repertoire of skills. This will assist occupational therapists, cochlear teams and parents to guide their decisions and therapeutic processes when working with other similar cases so that the child can optimally benefit from the cochlear implants. Having access to sound and making sense of all kinds of auditory input in combination with other sensory experiences will promote optimal participation in childhood occupation such as play, activities of daily living, social interaction and education.

### Confidentiality:

All personal information will be handled confidentially. No names of people or places will be included when reporting the results. This will protect your identities and keep all records as confidential as possible.

### Explanation of procedures:

It will not be necessary for your child to participate in any additional occupational therapy procedures. You need not incur any costs. The case study is designed in such a manner that documents (such as reports and test results) and existing video material with be reviewed and analysed to obtain supportive data from various sources. All electronic information will be stored on a password protected computer. To obtain approval from the Research and Ethics Committee of the Faculty of Health Sciences of the University of Pretoria, written consent has to be obtained from you as parents. Kindly complete and sign the attached form if you provide permission for your child's information pertaining to therapeutic procedures to be used in this case study.

### **Consent and assent:**

If your child is younger than 7 years, the parents give consent on his/her behalf, For children between 7 and 18 years, parents give consent for their child to participate in the study and the child gives assent. Please see attached assent form for children older than 7.

### Risks and benefits:

Your child will not be exposed to any risk or discomfort. The SIPT test is regularly done on children to establish difficulties in sensory perception and motor performance. However, not many children in South Africa with cochlear implants have been tested on the SIPT. Therefore, possible benefits may include that findings from this project will expand knowledge and skills within the field of occupational therapy to better assist children with cochlear implants, as well as their families and other members of the cochlear team. If you have any questions concerning this study, please contact the following contact person of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria: **Dr R Sommers (Deputy Chairperson),** tel: 012-3563084 email: deepeka.behari@ up.ac.za. Please contact me if you have any other queries related to clinical procedures. Your consideration is greatly appreciated.

Kind regards,

Jullenger

Stefanie Kruger Occupational Therapist (UP 1997); Qualified SIPT user (SAISI 2008)

### **PARENT CONSENT**

I, \_\_\_\_\_\_\_ parent of \_\_\_\_\_\_\_ agree to be part of this research project by Ms Stefanie Kruger. Ms Maretha Bekker and Dr Ronell Leech (University of Pretoria) are acting as supervisors for this case study research. I understand and provide permission that relevant information obtained from my child's records (e.g. reports, test results, videos) may be used to obtain more information for a better understanding of this case. All names will be removed to respect your right to privacy. No other identifiable information will be included.

Please note:

- You may, at any time, withdraw from this study without any disadvantage towards your child.
- Participation is completely voluntary and this right will be respected.
- Your child will not be exposed to any form of invasive or harmful procedures.

Your participation is greatly appreciated. Thank you.

Signature

Witness

Thank you! Kind regards,

Jullenger

Stefanie Kruger Occupational Therapist (UP 1997) Qualified SIPT user (SAISI 2008) Date

Date

## ANNEXURE D 2 Assent form

### TO ACCOMPANY PARENT CONSENT FORM

#### Dear Parents,

Seeing that your child is older than 7 years, please read this section to her so that she understands what this project is about and what participation entails. If your child agrees to be part of this project, please ensure that your child writes her name where indicated.

### Dear child,

May I please share your OT story with OTs and other interested people, who work with children who have the same ears as yours? This will help OTs and other interested people to understand better and to help children who have new ears like yours who are learning to play with friends and how to do things at school. I will not use your name, but write to them of what we have done at OT, the games we have played, and everything we learnt together.

Please note:

- You may, at any time, change your mind and withdraw from this project
- You will not be scared or get hurt
- Your name will not be used

If your answer is yes, please write your name here: \_\_\_\_\_\_

Thank you! Kind regards,

Jullenger

Stefanie Kruger Occupational Therapist (UP 1997) Qualified SIPT user (SAISI 2008)

## ANNEXURE D 3 Informed consent cochlear team

## Stefanie Kruger Occupational Therapist

stefanie@dreamnet.co.za • 082 820 1837

PR Nr 6617093	482 The Wishbone North
HPCSA Nr OT0032514	Lynnwood 0081

Date: 18 February 2019

Dear member of the cochlear team,

### INVITATION TO BE PART OF A MASTERS DEGREE CASE STUDY RESEARCH

I am an occupational therapist working in private practice with a special interest in Ayres Sensory Integration (ASI<sup>®</sup>) and young children with bilateral cochlear implants.

Nature and purpose of this study:

An unusual and unique case was referred to me by you for occupational therapy focusing on sensory integration. I have learnt a great deal from working with this child, with supportive parents, and with you as members of the cochlear team. It sparked a particular interest to do further research. I would like to gather information from the cochlear team in the form of reviewing documents to obtain an indepth knowledge and understanding in her behaviour (e.g. when she had to initially adapt to the cochlear implants in order to learn language), as well as her overall skills development. The intention is to reflect on assessment and intervention processes and to convey relevant information to other occupational therapists and interested team members, to build onto the existing body of knowledge and to expand the repertoire of skills. In the future, this will potentially assist occupational therapists, cochlear teams and parents to guide their decisions and therapeutic processes when working with other similar cases so that children can optimally benefit from their cochlear implants. Having access to sound and making sense of all kinds of auditory input in combination with other sensory experiences will promote optimal participation in childhood occupation such as play, activities of daily living, social interaction and education.

### Confidentiality:

All personal information will be handled confidentially. No names of people or places will be included when reporting the results. This will protect your identities and keep all records as confidential as possible

### Explanation of procedures:

It will not be necessary to perform any additional procedures to participate in this case study research. The case study is designed in such a manner that documents (such as reports and test results) will be reviewed and analysed to obtain supportive data from various sources. All electronic information will be stored on a password protected computer and a back-up will be saved in a folder on Google Drive.

Approval from the Research and Ethics Committee of the Faculty of Health Sciences of the University of Pretoria was obtained with reference number 367/2018. As part of my ethical obligation, written consent has to be obtained from you as member of the cochlear team. Kindly complete and sign the attached form if you provide permission for your clinical information pertaining to medical and therapeutic procedures to be used in this case study.

### Risks and benefits:

You will not be exposed to any risk or discomfort. Possible benefits may include that findings from this project will expand knowledge and skills within the field of occupational therapy to better assist children with cochlear implants, as well as their families and other members of the cochlear team.

If you have any questions concerning this study, please contact the following contact person of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria: **Dr R Sommers (Deputy Chairperson),** tel : 012-3563084 email: deepeka.behari@up.ac.za. Please contact me if you have any other queries related to clinical procedures. Your consideration is greatly appreciated.

Kind regards,

Jullenger

Stefanie Kruger Occupational Therapist (UP 1997)

### COCHLEAR TEAM CONSENT

I, \_\_\_\_\_\_ member of the cochlear team in the capacity of \_\_\_\_\_\_ agree to be part of this research project by Ms Stefanie Kruger. Prof Kitty Uys and Dr Ronell Leech (University of Pretoria) are acting as supervisors for this case study research. I understand and provide permission that information obtained from my documents e.g. information from previous reports may be used. All names will be removed to protect the identities of everyone involved.

Please note:

- You may, at any time, withdraw from this study without any disadvantage towards you or the child
- Participation is completely voluntary and this right will be respected.
- You nor the child will not be exposed to any form of invasive or harmful procedures.

Your participation is greatly appreciated. Thank you.

Signature

Date

## ANNEXURE E

<u>Rationale for inclusion of items in the OT-PICS observation tool:</u> Occupational Therapy (OT) Paediatric (P) Intervention outcomes (I) for Cochlear Implants (C) using Sensory-based (S) activities

Dear expert participant,

A checklist was designed for occupational therapists working with children with cochlear implants to identify and describe their responses to sensory input.

The checklist was divided into two developmental domains namely: sensory-motor (proximal outcomes) and functional participation (distal outcomes).<sup>9</sup> Each domain consists of different categories. Each category consists of different items to identify and describe children's responses to sensory input. Your opinion will be greatly appreciated to assist with the evaluation of this checklist.

Proximal outcomes or sensory-motor factors are described as the clinical aspects identified after assessment that require intervention. These include the following categories: sensory perception, motor related functions and sensory reactivity.<sup>9</sup>

Distal outcomes, or functional participation factors are described as the skills, abilities and behaviours expected to change in response to the intervention.<sup>9</sup> These include the following categories: speech, language and communication skills, play and cochlear usage.

The purpose of this document is to:

- 1. Provide an overview of the checklist
- Clarify if the items that have been selected and included in the checklist, are appropriate according to the Ayres Sensory Integration<sup>®</sup> theory, and relevant for children with cochlear implants. The aim of the rationale is to provide theoretical support for each item.

**Question 1:** Do you agree that the categories match the developmental domains?

Developmental	Category	Yes	No	Comments and suggested
Domain				changes
Sensory-motor	1. Sensory Perception			

(Proximal Outcomes)	2. Motor related functions	
	3. Sensory reactivity	
Functional	4. Speech, language and	
participation	communication skills	
(Distal Outcomes)	5. Play as childhood	
	occupation	
	6. Cochlear usage	

The checklist is summarised as follows:

	Developmental Domain: Sensory-Motor Factors (Proximal Outcomes)				
	Category	Description of the child's responses to sensory input			
7.	Sensory perception:	1.1 Using excessive force / participates in heavy work activities			
	ability to identify,	1.2 Preference for visual perceptual games			
	discriminate and	1.3 Participates in activities including rotation and fast acceleration			
	interpret sensory	1.4 Tolerates changes in head position			
	input from various	1.5 Bumping into objects / appears clumsy			
	sensory systems	1.6. Looks at body or limbs while performing a motor task			
		1.7 Orientating towards natural sounds in environment			
8.	Motor related	2.1 W-sitting			
	functions: postural	2.2 Able to maintain balance on a stable surface			
	control, balance	2.3 Able to maintain balance on a moving surface			
	and equilibrium,	2.4 Using arms together in a coordinated manner			
	bilateral	2.5. Can perform a sequential movement pattern (arms and legs)			
	coordination	2.6 Able to get on / off equipment independently			
		2.7 Uses preferred hand consistently throughout the session			
		2.8 Uses trunk rotation to cross body midline			
9.	Sensory reactivity:	3.1 High activity levels / disorganised behaviour / impulsive / spends a			
	hyper- or hypo-	short period of time at an activity before moving onto next game			
	reactivity to typical	3.2 Intentionally seeking certain sensory experiences			
	levels of sensation	3.3 Avoiding certain sensory experiences			
	(emotional and/or	3.4 "Muting" of surfaces to reduce noise			
	behavioural	3.5 Participates in tactile experiences			
	responses)	3.6 Making use of quiet spaces e.g. tent / box			
		3.7 Indicates discomfort or requests to stop			

Developmental Domain: Functional Participation Factors (Distal Outcomes)				
Category	Description of child's responses to sensory input			
10. Speech, language	4.1 Using gestures as a means to make a request			
and communication	4.2 Using single words to describe an action or make a request			
skills	4.3 Noisy / unclear vocalisations			
	4.4 Makes eye contact			
	4.5 Depends on visual cues e.g. demonstration, lipreading or pictures to			
	follow instructions / conversation			
	4.7 Makes use of 2 to 3-word sentences			
	4.8 Makes use of sentences 4 words or more			

11. Play as childhood	5.1 Comfortable to try new equipment / sensory experiences /			
occupation	suggestions from therapist			
	5.2 Rigid / prefers to play familiar games			
	5.3 Sorting or lining up similar looking toys			
	5.4 Involves therapist or parent as playmate			
	5.5. Participates in destructive activities			
	5.6 Participates in incidental and explorative activities			
	5.7 Participates in construction activities			
12. Cochlear usage	6.1 Removes cochlear apparatus?			
	Time of cochlear usage before apparatus are removed:			
	6.2 Hides cochlear apparatus			
	6.3 Able to put cochlear apparatus back on after taking a break?			
	How long was the break?:			
	6.4 Able to process sound and movement at the same time (wearing			
	cochlear apparatus during movement activities)			

Question 2: Does each rationale support the inclusion of the item?

Category 1. Sensory perception: ability to identify, discriminate and interpret sensory input from

various sensory systems9

Item	Rationale	Yes	No	Comments and suggested
				changes
1.1 Using excessive	Indication of the amount of			
force / enjoys heavy	proprioceptive feedback needed from			
work activities	muscles, joints and ligaments to guide			
	motor actions <sup>1,11</sup> . Links with			
	inadequate body scheme <sup>3</sup> .			
1.2 Preference for	Tapping into stronger sensory system			
visual perceptual	of child with hearing impairment,			
games	postural challenges are limited <sup>15</sup> .			
1.3 Participates in	Indication of vestibular feedback from			
activities including	semi-circular canals <sup>13</sup> . Compromised in			
rotation and fast	children with cochlear implants			
acceleration	evident in depressed PRN scores <sup>7</sup> .			
1.4 Tolerates changes	Indication of vestibular feedback from			
in head position	otolith organs <sup>13</sup> . Links with possible			
	gravitational insecurity <sup>1,13</sup>			
1.5 Bumping into	Children with hearing loss show			
objects / appears	significantly lower scores on tests of			
clumsy	motor abilities and balance <sup>7</sup> . Links with			
	inadequate body scheme <sup>3</sup> .			

1.6. Looks at body or	Visually compensating for lack of		
limbs while	vestibular-proprioceptive feedback		
performing a motor	from body <sup>13</sup> .		
task			
1.7 Orientating	Auditory system works closely with		
towards natural	vestibular system and contributes to		
sounds in	3D spatial awareness and body		
environment	scheme. <sup>1</sup>		

### Category 2. Motor related functions: postural control, balance and equilibrium, bilateral coordination

Question	Rationale	Yes	No	Comments and suggested
				changes
2.1 W-sitting	Children with hearing loss have			
	demonstrated vestibular dysfunction. <sup>7</sup>			
	Static balance of children with hearing			
	impairment is poorer than children			
	with normal hearing <sup>16</sup>			
2.2 Able to maintain	Strong correlation between			
balance on a stable	compromised vestibular functioning			
surface	and deterioration in motor			
	performance in children with hearing			
	impairment <sup>16</sup>			
2.3 Able to maintain	Integration of vestibular and			
balance on a moving	proprioceptive input for optimal			
surface	postural control and stabilising eye			
	movements, as well as orientation of			
	body in space. <sup>1,81</sup>			
2.4 Using arms	Children with cochlear implants have			
together in a	difficulty with postural, ocular,			
coordinated manner	bilateral integration and sequencing			
	skills. <sup>7,12</sup>			
2.5. Can perform a	Links with the ability to coordinate			
sequential movement	movements, as well as crossing of the			
	body midline which requires			

pattern (arms and	integration of the two sides of the		
legs)	body. <sup>12,13</sup>		
2.6 Able to get on / off	Links with balance and weight shift		
equipment	required for transitioning between		
independently	pieces of equipment and different		
	body positions. <sup>1,3</sup>		
2.7 Uses preferred	Establishing a skilled preferred hand,		
hand throughout the	able to use ipsi- and contralaterally <sup>13</sup>		
session			
2.8 Uses trunk	Links with bilateral integration,		
rotation to cross body	postural control <sup>13</sup>		
midline			

Category 3. Sensory reactivity: hyper- or hypo-reactivity to typical levels of sensation (emotional

Question	Rationale	Yes	No	Comments and suggested
				changes
3.1 High activity levels	Reflection of state of alertness, links			
/ disorganised	with possible sensory sensitivity,			
behaviour / spends a	ability to block out irrelevant input,			
short period of time at	possible sensory overload <sup>1,2,11</sup>			
an activity before				
moving onto next				
game				
3.2 Intentionally	Possibly attempting to obtain more			
seeking certain	sensory information, possible self-			
sensory experiences	regulation strategy. <sup>9</sup>			
3.3 Avoiding certain	Linking with possible sensory			
sensory experiences	sensitivities, possible self-regulation			
	strategy <sup>1,3,9,11</sup>			
3.4 "Muting" of	Attempt from therapist to reduce			
surfaces to reduce	auditory input from environment to			
noise	facilitate multi-sensory processing e.g.			

	to tolerate sound and movement together		
3.5 Seems to enjoy	Emotional and behavioural responses		
tactile experiences	towards tactile experiences, links with reactivity towards light touch input. <sup>9</sup>		
3.6 Making use of	Calming sensory strategy to assist		
quiet spaces e.g. tent /	child with processing of multi-sensory		
box	input <sup>66</sup>		
3.7 Indicates	Attempt to give some sense of control		
discomfort or requests	to the child when experiencing		
to stop	possible unpleasant sensations to		
	avoid sensory overload and fight/flight		
	responses. <sup>1,3,4,66</sup>		

### Category 4. Speech, language and communication skills

Question	Rationale	Yes	No	Comments and suggested
				changes
4.1 Using gestures as a	Non-verbal requests linking with			
means to make a	intention to communicate <sup>20</sup>			
request				
4.2 Using single words	Matching a word and action for			
to describe an action	meaningful experience during an			
or make a request	activity <sup>82</sup>			
4.3 Noisy / unclear	Unclear expressive language skills			
vocalisations	linking with hearing impairment <sup>17</sup>			
4.4 Makes eye contact	Making non-verbal contact with the			
	communication partner, joint			
	attention on same topic⁵			
4.5 Depends on visual	Visual compensation <sup>26</sup>			
cues e.g.				
demonstration,				
lipreading or pictures				
to follow instructions /				
conversation				

4.7 Makes use of 2 to	Links with vocabulary, quality of		
3-word sentences	expressive language skills <sup>17</sup>		
4.8 Makes use of	Links with vocabulary, language		
sentences 4 words or	sequencing e.g. sentence		
more	construction <sup>7,26</sup>		

# Category 5. Play as childhood occupation

Question	Rationale	Yes	No	Comments and suggested
				changes
5.1 Comfortable to try new	Links with praxis and ideation,			
equipment / sensory	ability to adapt to another			
experiences / suggestions	person's agenda <sup>3</sup> . Play provides			
from therapist	a safe context in which ideas			
	and behaviours can be			
	combined in new ways. <sup>83</sup>			
5.2 Rigid / prefers to play	Links with development of play			
familiar games	in relation to sensory processing			
	difficulties <sup>50</sup> . Links with praxis:			
	translating an idea into action,			
	enabling interaction with the			
	environment. <sup>84</sup>			
5.3 Sorting or lining up	Stereotypical play behaviours <sup>83</sup>			
similar looking toys				
5.4 Involves therapist or	Links with social skills <sup>20</sup> ,			
parent as playmate	intention to communicate with			
	another person <sup>17,62</sup>			
5.5. Enjoys destructive	Links with development of			
activities	play <sup>1,83</sup>			
5.6 Enjoys incidental and	Links with development of			
explorative activities	play <sup>83</sup> and curiosity about			
	environment, discovering			
	affordances <sup>9,85</sup>			

5.7 Enjoys construction	Links with motor abilities,		
activities	praxis, ideation, play		
	preferences <sup>1,3,82,83</sup>		

# Category 6. Cochlear usage

Item	Rationale	Yes	No	Comments and suggested changes
6.1 Removes cochlear	"Eyes open ears on" allows full-			
apparatus	time access to all auditory input.			
	It is crucial in the first few years			
	of life for optimal language and			
	auditory skills to develop. <sup>17</sup>			
6.2 Hides cochlear	Self-regulation strategy <sup>9</sup> ,			
apparatus	possibly indicating discomfort			
6.3 Able to put cochlear	Adaptive response: ability to			
apparatus back on after	tolerate putting the CI device			
taking a break? How long	back after taking it off to give			
was the break?	some time to the brain to adapt			
	to the input and regain a calm-			
	alert state <sup>1,9,11</sup>			
6.4 Able to process sound	Multi-sensory processing as an			
and movement at the same	indication of adapting to a			
time (wearing cochlear	variety of environmental			
apparatus during movement	input <sup>1,66</sup>			
activities)				

References:

# ANNEXURE F Expert evaluation of usability of OT-PICS

# Rationale for including each item in the OT-PICS video checklist: Occupational Therapy (OT) Paediatric (P) Intervention outcomes (I) for Cochlear Implants (C) using Sensory-based (S) activities

Dear expert participant,

A checklist was designed for occupational therapists working with children with cochlear implants to identify and describe their responses to sensory input.

The checklist was divided into two developmental domains namely: sensory-motor (proximal outcomes) and functional participation (distal outcomes).<sup>9</sup> Each domain consists of different categories. Each category consists of different items to identify and describe children's responses to sensory input. Your opinion will be greatly appreciated to assist with the evaluation of this checklist.

Proximal outcomes or sensory-motor factors are described as the clinical aspects identified after assessment that require intervention. These include the following categories: sensory perception, motor related functions and sensory reactivity.<sup>9</sup>

Distal outcomes, or functional participation factors are described as the skills, abilities and behaviours expected to change in response to the intervention.<sup>9</sup> These include the following categories: speech, language and communication skills, play and cochlear usage.

The purpose of this document is to:

- 3. Provide an overview of the checklist
- 4. Clarify if the items that have been selected and included in the checklist, are appropriate according to the Ayres Sensory Integration<sup>®</sup> theory, and relevant for children with cochlear implants. The aim of the rationale is to provide theoretical support for each item.

Question 1: Do you agree that the categories match the developmental domains?

Developmental	Category	Yes	No	Comments and suggested
Domain				changes
Sensory-motor	7. Sensory Perception			
(Proximal Outcomes)	8. Motor related functions			
	9. Sensory reactivity			
Functional	10. Speech, language and			
participation	communication skills			
(Distal Outcomes)	11. Play as childhood			
	occupation			
	12. Cochlear usage			

The checklist is summarised as follows:

Developmer	Developmental Domain: Sensory-Motor Factors (Proximal Outcomes)					
Category	Description of the child's responses to sensory input					
13. Sensory perception:	1.1 Using excessive force / participates in heavy work activities					
ability to identify,	1.2 Preference for visual perceptual games					
discriminate and	1.3 Participates in activities including rotation and fast acceleration					
interpret sensory	1.4 Tolerates changes in head position					
input from various	1.5 Bumping into objects / appears clumsy					
sensory systems	1.6. Looks at body or limbs while performing a motor task					
	1.7 Orientating towards natural sounds in environment					
14. Motor related	2.1 W-sitting					
functions: postural	2.2 Able to maintain balance on a stable surface					
control, balance	2.3 Able to maintain balance on a moving surface					
and equilibrium,	2.4 Using arms together in a coordinated manner					
bilateral	2.5. Can perform a sequential movement pattern (arms and legs)					
coordination	2.6 Able to get on / off equipment independently					
	2.7 Uses preferred hand consistently throughout the session					
	2.8 Uses trunk rotation to cross body midline					
15. Sensory reactivity:	3.1 High activity levels / disorganised behaviour / impulsive / spends a					
hyper- or hypo-	short period of time at an activity before moving onto next game					
reactivity to typical	3.2 Intentionally seeking certain sensory experiences					
levels of sensation	3.3 Avoiding certain sensory experiences					
(emotional and/or	3.4 "Muting" of surfaces to reduce noise					
behavioural	3.5 Participates in tactile experiences					
responses)	3.6 Making use of quiet spaces e.g. tent / box					
	3.7 Indicates discomfort or requests to stop					

Developmental Domain: Functional Participation Factors (Distal Outcomes)					
Category	Description of child's responses to sensory input				
16. Speech, language	4.1 Using gestures as a means to make a request				
and communication 4.2 Using single words to describe an action or make a request					
skills	4.3 Noisy / unclear vocalisations				

4.4 Makes eye contact			
4.5 Depends on visual cues e.g. demonstration, lipreading or pictures to			
follow instructions / conversation			
4.7 Makes use of 2 to 3-word sentences			
4.8 Makes use of sentences 4 words or more			
5.1 Comfortable to try new equipment / sensory experiences /			
suggestions from therapist			
5.2 Rigid / prefers to play familiar games			
5.3 Sorting or lining up similar looking toys			
5.4 Involves therapist or parent as playmate			
5.5. Participates in destructive activities			
5.6 Participates in incidental and explorative activities			
5.7 Participates in construction activities			
6.1 Removes cochlear apparatus?			
Time of cochlear usage before apparatus are removed:			
6.2 Hides cochlear apparatus			
6.3 Able to put cochlear apparatus back on after taking a break?			
How long was the break?:			
6.4 Able to process sound and movement at the same time (wearing			
cochlear apparatus during movement activities)			

### Question 2: Does each rationale support the inclusion of the item?

<u>Category 1. Sensory perception: ability to identify, discriminate and interpret sensory input from</u> <u>various sensory systems<sup>9</sup></u>

Item	Rationale	Yes	No	Comments and suggested
				changes
1.1 Using excessive	Indication of the amount of			
force / enjoys heavy	proprioceptive feedback needed from			
work activities	muscles, joints and ligaments to guide			
	motor actions <sup>1,11</sup> . Links with			
	inadequate body scheme <sup>3</sup> .			
1.2 Preference for	Tapping into stronger sensory system			
visual perceptual	of child with hearing impairment,			
games	postural challenges are limited <sup>15</sup> .			
1.3 Participates in	Indication of vestibular feedback from			
activities including	semi-circular canals <sup>13</sup> . Compromised in			
rotation and fast	children with cochlear implants			
acceleration	evident in depressed PRN scores <sup>7</sup> .			
1.4 Tolerates changes	Indication of vestibular feedback from			
in head position	otolith organs <sup>13</sup> . Links with possible			
	gravitational insecurity <sup>1,13</sup>			

1.5 Bumping into	Children with hearing loss show		
objects / appears	significantly lower scores on tests of		
clumsy	motor abilities and balance <sup>7</sup> . Links with		
	inadequate body scheme <sup>3</sup> .		
1.6. Looks at body or	Visually compensating for lack of		
limbs while	vestibular-proprioceptive feedback		
performing a motor	from body <sup>13</sup> .		
task			
1.7 Orientating	Auditory system works closely with		
towards natural	vestibular system and contributes to		
sounds in	3D spatial awareness and body		
environment	scheme. <sup>1</sup>		

## Category 2. Motor related functions: postural control, balance and equilibrium, bilateral coordination

Question	Rationale	Yes	No	Comments and suggested changes
2.1 W-sitting	Children with hearing loss have			
	demonstrated vestibular dysfunction. <sup>7</sup>			
	Static balance of children with hearing			
	impairment is poorer than children			
	with normal hearing <sup>16</sup>			
2.2 Able to maintain	Strong correlation between			
balance on a stable	compromised vestibular functioning			
surface	and deterioration in motor			
	performance in children with hearing			
	impairment <sup>16</sup>			
2.3 Able to maintain	Integration of vestibular and			
balance on a moving	proprioceptive input for optimal			
surface	postural control and stabilising eye			
	movements, as well as orientation of			
	body in space. <sup>1,81</sup>			
2.4 Using arms	Children with cochlear implants have			
together in a	difficulty with postural, ocular,			
coordinated manner				

	bilateral integration and sequencing skills. <sup>7,12</sup>		
2.5. Can perform a sequential movement pattern (arms and legs)	Links with the ability to coordinate movements, as well as crossing of the body midline which requires integration of the two sides of the		
	body. <sup>12,13</sup>		
2.6 Able to get on / off equipment independently	Links with balance and weight shift required for transitioning between pieces of equipment and different body positions. <sup>1,3</sup>		
2.7 Uses preferred hand throughout the session	Establishing a skilled preferred hand, able to use ipsi- and contralaterally <sup>13</sup>		
2.8 Uses trunk rotation to cross body midline	Links with bilateral integration, postural control <sup>13</sup>		

# <u>Category 3. Sensory reactivity: hyper- or hypo-reactivity to typical levels of sensation (emotional</u> <u>and/or behavioural responses)</u>

Question	Rationale	Yes	No	Comments and suggested
				changes
3.1 High activity levels	Reflection of state of alertness, links			
/ disorganised	with possible sensory sensitivity,			
behaviour / spends a	ability to block out irrelevant input,			
short period of time at	possible sensory overload <sup>1,2,11</sup>			
an activity before				
moving onto next				
game				
3.2 Intentionally	Possibly attempting to obtain more			
seeking certain	sensory information, possible self-			
sensory experiences	regulation strategy. <sup>9</sup>			

3.3 Avoiding certain	Linking with possible sensory		
sensory experiences	sensitivities, possible self-regulation		
	strategy <sup>1,3,9,11</sup>		
3.4 "Muting" of	Attempt from therapist to reduce		
surfaces to reduce	auditory input from environment to		
noise	facilitate multi-sensory processing e.g.		
	to tolerate sound and movement		
	together		
3.5 Seems to enjoy	Emotional and behavioural responses		
tactile experiences	towards tactile experiences, links with		
	reactivity towards light touch input. <sup>9</sup>		
3.6 Making use of	Calming sensory strategy to assist		
quiet spaces e.g. tent /	child with processing of multi-sensory		
box	input <sup>66</sup>		
3.7 Indicates	Attempt to give some sense of control		
discomfort or requests	to the child when experiencing		
to stop	possible unpleasant sensations to		
	avoid sensory overload and fight/flight		
	responses. <sup>1,3,4,66</sup>		

# Category 4. Speech, language and communication skills

Question	Rationale	Yes	No	Comments and suggested changes
4.1 Using gestures as a means to make a request	Non-verbal requests linking with intention to communicate <sup>20</sup>			
4.2 Using single words to describe an action or make a request	Matching a word and action for meaningful experience during an activity <sup>82</sup>			
4.3 Noisy / unclear vocalisations	Unclear expressive language skills linking with hearing impairment <sup>17</sup>			
4.4 Makes eye contact	Making non-verbal contact with the communication partner, joint attention on same topic <sup>5</sup>			

4.5 Depends on visual	Visual compensation <sup>26</sup>		
cues e.g.			
demonstration,			
lipreading or pictures			
to follow instructions /			
conversation			
4.7 Makes use of 2 to	Links with vocabulary, quality of		
3-word sentences	expressive language skills <sup>17</sup>		
4.8 Makes use of	Links with vocabulary, language		
sentences 4 words or	sequencing e.g. sentence		
more	construction <sup>7,26</sup>		

# Category 5. Play as childhood occupation

Question	Rationale	Yes	No	Comments and suggested
				changes
5.1 Comfortable to try new	Links with praxis and ideation,			
equipment / sensory	ability to adapt to another			
experiences / suggestions	person's agenda <sup>3</sup> . Play provides			
from therapist	a safe context in which ideas			
	and behaviours can be			
	combined in new ways. <sup>83</sup>			
5.2 Rigid / prefers to play	Links with development of play			
familiar games	in relation to sensory processing			
	difficulties <sup>50</sup> . Links with praxis:			
	translating an idea into action,			
	enabling interaction with the			
	environment. <sup>84</sup>			
5.3 Sorting or lining up	Stereotypical play behaviours <sup>83</sup>			
similar looking toys				
5.4 Involves therapist or	Links with social skills <sup>20</sup> ,			
parent as playmate	intention to communicate with			
	another person <sup>17,62</sup>			
5.5. Enjoys destructive	Links with development of			
activities	play <sup>1,83</sup>			

5.6 Enjoys incidental and	Links with development of		
explorative activities	play <sup>83</sup> and curiosity about		
	environment, discovering		
	affordances <sup>9,85</sup>		
5.7 Enjoys construction	Links with motor abilities,		
activities	praxis, ideation, play		
	preferences <sup>1,3,82,83</sup>		

# Category 6. Cochlear usage

Item	Rationale	Yes	No	Comments and suggested
				changes
6.1 Removes cochlear	"Eyes open ears on" allows full-			
apparatus	time access to all auditory input.			
	It is crucial in the first few years			
	of life for optimal language and			
	auditory skills to develop. <sup>17</sup>			
6.2 Hides cochlear	Self-regulation strategy <sup>9</sup> ,			
apparatus	possibly indicating discomfort			
6.3 Able to put cochlear	Adaptive response: ability to			
apparatus back on after	tolerate putting the CI device			
taking a break? How long	back after taking it off to give			
was the break?	some time to the brain to adapt			
	to the input and regain a calm-			
	alert state <sup>1,9,11</sup>			
6.4 Able to process sound	Multi-sensory processing as an			
and movement at the same	indication of adapting to a			
time (wearing cochlear	variety of environmental			
apparatus during movement	input <sup>1,66</sup>			
activities)				

References:

# ANNEXURE G

# **OT-PICS OBSERVATION TOOL**

# Occupational Therapy (OT) Paediatric (P) Intervention outcomes (I) for Cochlear Implants (C) using Sensory-based (S) activities

Name of reviewer:	Date of review:	Date of session:
Name of child:	Date of birth:	Child's age:
Bilateral apparatus: $\Box$ Unilateral: L $\Box$ R $\Box$ Hear	ing aid on other side? Yes $\Box$ No $\Box$	Other diagnosis? Yes □ No □Specify:
Place of OT intervention: Duration of session: Par		Parents sitting in on session? Yes $\Box$ No $\Box$
Reason for referral / care giver concerns:		
Additional comments / observations:		
Signature		Date

Dissertation for Master's Degree in OT by S Kruger 94285269

## Part 1: Please tick the applicable description to determine the complexity of the session:

Description of complexity items	1	1 2 3		Item Score
	Low level	Medium level	High level	
1.1 Number of activities	1 - 2	3 - 5	6 or more	
1.2 Steps of activity	1 -2 step	3 – 5 steps	6 or more	
1.3 Number of Equipment	1 – 2 pieces	3 – 5 pieces	6 or more	
1.4. Variety of Sensory input	Single system	Combined 2	Combined various	
	l	TOTAL	COMPLEXITY SCORE	

### **DESCRIPTION OF COMPLEXITY RATING:**

TOTAL SCORE	DESCRIPTION
10 - 12	High level
6 - 9	Medium level
5 and lower	Low level

# Part 2: Please make use of the following scale to measure the frequency of the child's responses observed in the session:

1 = Never

- 2 = Seldom (observed 1 2 times during session)
- 3 = Often (observed 3 5 times during the session)
- 4 = Frequently (observed more than 5 times during the session)

	Developmental Domain: Sensory-Motor Factors (Proximal Outcomes)		
Section	Description of the child's responses to sensory input	Comments	Score
19. Sensory perception:	Favourable Outcomes (FO):		
ability to identify,	1.1 Participates in heavy work activities with whole body		
discriminate and	1.2 Participates in movement activities e.g. rotation, acceleration	Specify:	
interpret sensory	1.3 In-hand identification of objects without vision		
input from various	1.4 Orientates towards natural sounds in environment		
sensory systems	Unfavourable Outcomes (UO):		
	1.5 Participates in sedentary activities		
	1.6 Bumps into objects / appears clumsy		
	1.7. Looks at body or limbs while performing a motor task		
	1.8 Uses excessive force		
20. Motor related	Favourable Outcomes (FO):		
functions: postural	2.1 Able to maintain balance on a stable surface		
control, balance and	2.2 Able to maintain balance on a moving surface		
equilibrium, bilateral	2.3 Uses arms together in a coordinated manner		
coordination	2.4 Performs a sequential movement pattern (arms and legs)		
	2.5 Able to get on / off equipment independently		
	2.6 Uses preferred hand	Specify:	
	2.7 Uses trunk rotation to cross body midline	Specify:	
	Unfavourable Outcomes (UO):		
	2.8 W-sitting		
	2.9 Toe walking		
21. Sensory reactivity:	Favourable Outcomes (FO):		
hyper- or hypo-	3.1 Participates in tactile experiences		
reactivity to typical	3.2 Tolerates changes in head position		
levels of sensation	3.3 Indicates discomfort or requests to stop		
(emotional and/or	Unfavourable Outcomes (UO):		
behavioural	3.4 Preference for certain sensory experiences	Specify:	
responses)	3.5 Avoids certain sensory experiences	Specify:	
	3.6 High activity levels / disorganised behaviour / impulsive / spends a short period of	Specify:	
	time at an activity before moving onto next game		
	3.7 "Muting" of surfaces to reduce noise	Specify:	
	3.8 Makes use of quiet spaces e.g. tent / box	Specify:	

	Developmental Domain: Functional Participation Factors (Distal Outcomes)		
Section	Description of child's responses to sensory input	Comments	Score
22. Speech,	Favourable Outcomes (FO):		
language and	4.1 Makes eye contact		
communication	4.2 Responds when name is called		
skills	4.3 Uses single words to describe an action or make a request	Words:	
	4.4 Makes use of 2 to 3-word sentences	Specify:	
	4.5 Makes use of sentences with 4 words or more		
	4.6 Follows verbal commands	1 / 2 / more steps	
	Unfavourable Outcomes (UO):	· · · · ·	
	4.7 Makes noisy / unclear vocalisations		
	4.8 Uses gestures as a means to communicate		
	4.9 Uses visual aids e.g. demonstration, lipreading or pictures to assist with an instruction /		
	conversation		
23. Play as	Favourable Outcomes (FO):		
childhood	5.1 Actively participates in play: possible play behaviours:	Specify:	
occupation	Explorative / imitation / constructive / symbolic / pretend		
	5.2 Involves a playmate e.g. therapist, parent, peer or sibling	Specify:	
	5.3 Shows initiative	Specify:	
	5.4 Shows enjoyment	Specify:	
	5.5 Comfortable to try new equipment / sensory experiences / open to suggestions from therapist	Specify:	
	Unfavourable Outcomes (UO):		
	5.6 Rigid / prefers to play familiar games	Specify:	
	5.7 Sorting or lining up similar looking toys	Specify:	
	5.8 Withdraws from play environment	Possible trigger:	
	5.9 Repetitive and/or stereotyped behaviours	Specify:	
24. Cochlear	Favourable Outcomes (FO)		
usage	6.1 Able to process sound and movement at the same time (wearing cochlear apparatus during	YES/NO	
-	movement activities)	Specify:	
	6.2 Able to put cochlear apparatus back on after taking a break?	YES/NO	
	How long was the break?:	Specify:	
	Unfavourable Outcomes (UO)		
	6.3 Removes / hides one or both pieces of cochlear apparatus?	YES/NO	
	Time of cochlear usage before apparatus are removed:		

# ANNEXURE H

# Declaration of storage

# **Principal Investigator's Declaration for the storage of research**

# data and/or documents

I, the Principal Investigator(s), <u>Stefanie Kruger</u> of the following trial/study titled <u>The impact of Ayres Sensory Integration® on occupational performance in a child</u> <u>with bilateral cochlear implants</u>

will be storing all the research data and/or documents referring to the above mentioned trial/study at the following non-residential address:

Hard copies of collected data will be stored in a fire-proof and locked filing cabinet at the occupational therapist's private practice. Documents will be stored electronically (if not electronic, it will be scanned) and saved in a dedicated folder on a password-protected computer to which only the researcher and supervisors have access. A back-up will be kept in a folder on Google Drive.

I understand that the storage for the abovementioned data and/or documents must be maintained for a minimum of <u>15 years</u> from the end of this trial/study.

START DATE OF TRIAL/STUDY: <u>01/03/2017</u> END DATE OF TRIAL/STUDY: <u>31/12/2019</u>

SPECIFIC PERIOD OF DATA STORAGE AMOUNTING TO NO LESS THAN 15 YEARS: <u>March 2017</u> until <u>March 2023</u>

Name: Stefanie Kruger

Signature: Jullanger

Date: 15 November 2019

# ANNEXURE I Declaration of Helsinki

**Clinical Review & Education** 

# 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, Bong Kong, September 1989 52nd WMA General Assembly, Edinburgh, Scotland, October 2000 53rd WMA General Assembly, Bedinburgh, Scotland, October 2000 53rd WMA General Assembly, Tokyo, Japan, October 2004 (Note of Clarification added) 55th WMA General Assembly, Seoul, Republic of Korea, October 2008 64th WMA General Assembly, Soreal, Brazil, October 2013

#### Preamble

 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.

 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.
- 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

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best proven interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality.

- Medical research is subject to ethical standards that promote and ensure respect for all human subjects and protect their health and rights.
- 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 selfdetermination, 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.
- Medical research should be conducted in a manner that minimises possible harm to the environment.
- 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.

JAMA Published online October 19, 2013

# ANNEXURE J 1 Ethical approval

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

26/07/2018

Approval Certificate New Application

### Ethics Reference No: 367/2018

Title: The impact of Ayres Sensory Integration® on occupational performance in a child with bilateral cochlear implants

### Dear Mrs Stefanie Kruger

The **New Application** as supported by documents specified in your cover letter dated 18/07/2018 for your research received on the 19/07/2018, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 25/07/2018.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year
- Please remember to use your protocol number (367/2018) 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 <u>6 monthly written Progress Reports</u>, 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.

We wish you the best with your research.

### Yours sincerely

\*\* Kindly collect your original signed approval certificate from our offices, Faculty of Health Sciences, Research Ethics Committee, Tswelopele Building, Room 4.59 / 4.60.

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).

 <sup>2</sup> 012 356 3084

 <sup>2</sup> deepeka.behari@up.ac.za / fhsethics@up.ac.za

 <sup>3</sup> http://www.up.ac.za/healthethics

 <sup>1</sup> Private Bag X323, Arcadia, 0007 - Tswelopele Building, Level 4, Room 60 / 61, 31 Bophelo Road, Gezina, Pretoria

 <sup>1</sup> Private Bag X323, Arcadia, 0007

# ANNEXURE J 2 Ethical extension

Samantha Hodgson <samantha.hodgson@up.ac.za> To: Stefanie Kruger <Stefanie@dreamnet.co.za> Cc: Kitty Uys <kitty.uys@up.ac.za> Tue, Feb 19, 2019 at 8:37 AM

Morning

Your request for extension has been approved. See attached.

The hard copies have been sent to the Postgraduate Office at Tswelopele for processing.

Regards

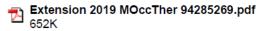
### Samantha Hodgson Dean's Office



Tel +27 (0)12 319 2191 Email samantha.hodgson@up.ac.za www.up.ac.za

Faculty of Health Sciences Room 5-21, Level 5, Health Sciences Building University of Pretoria, Private Bag X323 Arcadia, South Africa

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Titel / Title		Mrs			
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Posadres / Postal address		482 The	Wishb	one North	
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### Motivational letter to request for extension of study period: Masters degree in occupational therapy

To whom it may concern,

Please find herewith my motivation to extend the study period of my master's degree in occupational therapy with another year.

### Title:

# The impact of Ayres Sensory Integration<sup>®</sup> on occupational performance in a child with bilateral cochlear implants

# Ethical clearance number: 367/2018

My laptop was stolen during the course of 2017 which had a significant impact on the flow and momentum of my research process. I managed to continue after recovering documents and articles that I collected over a period of time and received ethical clearance in July 2018. My study supervisor Ms Maretha Bekker resigned in July 2018 which made another significant impact on my research process.

Prof Kitty Uys has been assigned as my new study leader, together with Dr Ronell Leech as my cosupervisor. We have scheduled regular skype meetings to ensure the completion of identified critical tasks for that week or two-week period. My studies have regained momentum and I will be able to submit my dissertation by November 2019.

### Timeline:

May	June	July	Aug	Aug	Sept	Oct	Nov
2019	2019	2019	2019	2019	2019	2019	019
Data collection	Data analysis	Results chapter	Discussion chapter	Submits notification to submit thesis	Conclusion chapter	Submit final thesis to supervisors	Submit thesis for examination

Thank you for considering the application for extension.

Kind regards,

Jullenger

Stefanie Kruger Occupational Therapist Student number: 94285269

# **ANNEXURE K SIPT REPORT PAGES 4 and 5**

WPS SIPT TEST REPORT

Name:

### Page: 4

# **Complete Listing of SIPT Scores**

Test	Score	Test Score
Space Visualization (SV)		Design Copying (DC)
<ul> <li>Time-adjust accuracy</li> </ul>	-0.88	* Total accuracy 0.10
Accuracy	-0.89	Adjusted accuracy0.04
Time	-0.18	Part I accuracy 0.11
Contralateral use	-0.27	Part II accuracy 0.09
Preferred hand use	-0.10	Part II SNH listed on next page
Figure-Ground Perception (FG)		Constructional Praxis (CPr)
* Accuracy	0.96	* Total accuracy0.39
Time	-0.35	Part I accuracy1.11
Manual Form Perception (MFP)		Part II accuracy 0.33
* Total accuracy	-0.72	Part II errors listed on next page
Total time		Postural Praxis (PPr)
Part I accuracy	1.07	* Total accuracy 1.00
Part I right accuracy	0.26	Oral Praxis (OPr)
Part I left accuracy	1.51	* Total accuracy 0.72
Part I time	-2.57	Sequencing Praxis (SPr)
Part I right time	-2.21	* Total accuracy
Part I left time	-2.45	Hand accuracy
Part II accuracy	-1.60	Finger accuracy U/S
Part II right accuracy	-1.44	Bilateral Motor Coordination (BMC)
Part II left accuracy	-1.32	* Total accuracy
Part II time	0.47	Arm accuracy0.40
Part II right time	0.05	Feet accuracy0.07
Part II left time	0.77	Standing and Walking Balance (SWB)
Kinesthesia (KIN)		* Total score1.92
* Total accuracy	-1.99	Eyes open1.80
Right hand accuracy	-0.82	Eyes closed1.72
Left hand accuracy	-2.62	Right foot
Finger Identification (FI)		Left foot1.60
* Total accuracy	-2.16	Motor Accuracy (MAc)
Right hand accuracy	-1.29	* Weighted total acc0.37
Left hand accuracy	-2.20	Unweighted total acc0.44
Graphesthesia (GRA)		Pref hand weight acc0.95
* Total accuracy	-0.30	<ul> <li>Pref hand unweight acc1.05</li> </ul>
Right hand accuracy	0.68	Nonpref hand weight acc 0.22
Left hand accuracy	-1.27	Nonpref hand unweight acc 0.17
Localization of Tactile Stimuli	(LTS)	Postrotary Nystagmus (PRN)
* Total accuracy	-0.94	* Average nystagmus1.42
Right hand accuracy	-0.62	Average clockwise
Left hand accuracy	-0.68	Average of clockwise
Praxis on Verbal Command (PrVC)		Average cnt clockwise1.46
* Total accuracy	-3.00	Time 1 clockwise1.22
Total Time	-3.00	Time 1 cnt clockwise1.40
		Time 2 clockwise1.53
Kove U/C. Main		Time 2 cnt clockwise1.27
Key: U/S: Major score unscorable	N/A: Tost	

**Key:** U/S: Major score unscorable N/A: Test was not administered SD Score below -3.00 are reported as -3.00 SD Scores above 3.00 are reported as 3.00

Complete	Listing	of SIPT	Scores,	continued
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Test	Score
Design Copying (DC) Atypical approach parameters: (B)Boundaries	-0.85 -0.93 0.60 0.51 0.20 -1.57
Contructional Praxis (CPr) Part II errors parameters: (1)Displacement 1-2.5 cm (2)Displacement > 2.5 cm (3)Rotation > 15 degrees (4)Reversals (5)Incorrect but logical (6)Gross mislocations (7)Omissions	1.11 0.18 0.92 -1.09
<b>Key:</b> U/S: Major score unscorabl SD Score below -3.00 are report SD Scores above 3.00 are report	e N/A: Test was not administered ed as -3.00 ed as 3.00

# ANNEXURE L

# **TURNITIN CONFIRMATION**

The impact of Ayres Sensory Integration® on occupational performance in a child with bilateral cochlear implants.

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cochlear implantation outcomes in South Africa", International Journal of Pediatric Otorhinolaryngology, 2016. Publication

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File size:	179.62K	
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Character count:	48,830	
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