Research topic:

D/deaf and hard-of-hearing young adults with intellectual disability's experience of and their caregivers' and audiologists' perceptions of aural rehabilitation practices and tools utilized at schools for the D/deaf in Western Cape Province, South Africa

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MSHSAN007

Submitted in partial fulfilment of the requirements of Master of Philosophy in Intellectual Disability

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Date: 22 October 2023

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Acknowledgments

I am extremely grateful for all the support I received while completing my master's degree.

To Professor Sharon Kleintjes: I want to thank you for your support over the past two years. I am grateful for your faith in me and in this research project. I will always be grateful for all the advice you have given me, for sharing your knowledge and for constantly motivating me.

To Dr Siyabulela Mkabile: Thank you for all the valuable advice you have given me. I shall be eternally grateful for the encouragement you have given me over the past two years and thank you for sharing your wisdom with me.

Thank you to Vera Grover Scholarship Trust administered by the Western Cape Forum for Intellectual Disability for funding this research study. Thank you to the Ada and Bertie Levenstein bursary, the Glickman/Elliott and the UCT Masters financial aid scholarship for funding my degree.

Thank you to all the participants who took part in my study; I will be eternally grateful for you giving up your time to participate in my study and thank you for trusting me to share your experiences.

Thank you to my family and close friends, in particular my mother Thozama Mashologu and my late sister Noluvo Mashologu, for your unwavering encouragement and support. Thank you to my dear friend Vuyo Tshawekazi Bangilizwe for all your assistance and motivation throughout this study.

Abstract

Background: Hearing loss is one of the leading causes of disability worldwide. Aural rehabilitation may aid in reducing participation barriers and facilitating improved personal and environmental strategies to mitigate the disabling effects of hearing loss. It has been documented in research that there is limited literature available on aural rehabilitation practices and tools available for D/deaf and hard-of-hearing children and adolescents with an intellectual disability. Available literature on this topic showed that studies were mostly conducted in high-income countries, with no research studies conducted in South Africa. **Aim**: This study aimed to explore aural rehabilitation practices and tools utilized with D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in public schools for D/deaf in the Western Cape, South Africa. **Methods**: An exploratory qualitative research design was chosen for this study to gather information and explore participants' experiences and perceptions of aural rehabilitation practices and tools utilized by them or on them. Semi-structured interviews were conducted with three audiologists to gather information on their perceptions and experiences of aural rehabilitation practices and tools utilized with D/deaf and hard-of-hearing children with an intellectual disability. Semi-structured interviews were also done with four Deaf young adults with a coexisting intellectual disability, as well as two caregivers and two parents of these young adults, to gather information on their experiences and perceptions of aural rehabilitation practices and tools that were utilized on them. **Results**: The scoping review findings indicate that management plans should be individualized and tailored to the child's specific needs, and practices and counselling should be family centred, particularly as inclusion of family members can provide practice in and improve communication at home with their child. Review findings also support consideration of cochlear implants as a treatment option for rehabilitation for deaf and hard-of-hearing children and adolescents with intellectual disability. From the data collected during the interviews there were four themes highlighted: (1) counselling (2) tools, which included three subthemes of hearing aids, cochlear implants as well as scales, checklists, and questionnaires (3) practices and (4) accessibility of audiology services. Discussion: Aural rehabilitation practices and tools that are utilized on D/deaf and hard-of-hearing children and adolescents without an additional disability are also utilized on D/deaf and hard-of-hearing children and adolescents with an intellectual disability in South Africa, even though their speech and language outcomes are generally poorer. The severity of intellectual disability is a major factor influencing this population's speech, language, and auditory outcomes. The findings of this study indicate that aural rehabilitation practices and tools should be selected based on the needs of the child or adolescent, and a family-centred approach to aural rehabilitation should be encouraged. Further, there is a significant need for additional research focusing on aural rehabilitation practices and tools utilized on this population in other settings within the South African context. **Conclusion**: To conclude it is a clear that there is aural rehabilitation practices and tools that are applicable for this population although one must consider that this population presents with unique needs thus they require more support than D/deaf and hard-of-hearing children and adolescents without an additional disability. Furthermore, there is gap in research relating aural rehabilitation practices and tools for this population.

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Definition of terms

Auditory brainstem implant: a neuroprosthetic device that provides hearing sensations to deaf children who are not candidates for cochlear implants, due to an absence of intact cochlear nerves or implantable cochlea. Using a multichannel surface array placed in the auditory brainstem, it bypasses the cochlear nerve to electrically stimulate second order neurons in the cochlear nucleus (Wong et al., 2019).

Aural rehabilitation: is an umbrella term for intervention techniques that can be used to manage hearing loss (Rutherford & Petersen, 2018).

Aural rehabilitation tools: any devices, checklists, or programmes that help improve communication or ease access to auditory stimuli are considered aural rehabilitation tools (Boothroyd, 2007).

Bimodal bilingual language: use is used to describe bilingualism in at least one spoken language and sign language (Lillo-Martin, de Quadros & Pichler, 2016).

Cochlear implants: electronic stimulus prostheses used to substitute the function of the cochlea. They do not restore normal hearing, but they can receive auditory stimuli from the environment and transmit them to the auditory nerve. They provide an electronic perception of sound, and they allow deaf people to perceive sound through additional auditory training (Bernicchia-Freeman, 2018).

Communication: an individual's ability to comprehend, detect, or apply language or speech to effectively engage in discourse with others. This can be done through facial expressions, sign language, body language and gestures, hand gestures, reading, writing, speaking, and listening (Friedman & McNamara, 2018).

Differentiated National Curriculum and Assessment Policy Statement (dCAPS): South African schools' National Curriculum and Assessment Policy Statement for students with severe intellectual disability in grades R to 5. dCAPS was created to meet the aptitude, knowledge, and vocational needs of students with a severe intellectual disability. dCAPS subjects include first additional and home languages, life skills, mathematics, and vocational subjects such as arts and crafts, welding, and agricultural studies (Department of Education, 2018). The Mental Health Care Act no 17 of 2002 (Republic of South Africa, 2004) defines severe or profound intellectual disability as "referring to a range of intellectual functioning ranging from partial self-care under close supervision, together with limited self-defense skills in a controlled setting through limited self-care and requiring constant aid and supervision, to severely limited sensory and motor functioning and requiring nursing care". This definition is not consistent with the International Classification of Disability-11 and Diagnostic and Statistical Manual of Mental Disorders V definitions (American Psychiatric Association, 2013; WHO, 2018).

Expressive language: the ability to use verbal and non-verbal language skills to express needs and wants (McIntyre, Hellsten, Bidonde, Boden & Doi, 2017).

Hearing aids: amplification assistive devices that you wear behind or in your ear to improve audibility of environmental and speech sounds. They amplify sounds in the individual's environment so that the individual with a hearing loss can listen, communicate via the speech modality, and participate fully in auditory activities. Hearing aids receive sounds in the listening environment through a microphone,

which then converts sound waves to electrical signals and sends them to the amplifier, which then increases the loudness of the sounds and sends them to the ear via the speaker (Atcherson et al., 2015).

Intellectual disability: the Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) defines intellectual disability as impairment of mental abilities with intellectual functioning, and adaptive functioning (American Psychiatric Association, 2013). In the ICD-11, intellectual disability is classified as Disorders of Intellectual Development (DID), a set of disorders with many causes that begin during the developmental period or before the age of 18 years and includes deficits in intellectual functioning and adaptive behaviour (WHO, 2018).

Mainstream schools: schools for children with no disabilities, or students with disabilities that can be integrated into a mainstream classroom setting with extra support (Department of Education, 2001).

Middle ear implant: an electronic device that is implanted in the middle ear and mechanically stimulates the inner ear. It may be useful for people with conductive hearing loss who are unable to wear conventional hearing aids. It is made up of two parts: the internal implant and the external processor, which is worn on the side of the head (Shohet & Bibee, 2021).

National Curriculum and Assessment Policy Statement (CAPS): a policy document for learning and teaching in South African schools for grades R to 12. It contains the national curriculum statement's program and promotion requirements, as well as information on the approved school subjects, the number of subjects offered to students in each grade, the promotion requirement to be obtained, and standardized recording and reporting processes (Department of Basic Education, 2011).

Prelingual hearing loss: hearing loss that occurs at birth or early in childhood development, before language development (Jallu et al., 2019).

Postlingual hearing loss: hearing loss that occurs after a child has developed speech and language skills (Lee et al., 2021).

Receptive language: the ability to understand and comprehend verbal and non-verbal language (McIntyre, Hellsten, Bidonde, Boden & Doi, 2017).

Sensory management: is a term used to describe the fitment of hearing aids, FM systems and middle ear implants (Rutherford & Petersen, 2018).

Severe and profound Intellectual disability: The Mental Health Care Act no 17 of 2002 (Republic of South Africa, 2004) defines severe or profound intellectual disability as "referring to a range of intellectual functioning ranging from partial self-care under close supervision, together with limited self-defense skills in a controlled setting through limited self-care and requiring constant aid and supervision, to severely limited sensory and motor functioning and requiring nursing care". This definition is not consistent with the International Classification of Disability-11 and Diagnostic and Statistical Manual of Mental Disorders V definitions (American Psychiatric Association, 2013; WHO, 2018).

Sign language: a language that uses the visual-manual modality to convey meaning rather than just spoken words. The five components of sign language are handshape, orientation, location, movement, and non-manual features (Casoojee, Kanji & Khoza-Shangase, 2021).

Special needs schools: schools that serve students with special educational needs due to intellectual, learning, sensory, or physical disabilities and are thus unable to cope or receive the necessary support in mainstream schools (Department of Education, 2001).

Spoken language: any language that requires listening to auditory input and verbal response through speech (Lillo-Martin, de Quadros & Pichler, 2016).

Vocational training: training that focuses on teaching students the skills and knowledge required for a particular job, through vocational subjects (Department of Education, 2018).

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Chapter one: Introduction

This introductory chapter defines terms relevant to the study, including intellectual disability, hearing loss, hard-of-hearing, Deaf, and deaf. It also included statistics relating to the prevalence of hearing loss, intellectual disability, and the prevalence of these disabilities coexisting. It additionally provides an overview of the scope of aural rehabilitation services relevant to the study. This introduction includes a section on the impact of early intervention among D/deaf and hard-of-hearing children with an intellectual disability, the provision of audiology services for these children and adolescents, a section on language acquisition for this population, and inclusive education in special needs schools. Finally, this chapter includes the rationale and conceptual frameworks for the study and outlines the research question and objectives for the study.

Background to the study

1.1 Disability definitions

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) views individuals with disabilities as any physical, mental, intellectual, or sensory impairment that, when combined with other barriers, prevents them from partaking in society on an equal basis with their peers (UNCRPD, 2006). Social and human rights models of disability are incorporated into the UNCRPD's definition of disability. In accordance with Article 25 of the UNCRPD (UNCRPD, 2006), persons with disabilities must have access to the best available healthcare without discrimination or exclusion because of their disability. South Africa (SA) signed and ratified the UNCRPD in 2007.

However, SA still has a long way to go before it is fully compliant, because South Africans with disabilities face significant barriers to accessing healthcare and rehabilitation. There are psychological, physical, communication, political, financial, and healthcare system barriers to implementing the UNCRPD's health and rehabilitation articles in SA (Hussey, MacLachlan & Mji, 2017).

Intellectual and hearing disability are as important as any other disability noted in the UNCRPD because they can significantly affect an individual's quality of life, particularly when these disabilities co-exist. These disabilities are considered invisible because they cannot be easily detected in young children, may not be immediately evident to first-time acquaintances with the individual, and sometimes may be confused with each other. Therefore, children with a hearing disability may be incorrectly identified as children with an intellectual disability and vice versa (Abbas, 2015).

Difficulties in identifying and detecting D/deaf and hard-of-hearing children with an intellectual disability result in poorer language and auditory outcomes because appropriate intervention is

frequently provided at a later stage compared to D/deaf and hard-of-hearing children without an additional disability (Nelson & Bruce, 2019). To distinguish between and diagnose intellectual disability and hearing loss, these two disabilities must first be defined.

1.2 Intellectual disability

The Diagnostic and Statistical Manual of Mental Disorders 5th edition (DSM-5) defines intellectual disability as impairment of mental abilities which impact on three domains of adaptive functioning, the conceptual, social and practical domains (Saad & ElAdl, 2019). Previously, intellectual disability was referred to as mental retardation in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV). Partly because of its negative connotations, this term was changed. The DSM-5 criteria of intellectual disability places emphasis on adaptive functioning in academic, social, and practical settings, rather than the DSM-IV reliance on formal intelligence testing to obtain intelligence quotient (IQ) scores (Mahour, & Panday, 2015).

The following criteria for diagnosing intellectual disability are listed in the DSM-5 (American Psychiatric Association, 2013): (1). Problems with intellectual functioning, including reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning through experience, as assessed with clinical evaluation, along with individualized standardized intelligence testing to confirm intellectual functioning impairments. (2) Deficits in adaptive functioning related to difficulties in meeting developmental and sociocultural requirements for personal independence and social responsibility in areas including communication, social interaction, and personal independence. Intellectual and adaptive functioning issues will be experienced in a variety of situations at home, at school, in the workplace, and in the community. (3) The onset of (1) and (2) must have occurred during the developmental period (American Psychiatric Association, 2013; p. 33).

While the above description of intellectual disability according to the DSM-5 places a strong emphasis on both cognitive and adaptive functioning deficits, the American Association for Intellectual and Developmental Disabilities (AAIDD), a leading non-governmental organization that supports people with an intellectual disability, emphasizes the importance of taking into consideration the impact of environmental, linguistic, cultural, support, and other factors that can affect a person's daily functioning. They also urge that professional assessments and treatment plans consider potential limitations as well as strengths in various life domains in their evaluations and support plans (AAIDD, 2021).

The 11th edition of the International Classification of Disorders (ICD-11) is an international classification system for mental and physical disorders, including intellectual and hearing disabilities. The

International Classification of Diseases (ICD 11), which was launched in June 2018 and tabled at the World Health Assembly in May 2019 for acceptance by member countries, which included South Africa, went into effect in January 2022. (WHO, 2019). According to the ICD-11, intellectual disability is classified as Disorders of Intellectual Development (DID), a set of disorders with many causes that begin during the developmental period or before the age of 18 years and includes deficits in intellectual functioning and adaptive behaviour (WHO, 2018). Intellectual disability, with onset before 18 years, manifests itself in significant limitations in cognitive functioning and adaptive skills in the social, practical, and conceptual domains.

Both the DSM-5 and the ICD-11 categorize the severity of intellectual disability as mild, moderate, severe, and profound intellectual disability.

Due to their ability to adapt to social norms, individuals with a mild intellectual disability can be self-sufficient and learn practical life skills that allow them to function in everyday life with minimal assistance. Individuals with a moderate intellectual disability can work under routine supervision on jobs that require limited conceptual and social skills, become independent for basic self-care (with regular reminders), visit familiar places in their community, and learn basic safety and health skills.

On the other hand, individuals with severe intellectual disability frequently understand uncomplicated communication but may have limited communication skills. They can perform some basic self-care activities under supervision, with regular assistance needed for most activities of daily living. Individuals with profound intellectual disability require round-the-clock care and support due to limitations in their cognitive, social, and in many cases, motor abilities (Saad & ElAdl, 2019).

Individuals with severe to profound intellectual disability can be diagnosed clinically within the first three years of life because they typically have significantly delayed motor, language, and social development. Conversely, individuals with a mild to moderate intellectual disability may be diagnosed later, most often between ages 4 to 9 years old because their difficulties may become more apparent once they enter the academic learning environment (Patel, Apple, Kanungo & Akkal, 2018).

1.3 Hearing loss

Hearing is the sensory ability to detect, process, discriminate and interpret auditory stimuli (Katz, 2014). Hearing and communication are inextricably linked, and hearing loss can have a negative impact on communication (Goman, Reed & Lin, 2017). Hearing loss can be classified according to its degree, configuration, and type (Stewart & Bentley, 2019).

The degree of hearing loss refers to its severity and can be classified as slight, mild, moderate, moderately severe, severe, and profound (Stewart & Bentley, 2019). It is categorized by decibel (dB) values. The level of sound pressure is measured in decibels (dB). The sound pressure level determines the volume or loudness of a sound. The greater this value, the louder the sound is required to be.

Individuals with a slight hearing loss (16 to 25 dB) can hear well during one-on-one conversations. They are able to hear someone whispering from 1.5m away but have difficulty hearing each word being said.

Individuals with mild hearing loss (26 to 40 dB) struggle to hear soft sounds; to hear if the distance between them and the speaker is large, and when there is background noise. They have difficulty in hearing someone even if the distance between them and the speaker is short, and the conversations are at a normal level of loudness. Even if the distance between them and the speaker is short, individuals with moderate hearing loss (41 to 55 dB) will have difficulty hearing someone compared to those with a moderately severe hearing loss (56 to 70 dB) who will have great difficulty hearing in normal conversations (Michels, Duffy & Rogers, 2019).

Individuals with severe hearing loss (71 to 90 dB), are unable to hear most speech sounds. They can hear loud sounds, only. Finally, individuals with profound hearing loss (+90 dB) perceive loud sounds as vibrations (Michels, Duffy & Rogers, 2019).

The configuration provides information on the frequency or pitch ranges where the hearing loss occurs. The damaged part of the auditory system (i.e., the outer ear, the middle ear, and the inner ear) determines the type of hearing loss. For instance, conductive hearing loss occurs when a blockage prevents sound from passing through the outer or middle ear. The damage to the inner ear or the auditory nerve causes sensorineural hearing loss. Sensorineural hearing is usually permanent whereas conductive hearing loss is potentially treatable.

The term "mixed hearing loss" refers to a combination of conductive and sensorineural hearing loss. Abnormalities in auditory processing at higher levels of the central nervous system can cause central hearing loss (Stewart & Bentley, 2019).

Additionally, the ICD-11 classifies disorders of hearing impairment according to the type of hearing loss. Disorders of hearing impairment can be acquired or congenital. Acquired hearing loss refers to loss of hearing that occurs after birth, whereas congenital hearing loss refers to a loss that occurs before birth or within the first month after birth and is the result of an underlying congenital condition (WHO, 2021).

The term "hearing-impaired" is frequently used to describe individuals with any degree of hearing loss, from mild to profound. Individuals with hearing loss are more likely to refer to themselves as D/deaf

or hard-of-hearing than the term hearing impaired. Individuals who identify as culturally Deaf consider the term "hearing-impaired" to be outdated and derogatory, as it focuses primarily on Deaf individual's inability to hear as a condition that must be treated to "normalize'' their lives (Bennett, 2019).

A deaf individual who refers to himself or herself as Deaf spelled with a capital "D," can have any degree of hearing loss. The capitalized term denotes that the person belongs to a cultural community of Deaf individuals who share similar beliefs, culture, norms, and histories (Kemmery & Compton, 2014; Orrie & Motsohi, 2018; National Association of the Deaf, 2021).

Globally, the vast majority of individuals within the Deaf community, appear to be those who have a profound hearing loss (World Health Organization, 2021). Deaf individuals do not consider themselves to be disabled. They communicate primarily through sign language. In SA, Deaf individuals use South African Sign Language (SASL) which has the same syntactic structure as any other signed language, but there are lexical differences related to regional and educational backgrounds (Penn & De Andrade, 2017). The Deaf community is a minority culture in SA, with the 2011 census revealing that 400 000 citizens use SASL as their primary language. This highlights the importance of acknowledging and including D/deaf citizens in all aspects of a diverse society like South Africa, the South African Parliament voted for an amendment to Section 6 (1) of the Constitution of the Republic of South Africa on the 2 May 2023, signed into law on the 19th July 2023, and due to take effect from the 1 July 2024, the recognition of SASL as the 12th official language of the country (McKenzie et al., 2019).. About 95% of Deaf children are born to hearing parents who do not understand SASL. Some of these children learn the language at school, where they are taught speech and SASL (NID, 2022).

A deaf individual with a lowercase ''d'' refers to the medical and audiological definition of hearing loss (Paul, 2020). Individuals who are deaf may not identify with the Deaf community but rather consider the hearing world to be their cultural home. They do not use sign language as a means of communication and prefer to rely on spoken language (NID, 2022). Hard-of-hearing is a commonly used term to describe someone who has mild to moderate hearing loss. These individuals may choose to use an assistive device, such as hearing aids, an FM system, or cochlear implants, to improve their hearing abilities (World Health Organisation, 2021).

D/deaf and hard-of-hearing individuals are more likely to have additional disabilities like an intellectual disability if they have risk factors such as exposure to rubella, measles, cytomegalovirus, syphilis, and toxoplasmosis, if they had a traumatic brain injury or if they have genetic conditions such as Down's syndrome (Wiley, 2014; Luft, 2022). Although hearing loss and intellectual disability can coexist, it is crucial to avoid misdiagnosing intellectual disability among D/deaf and hard-of-hearing children (Bruce & Borders, 2015).

1.4 Differentiating intellectual disability from hearing loss

It is also crucial to differentiate between learning and adaptive challenges impacted by a hearing loss and those that are due to the impact of cognitive and adaptive limitations because of an intellectual disability (Simpson, Mizen & Cooper, 2016). Delays in language and reading may be mistakenly attributed to an intellectual disability rather than hearing loss. Hearing loss may be overlooked in children with an intellectual disability because language delays are mistakenly attributed to an intellectual disability rather than possible hearing loss. Poor assessment procedures can result in false identification of an intellectual disability among D/deaf and hard-of-hearing children and adolescents. Assessments must be carried out by a multidisciplinary team made up of individuals who have experience with both hearing loss and intellectual disability (Bruce & Borders, 2015).

Knoors & Vervloed (2010) published in the United States of America (USA), which reported that during assessment of deaf children the inability to obtain sufficient non-distorted information from their environment is frequently confused with their inability to process it. As a result, they recommended that it is critical to avoid using general population norms with deaf and hard-of-hearing children and to provide adequate test instruction. A D/deaf child should be diagnosed with an intellectual disability only when he/she has significant cognitive deficits more than is considered to be the norm for D/deaf children with severe to profound hearing loss (Knoors & Vervloed, 2010).

Once D/deaf and hard-of-hearing children with an intellectual disability are identified, appropriate intervention can be provided. Currently, there is a greater understanding of what being D/deaf means and what it entails, but unfortunately, there are still some individuals who have this misconception which causes bias and prejudice (Orrie & Motsohi, 2018).

1.5 Prevalence of intellectual disability, hearing loss, and the co-occurrence of the two disabilities.

According to the World Health Organization (WHO) and the World Bank, around 200 million individuals worldwide have an intellectual disability (WHO & World Bank, 2011). Studies report that the prevalence of intellectual disability varies between 1% and 3% worldwide. (Maulik et al., 2011; American Psychiatric Association, 2013; McKenzie et al., 2016). According to a study by Emerson (2007), low and middle-income countries have more individuals with an intellectual disability than high-income countries. No epidemiological study on the prevalence of intellectual disability has been conducted in SA. However, Adnams (2010) estimated that intellectual disability affects about 3% of the population in SA, due to the high prevalence of poverty-related avoidable conditions such as nutritional deficiencies, infectious diseases like HIV/AIDS and TB meningitis, foetal alcohol spectrum disorders (FASD), and violence and injuries. In SA, there is a wide range of terms and definitions used for the data collection on intellectual disability, contributing to the problems of accurate data collection and

reporting (Foskett, 2014). The prevalence of intellectual disability is also unclear due to diagnostic overshadowing. This is when behaviours that challenge are incorrectly attributed to be occurring because of an intellectual disability (Simpson, Mizen & Cooper, 2020).

While hearing loss can in many instances be avoidable if there is good quality healthcare and health promotion (WHO, 2012), according to World Health Organization (WHO) there are 1.33 billion D/deaf or hard-of-hearing people in the world, with 473 million having a disabling hearing loss. Hearing loss was estimated to be the fourth leading cause of disability globally (WHO, 2019). According to the WHO, the highest prevalence of disabling hearing loss in children is found in South Asia, the Asia Pacific, and Sub-Saharan Africa. A population-based study in the Cape Metropolitan area of the Western Cape Province of SA, where the current study took place, showed that 12.35 % of 2494 participants (0-3 years to 60 years) had some degree of hearing loss (Ramma & Sebothoma, 2016). Louw et al. (2018) conducted a cross-sectional design study on 1236 participants ranging in age from 3 to 97 years old at two primary healthcare clinics in Tshwane area of the Gauteng province of SA. They discovered a 17.5% prevalence rate of hearing loss across both clinics. Hussein et al. (2018) conducted a study in the community of Mamelodi, which is part of the city of Tshwane, to determine the prevalence of hearing loss in preschool children from a low-income South African community. The participants were 6424 children aged 3-6 years old, and 18.7% of the children had hearing loss. According to this literature, it is clear hearing loss has a high prevalence rate in SA.

In a preliminary overview of the literature for this study, few studies reported the prevalence rate of hearing loss among individuals with an intellectual disability. Most of the research did not utilize a diagnostic audiological assessment and had a small sample size. There were also no studies found in the overview that mentioned the co-occurring prevalence rate of hearing and intellectual disability in SA. Intellectual disability is one of the most common co-occurring disabilities among D/deaf and hard-of-hearing individuals (Davis et al., 2009). According to a study conducted in the Netherlands by Meuwese-Jongejeugd et al (2006), the prevalence of hearing loss was 35.8 % among 1598 participants with an intellectual disability aged 18 and up. The most recent study found was conducted by Herer (2012) at the Special Olympics (SO) from 2004 to 2011 for individuals with an intellectual disability, which included 9,961 SO athletes from around the world between the ages of 18 and 55. Herer's study in 2012 reported that just slightly less than a quarter (23.7 %) of the participants had hearing loss. Although hearing loss is significantly prevalent among individuals with an intellectual disability, according to Herer (2012) and MeuweseJongejeugd et al (2006) studies, hearing loss was previously undetected among 24 % and 47.6 % of the participants, respectively. When an individual with an intellectual disability has a 'visible' physical disability and assessments and interventions prioritise this, signs that indicate the individual may be D/deaf or hard-of-hearing may be overlooked, also resulting

in late identification (Erickson & Quick, 2016). Implementing universal hearing screening is recommended because it can allow for early detection and intervention in children with intellectual disability (Bruce & Borders, 2015).

1.6 Aural rehabilitation

Aural rehabilitation is an umbrella term for intervention techniques that can be used to manage hearing loss (Rutherford & Petersen, 2018). It is defined as the fitting of an assistive device, as well as counselling and therapy that can reduce the communication and psychosocial consequences of hearing loss. Any devices, checklists, or programmes that help improve communication or ease access to auditory stimuli are considered aural rehabilitation tools (Boothroyd, 2007).

A comprehensive approach to aural rehabilitation is recommended and it should consider factors related to the child, the activities that are important to the child, and the child's social and environmental circumstances. Aural rehabilitation in a school setting is provided by audiologists and speech-language therapists. The speech-language therapist would be responsible for providing speech and language therapy for the child. Audiologists create the management plan, coordinate the services provided by the speech-language therapist, and coordinate support provided by the child's teacher. Teachers use the audiologist's recommendations to meet the needs of the child in the classroom and provide feedback on the child's academic performance before and after aural rehabilitation. Caregivers or family members are responsible for implementing aural rehabilitation activities at home (Tye-Murray, 2020). D/deaf and hard-of-hearing children with an intellectual disability often require specialized services in addition to aural rehabilitation services. These services are provided by a multidisciplinary team that may include occupational therapists, social workers, and psychologists (Patel, Pratt & Patel, 2008). When providing these services, family members and caregivers of the child should also be involved. They understand the child's needs better than the audiologist and will be involved in all phases of the child's life. This approach is family-centred, and it allows the child's family to participate in decision-making regarding aural rehabilitation services provided (Nelson et al., 2011).

Aural rehabilitation counselling, sensory management, and communication intervention are the three major components of effective aural rehabilitation. Makhoba and Joseph (2016) developed a framework of aural rehabilitation, which addressed these components. Makhoba and Joseph’s framework is an adaption of Prendergast and Kelley's (2002) list of aural rehabilitation services considered to be appropriate for use in the South African context (Makhoba & Joseph, 2016).

(a) Counselling

Counselling entails providing individuals diagnosed with hearing loss with information as well as psychological and emotional support, for them to effectively deal with the changes and impact brought on by the hearing loss. Informational and psychosocial adjustment counselling are two types of counselling that are used. *Informational counselling* involves providing information on the hearing diagnosis, communication strategies, and management plans (Makhoba & Joseph, 2016). This also includes information about school placement, available support services, and available modes of communication (Moroe, 2018). This information will assist the individual and their family in developing realistic expectations of aural rehabilitation and may address issues of cultural or stereotypical beliefs that may reduce compliance with aural rehabilitation. *Psychosocial adjustment counselling* focuses on addressing the psychological and social impact of hearing loss on the D/deaf or hard-of-hearing individual, their family members, and their peers. Psychosocial adjustment counselling aims to optimize the client's emotional well-being and progress after receiving aural rehabilitation, since a decline in psychological or emotional well-being is associated with communication challenges (Makhoba & Joseph, 2016). This information is also crucial for D/deaf and hard-of-hearing individuals with a coexisting intellectual disability, as well as their families (Syed, Awan & Syeda, 2020).

(b) Sensory management

Sensory management includes the fitting of behind-the-ear (BTE), in-the-ear (ITE), in-the-canal (ITC), completely-in-the-canal (CIC), bone conductor (BC), contralateral signal routing (CROS), bilateral contralateral signal routing (BiCROS), body hearing aids as well as bone-anchored hearing aids (BAHA). Hearing aids are the most used sensory management device in South Africa because they are cost effective and can be used to manage a wide range of hearing losses (Makhoba & Joseph, 2016). Sensory management can also be in the form of the middle ear, auditory brainstem, or cochlear implants (Rutherford & Petersen, 2018). Sensory management is selected based on the type, severity, and cause of the hearing loss (Rutherford & Petersen, 2018).

Sensory management with cochlear implants is recommended for deaf children with an intellectual disability who, due to the severity of their hearing loss, and who receive little or no benefit from hearing aids. Cochlear implants improve their chances of developing age-appropriate speech and language skills (Youm et al., 2013; Bhamjee. et al., 2021).

Audiological, medical, rehabilitation, and financial criteria are used to determine cochlear candidacy at Tygerberg Hospital Cochlear Implant Unit in the Western Cape, South Africa which is based on South African Cochlear Implant Group's (2020) quality standards for cochlear implantation. The audiological criteria includes children six months and older with prelingual severe to profound sensorineural

hearing loss and with inadequate spoken language, older children with postlingual severe to profound sensorineural hearing loss whose primary communication mode is spoken language and who have received minimal to no benefit from bilateral hearing aids. The medical criteria stipulate that children must have an intact auditory nerve, cochlear patency for electrode insertion and that children are able to be implanted safely with minimal risks. Rehabilitation criteria require that the child and family members be highly motivated for the cochlear implant, and that they must commit to long-term aural rehabilitation and speech therapy. Children and their family members should have realistic expectations about the potential benefits of cochlear implantation. The financial criteria require families to demonstrate their financial ability to support the cochlear implant device's long-term maintenance and aural rehabilitation sessions (South African Cochlear Implant Group, 2020). Cochlear implant centres are based mostly in urban areas, thus additional traveling funds are required to access these services for individuals living in peri-urban and rural communities (Rutherford & Petersen, 2018).

Frequency modulation (FM) systems are a common additional tool used with hearing aids or cochlear implants. FM systems use wireless radio frequencies to transmit auditory signals from its microphone into the hearing aid's receiver. They are commonly used in schools by deaf and hard-of-hearing children because they allow the child to hear what the teacher is saying while reducing or eliminating background noise (Makhoba & Joseph, 2016).

D/deaf and hard-of-hearing children with coexisting intellectual disability can also benefit from sensory management in the form of hearing aids and cochlear implants (Nelson & Bruce, 2019). Trevisi et al., (2016) conducted a retrospective study in Italy with 31 children with CHARGE syndrome, which is an abbreviation for several conditions common in this syndrome, including coloboma, heart defect, atresia, retarded growth and development, genital abnormality, and ear abnormality. Their findings revealed that D/deaf or hard-of-hearing children with mild intellectual disability who used hearing aids on a long-term basis improved their social functioning, language skills, and academic progress (Trevisi et al., 2016). Similarly, a systematic review conducted in Ireland by Boot et al (2018) reported that when D/deaf or hard-of-hearing individuals with a coexisting intellectual disability were successfully fitted with appropriate hearing aids, their communication improved, and behaviours that challenge became less frequent than before the fitting.

According to a systematic review conducted in the USA by Wiley (2014) the severity of an intellectual disability negatively impacts speech and language outcomes. Increased cognitive deficits are associated with poorer language outcomes following hearing aid fitting and cochlear implantation (Wiley, 2014). Children who are deaf and present with a mild intellectual disability showed improved auditory perception and language acquisition after cochlear implantation; some of their speech and language outcomes were comparable to deaf children without any additional disabilities. Children with

moderate intellectual disability showed a limited gain post cochlear implantation. They made very slow progress and remained in the very early stages of auditory, speech, and language development (Youm et al., 2013). One of the recommendations for aural rehabilitation when dealing with D/deaf or hard-of-hearing children with an intellectual disability, is that aural rehabilitation should be tailored to their needs and modified to the child's cognitive abilities to improve language outcomes (Wiley, 2014).

Some Deaf individuals feel that the use of cochlear implants is intended to 'fix' deafness, which makes them feel unaccepted (Bernicchia-Freeman, 2018). According to a systematic review conducted by Bernicchia-Freeman (2018) in USA, to increase openness to cochlear implants in the Deaf community, the views and motivations of the patient and the patient's family for cochlear implants should be addressed. Cochlear implants are best received when viewed as a means of increasing or facilitating meaningful interactions between the hearing and Deaf community, rather than as a "cure" or "fix" for deafness (Marti & Recupero, 2019).

Audiologists should understand, accept, and support the Deaf community. In 2019, the Health Professions Council of South Africa (HPCSA) issued practice guidelines for audiologists who work with D/deaf and hard-of-hearing individuals. They emphasized that audiologists must provide contextually relevant audiological services within their scope of practice, as well as assessments and interventions that consider the influence of culture and linguistic diversity. They also emphasized the need for more audiology training that focuses on providing audiological services to Deaf individuals, as well as more research on audiological services for Deaf individuals in a local context to support contextually relevant practice (Health Profession Council of South Africa, 2019).

(c) Communication intervention

Communication intervention entails assisting an individual in effectively communicating if they are born deaf or hard-of-hearing, or if they develop a hearing loss later in life. Its purpose is to help individuals improve their communication abilities by providing communication strategies that can be used together with assistive technology (Makhoba & Joseph, 2016). Auditory training, which is part of communication intervention, is the deliberate and systematic presentation of sounds to teach listeners to make perceptual distinctions between those sounds. It aims to improve the patient's ability to listen effectively during everyday discussions (Makhoba & Joseph, 2016; Rutherford & Petersen, 2018). Speech-reading and lip-reading training consist of learning how to use audio-visual skills effectively to improve communication. Communication partner training entails teaching communication partners how to communicate effectively with a deaf or hard-of-hearing individual (Makhoba & Joseph, 2016). Increased responsiveness, appropriate pacing, and the use of pauses when communicating are strategies that are provided during communication partner training (Beukelman & Mirenda, 2013). The

communication partner training is intended to change how communication partners approach and respond to deaf or hard-of-hearing persons with an intellectual disability to improve communication (Friedman & McNamara, 2018). There are also computer-assisted aural rehabilitation tools available, but they are mostly internationally developed therefore they are contextually inappropriate for the South African context (Rutherford & Petersen, 2018). Bruce & Nelson's (2019) systematic review in the USA reported that communication intervention was also found to improve the communication, cognitive, and reading skills of D/deaf and hard-of-hearing people with a coexisting intellectual disability.

It is also possible to improve speech intelligibility, language skills, and pragmatics of D/deaf and hard of-hearing individuals with an intellectual disability using current aural rehabilitation tools like Augmentative and Alternative Communication (AAC) systems. AAC systems are methods that can be used to supplement or replace speech during communication (Davis et al., 2009). AAC encompasses all modes of communication other than verbal speech, and is used to express thoughts, desires, and needs. Common AAC systems can be classified as aided or unaided. Unaided AAC methods do not require additional materials or objects (e.g. use of manual signs), whereas aided AAC methods do require them (e.g. computer devices that can generate speech). The use of different AAC systems for individuals with an intellectual disability can also increase the likelihood of social interactions with other individuals (Davis et al., 2009; Friedman & McNamara, 2018).

1.7 Approaches to aural rehabilitation

In SA, auditory and visual intervention approaches to aural rehabilitation are used in public health care. *Auditory approaches* include auditory-verbal therapy (AVT), oral-aural approach, and cued speech. AVT is an approach to listening and spoken language that encourages children with hearing loss to use hearing as their primary source of sensory input when trying to develop their speech production skills, to fully integrate them into society. The oral-aural approach includes the use of amplification devices such as hearing aids, speech or lip-reading training, body language, and gestures. In cued speech, manual gestures are used in conjunction with speech. Sign language and total communication are examples of *visual approaches*. Sign language focuses on using the visual-manual modality to convey meaning rather than spoken words. Total communication entails the use of both visual and auditory communication methods (Casoojee, Kanji & Khoza-Shangase, 2021).

There are important considerations when teaching sign language to Deaf children with an intellectual disability and those considerations include the severity of intellectual disability, short-term memory skills, the ability to physically form signs, and the environment. As a result, it is recommended that signs might need to be adapted, and other communication methods such as AAC used to supplement

these signs (Nelson & Bruce, 2019). AVT is the most common intervention approach used in SA and high-income countries. Khoza-Shangase & Michal (2014) conducted a retrospective study in SA in public hospitals in Gauteng and discovered that 48.57 % of children with hearing loss received AVT intervention, 18.57 % of children with hearing loss received sign language intervention, and 11.43 % of children with hearing loss received total communication intervention.

1.8 Objective and subject measures for aural rehabilitation

The goal of any aural rehabilitation plan is to improve the communication capabilities of D/deaf and hard-of-hearing children and adolescents with an intellectual disability. Sensory management is only one aspect of the intervention. It is recommended that audiologists provide follow-up services for all D/deaf and hard-of-hearing children, including objective and subjective outcome measures. This is essential for this population. This is because they are often unable to provide reliable subjective evaluations of their hearing aid or cochlear implant use, have challenges in academic performance, speech, and language development, and listening difficulties that are still present post-hearing aid fitting or cochlear implantation (Meinzen-Derr et al., 2009; Tye-Murray, 2020).

Objective outcome measures include speech recognition tests that aim to validate the benefit of cochlear implants and hearing aids. The ability to perceive, recognize, and understand speech messages is defined as speech recognition or speech perception. Speech recognition testing evaluates one's ability to recognize speech (Tye-Murray, 2020). Children who are deaf and hard-of-hearing who also have an additional disability such as intellectual disability, also require monitoring of their auditory development. Children with more severe intellectual disability may be unable to perform these speech recognition tests.

Subjective outcome measures in the form of parent and teacher report measures may be more appropriate for obtaining information about thebenefit from cochlear implants and hearing aids for children with a severe intellectual disability (Meinzen-Derr et al., 2009). These include parent, teacher, and self-report measures in the form of checklists and questionnaires. They may be used to identify key areas that need to be addressed in aural rehabilitation, and to validate the outcomes of aural rehabilitation. The low literacy and cognitive demands of these self-report measures make them more appropriate for individuals with an intellectual disability (Pienaar, Stearn & Swanepoel, 2010; Meyer et al., 2016). They can also help audiologists evaluate activity limitations, participation restrictions, and contextual factors for children with hearing loss. Examples of self-report measures include the Paediatric Abbreviated Profile of Hearing Aid Benefit (PAPHAB), the Parent's Evaluation of Aural/Oral Performance of Children (PEACH), and the Teachers' Evaluation of Aural/Oral Performance of Children (TEACH) (Cupples et al., 2013; Meyer et al., 2016). These subjective outcome measures are useful and

recommended for determining the progress of hearing and language development in a listening situation for a deaf or hard-of-hearing child with an intellectual disability (Meinzen-Derr et al., 2009).

1.9 The impact of early intervention

Early detection and intervention before the age of six months are essential for normal speech and language development in D/deaf or hard-of-hearing children who do not have an additional disability, as well as those children who have a mild intellectual disability (Lee et al., 2010; Khoza-Shangase & Michal, 2014). Hearing loss that goes undetected and unmanaged has serious consequences, which is more pronounced in children with an intellectual disability. It can negatively affect already compromised cognitive development, communication, social interactions, and vocational aspirations (Herer, 2012). It can also lead to an increased risk of embarrassment, loneliness, depression, prejudice, abuse, and disruptive behaviour due to communication frustration (Abbas, 2015). Early intervention through aural rehabilitation creates an enriched language environment and promotes optimal language learning during a critical developmental period. Besides language acquisition, aural rehabilitation is also important for speech, cognitive, and psychosocial development (Stewart & Bentley, 2019).

1.10 Language acquisition in D/deaf and hard-of-hearing children with an intellectual disability

Language acquisition is the process by which children gain fluency in their native language. Access to auditory stimuli, cognitive abilities, socioeconomic status, and the quantity of "adult talk" around and with the child, as well as exposure to language use in a social context, all influence a child's ability to acquire language (Hutauruk, 2015; Safitri, 2020). Language develops naturally in young children, with the process of learning a language before the age of five known as the Golden age of language acquisition (Hutauruk, 2015). The acquisition of a foreign or second language, whether taught systematically in school or not, takes a very different path. Some older children who begin learning a second language often fail to achieve fluency, whereas younger children who are exposed to a second language appear to be as fluent in the second language as native speakers (Hutauruk, 2015; Safitri, 2020).

According to Chomsky (2009), the process of language acquisition is biologically determined, and human beings have developed a brain in which the neural circuits contain linguistic information at birth. Hearing speech activates the child's natural proclivity to learn a language, and the child's brain can interpret what she or he hears based on the underlying principles or structures it already possesses. This natural ability is called the Language Acquisition Device (LAD) (Chomsky, 2009). Moreover, the functioning of language ability is optimal at a certain "critical period" of intellectual development (Chomsky, 2009).

A systematic review conducted in the USA by Secora & Smith (2021) reported that bimodal/bilingual children who are exposed to both spoken and sign Language perform better overall than children who are only exposed to spoken or sign language. Bimodal bilingual language use is associated with improved language and social skills. Children exposed only to spoken language only outperformed those exposed to both spoken and sign language in terms of speech intelligibility, auditory reception, and grammatical closure (Hutauruk, 2015; Secora & Smith, 2021). D/deaf and hard-of-hearing children with additional disabilities, such as an intellectual disability, who are exposed to spoken and sign language have similar benefits from bimodal language exposure, although their outcomes are generally poorer than those of D/deaf and hard-of-hearing children without an additional disability. For optimal language development it is more beneficial to expose this population to sign and spoken language (Secora & Smith, 2021).

1.11 Provision of audiology services for children with an intellectual and hearing disability

The provision of audiology services for children and adolescents is done in the child's social context. The home and school context are the two primary contexts that are taken into consideration in the planning and implementation of audiology assessments and interventions. In Pakistan, Syed, Awan, and Syeda (2020) conducted a comparative cross-sectional survey from July 2018 to February 2019 of 162 parents of children who are D/deaf and hard-of-hearing and have a coexisting intellectual disability. They found that there is an increased caregiver burden experienced by parents caring for D/deaf or hard-of-hearing children with a coexisting intellectual disability. Increased financial implications, household disruptions, and restrictions to other relationships with individuals outside and within the family can all contribute to the caregiver burden. They emphasized that attempting to communicate with a child who has both disabilities can result in social isolation, grief, depression, disappointment, and anger, exacerbated when these caregivers do not receive appropriate training and support. Their study found that it is crucial to provide comprehensive information on how the affected child will be managed, as well as appropriate cochlear implants or hearing aids, communication approaches, educational methods, and school placements, to reduce caregiver burden (Syed, Awan & Syeda, 2020).

In a school environment, educational audiologists help children with hearing loss by advising teachers on how to accommodate students in the classroom and ensuring that the student has assistive hearing devices which enhance a student's listening environment and allow them to access the curriculum. They are primarily concerned with providing aural rehabilitation to students so that their hearing loss does not interfere with their academic performance and communication abilities (McNamara & Macione, 2011). Selecting and fitting hearing devices such as hearing aids and FM systems, as well as offering communication intervention, are all part of the aural rehabilitation services provided by an

educational audiologist. They are also in charge of delivering informational and psychological adjustment counselling to students and their families. They also offer students with cerumen management, if necessary (Wium & Louw, 2015). These audiology services are scarce in low and middle-income countries, particularly on the African continent (Makhoba & Joseph, 2016).

1.12 Inclusive education in special needs schools in SA

Many of the challenges that existed during Apartheid continue to exist in the special needs education system in SA. During Apartheid, schools were divided by disability and race. Special needs schools that served white disabled students had more resources than the few schools that served black disabled students. Children with learning disabilities and those living in extreme poverty did not qualify for educational assistance, leaving only children with medical disabilities eligible. Decades of segregation and systematic under-resourcing of schools that served black disabled students are still visible, with imbalances seen in special needs schools in SA (Department of Education, 2001).

On an international level, article 24 of the UNCRPD recognizes the right of children with disabilities to education. Children with disabilities, including those with intellectual and hearing disabilities, have the right to an education that is free of discrimination and based on equal opportunity. According to Article 24 of UNCRPD, these children should not be excluded from the general education system because of their disability. They should have access to education equal to the rest of the community, with such provided with reasonable accommodations and support to maximize academic and social development. To achieve these goals, appropriate measures should be taken to hire and train teachers of Deaf children and other staff to use sign language, educate staff about disability awareness, the use of AAC, modes of communication, educational techniques, and special materials to assist children with disabilities (UNCRPD, 2006).

On a national level, the Integrated National Disability Strategy (INDS) was adopted by the South African Cabinet in 1997. The INDS set out to change attitudes and remove social barriers that prevent people with disabilities from living full lives, as well as to take a person-centred approach to address issues unique to people with disabilities to ensure their inclusion in all aspects of life. INDS represents a paradigm shift in that it depicts disability as a social rather than a medical condition. It sees disability as a socio-political construct in which hostile communities and social attitudes lead to the exclusion of people with disabilities. The INDS and White paper 6 policy on inclusion education was implemented in 2001 (Department of Education, 2001; Kruger, 2015).

The Ministry of Education implemented White Paper 6 on special needs education building, inclusive education, and training systems. This policy focuses on creating a system that accommodates and respects diversity in inclusive education and training. According to White Paper 6, educational support

will be provided to disabled students. It aims to provide equal but separate education with additional support for children with disabilities. Interventions and strategies for inclusive education should be implemented at the school, district, provincial, and national levels. These interventions and strategies should aim to reduce or eliminate learning barriers that result in learners being excluded from the curriculum, as well as education and training centres. To achieve inclusivity nationally, the Departments of Health, Social Development, and Public Works must work together (Department of Education, 2001).

The Western Cape Forum of Intellectual Disability filed a case in the Western Cape High Court against the Government of the Republic of South Africa and the Government of the Province of Western Cape due to the government's failure to provide children with severe and profound intellectual disability with access to a appropriate education. Informal education and support for this population was available at a limited number of nongovernment organization (NGO) special care centres at the time of this case. These educational provisions for were inadequate when compared to education in schools for children with mild and moderate intellectual disabilities, and for children with other disabilities. The High Court ruled in 2010 that the State had failed to take reasonable steps to meet the educational needs of children with severe and profound intellectual disability in the Western Cape. This was in violation of these children's rights to basic education, equality, human dignity, and protection from neglect or degradation, as highlighted in the Constitution of the Republic of South Africa. The Court ordered the State to take reasonable measures to give effect to these children's rights. White paper 6 was central in the decision made in this case by the Western Cape High Court and this case signaled the start of holding the state accountable for providing education for all children (Kruger, 2015). At the time of the study, however, actions taken to provide education for these children still fall short of the constitutional order.

1.13 The rationale for the study

Most of the research on aural rehabilitation for D/deaf and hard-of-hearing individuals found in the preliminary overview of the literature did not consider a coexisting intellectual disability. Where research on aural rehabilitation for D/deaf and hard-of-hearing individuals with an intellectual disability is available, most of it focused on amplification devices and cochlear implants and was conducted in high-income countries. There is limited research on other aspects of a comprehensive service, such as informational and psychosocial adjustment counselling, as well as communication interventions, which are necessary for providing holistic and contextually relevant aural rehabilitation (Makhoba & Joseph, 2016).

There is very limited research on aural rehabilitation practices and tools in SA, particularly for D/deaf and hard-of-hearing individuals with a coexisting disability such as an intellectual disability (Rutherford

& Petersen, 2018). Given SA's cultural and linguistic diversity, it is crucial to provide contextually relevant aural rehabilitation practices and tools (Makhoba & Joseph, 2016). The primary goal of this research was to explore aural rehabilitation practices and tools utilized on D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability and their guardians as well as their caregivers in South African schools for the D/deaf. This information gathered will be used to make preliminary recommendations for future practice and research on aural rehabilitation for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in South African schools.

1.14 The conceptual frameworks for the study

In this study two conceptual frameworks underpinned the framing, analysis, and interpretation of the study findings. These two conceptual frameworks are the World Health Organization's International Classification of Functioning, Disability, and Health framework (ICF) and Makhoba & Joseph's (2016) framework of aural rehabilitation. The review of the literature highlights the need to holistically consider individual, environmental, and personal issues which might interact to enable or disable a person's participation in various life roles and activities. The ICF is a framework for conceptualizing a person's health and disability in relation to a health condition. The ICF consists of two parts: functioning and disability, and contextual factors. Functioning and disability consists of body structures and function as well as activities and participation, whereas contextual factors consist of personal and environmental factors (Figure 1).

The framework focuses on health and health-related domains and can be used to describe changes in the structure and function of the body. The ICF also describes an individual's ability to participate in activities within their environment, as well as any difficulties they may have when carrying out their daily activities and participating in their roles in life. The ICF adopts a bio-psychosocial model of disability, including elements of both the medical and social model of disability (World Health Organization, 2002).

The medical model of disability emphasizes the individual's impairment in functioning, whereas the social model of disability recognizes that disability occurs within and is influenced by the degree to which environmental supports and accommodations are made available to assist a person with impairments associated with a health condition or illness (Goering, 2015).

In addition to providing accessible services and activities, and mainstreaming disability to ensure full inclusion of individuals with disabilities as equals, the social model recognizes attitudinal and structural barriers in the environment that disable the individual, highlighting the need for broader systemic and attitude changes in society (Du Plessis, 2013; Retief & Letsosa, 2018). This framework holds that each

patient may have similar degrees and types of hearing loss, but the effects of the hearing loss and response to aural rehabilitation will differ. This happens because the impact of hearing loss and reactions to aural rehabilitation is dependent on the kinds of activities performed by the patient, their societal roles, and the environment in which they live (Meyer et al., 2016)

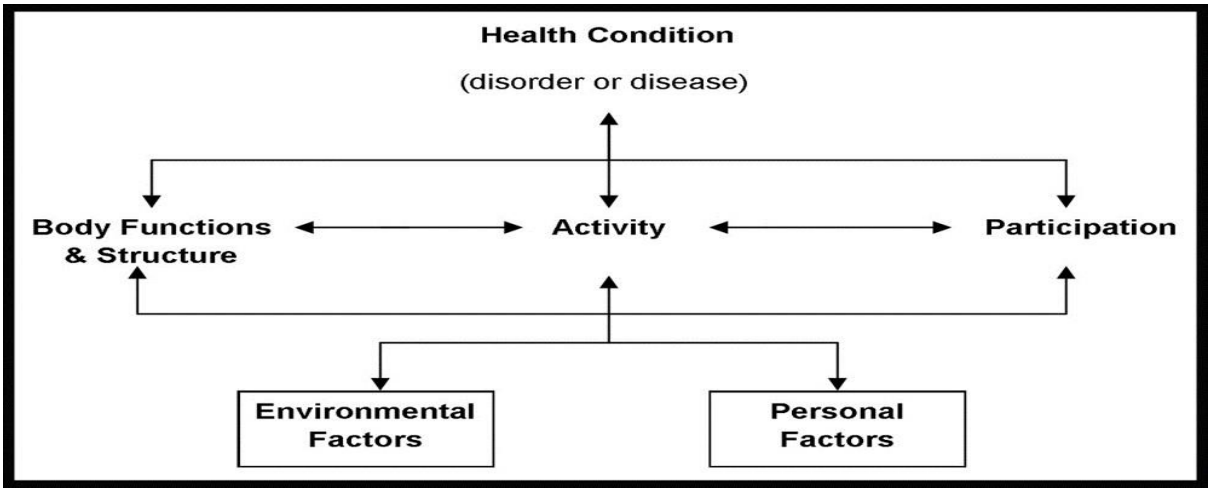

Figure 1: Interactions between the components of ICF (WHO 2002:18)

In addition to the ICF framework, Makhoba & Joseph's (2016) framework (Figure 2) will also be used to guide the study. This framework contains the 3 components of aural rehabilitation: 1) counselling, which includes information and psychosocial adjustment counselling, 2) a sensory management technology, which includes the fitting of hearing aid, cochlear implants, and FM systems, and 3) communication intervention, which includes auditory training, communication strategies, frequent communication partner training, and speech-reading or lip-reading training (Makhoba & Joseph, 2016).

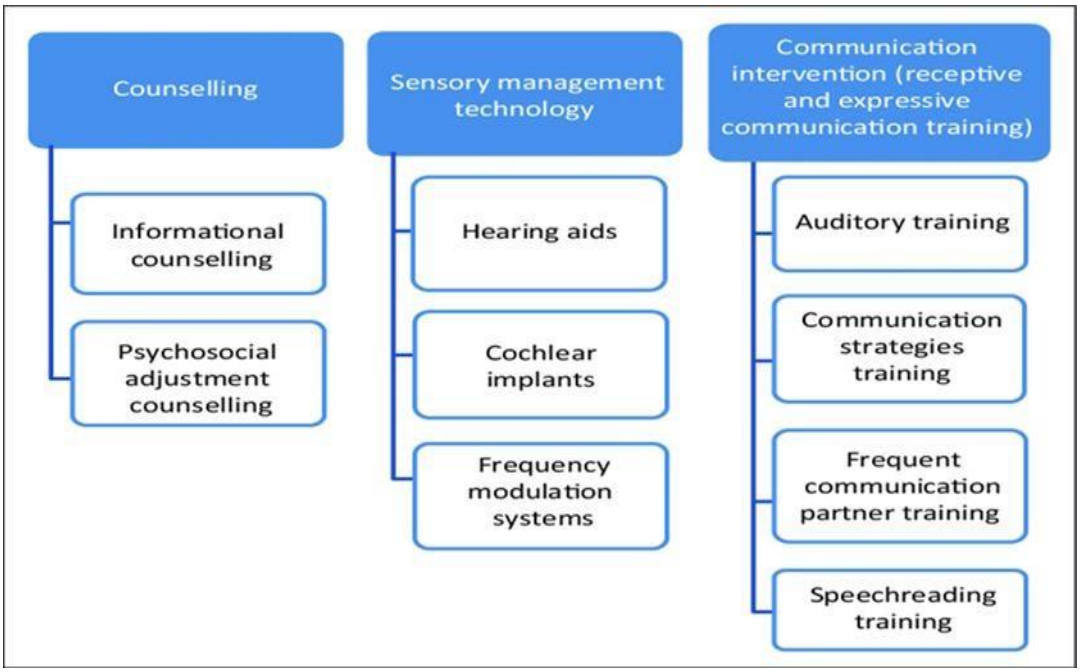

Figure 2: Aural rehabilitation components and services (Makhoba & Joseph, 2016, p. 2)

1.15 Aim

The study aimed to explore aural rehabilitation practices and tools utilized on D/deaf and hard-of-hearing children and adolescents and with a coexisting intellectual disability from the perspective of young adults who experienced these services, their caregivers, and audiologists working in public schools for the D/deaf in the Western Cape, South Africa.

1.16 Research questions

The primary research question is: What are the experiences of D/deaf and hard-of-hearing young adults with intellectual disability, and the perceptions of their caregivers and audiologists on aural rehabilitation practices and tools utilized in public schools for the D/deaf in the Western Cape, South Africa?

Sub questions:

a) What are the experiences and perceptions of audiologists regarding aural rehabilitation practices and tools historically and currently available for D/deaf and hard-of-hearing young adults with a coexisting intellectual disability in the Western Cape?

b) What are the experiences of these young adults regarding aural rehabilitation practices and tools which were utilized on them?

c) What are the experiences and perceptions of guardians of these young adults regarding aural rehabilitation practices and tools that were utilized on the young adults?

1.17 Objectives

Objective 1: Identify literature on aural rehabilitation practices and tools for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in low, middle, and high-income countries through a scoping review.

Objective 2: Interview audiologists to gather information on their experiences and perceptions on aural rehabilitation practices and tools historically and currently available for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in the Western Cape.

Objective 3: Interview young adults to gather information on their experiences of aural rehabilitation practices and tools utilized on them.

Objective 4: Interview the guardians and caregivers of these young adults to gather information on their experiences and perceptions of aural rehabilitation practices and tools utilized on the young adults.

This thesis consists of five chapters. Chapter one covers the introduction, background to the study, rationale for the study, the conceptual frameworks for the study, the aim of the study, research questions and objectives.

Chapter two outlines the study methodology, including research design, the study setting, the researcher stance, the study population, sampling methods, consent procedures, data collection methods, and data analysis. It will also include a section on how research rigour was ensured, and ethical considerations taken when the study was conducted.

Chapter three reports on the findings of the scoping review of literature on aural rehabilitation practices and tools utilized on D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability (objective 1).

Chapter four reports on the findings of the semi-structured interviews conducted with participants in this study, specifically audiologists (objective 2), young D/deaf adults with intellectual disability (objective 3) and caregivers (objective 4).

Chapter five discusses the findings of the study, the implications and limitations of the study, and recommendations from the research.

Chapter two: Methodology

Introduction

This study is a qualitative exploration of the current evidence on, and views of young adults, their caregivers, and audiologists on audiological rehabilitation practices to inform contextually appropriate understanding of ways in which school-based audiological services for D/deaf and hard-of-hearing children and adolescents may be improved in the South African context.

2.1 Research design

Qualitative research allows the researcher to best document the in-depth experiences of participants. Qualitative research explores participants subjective views of the study phenomenon, views which can bring a depth of perspective to our understanding of the phenomenon of study (Creswell, 2003; Reiners, 2012; McMillan, 2016). This study is qualitative by design as it aims to expand understanding of the research question through an in-depth exploration of what researchers have already found in relation to the topic in international and local contexts (through a scoping review) and through documenting current views of people who have experience of the phenomenon of study in the South African context (through semi-structured interviews). In-depth interviews allow for the collection of rich, descriptive data about how people think and behave (Rendle et al., 2019).

There are several approaches which may be taken in qualitative research (Creswell, 2003), and this study has taken a phenomenological approach to explore the research question. The views of Edmund Husserl, a 20th century philosopher thought to be the "Father" of phenomenological enquiry, have been interpreted by researchers to mean that there is a need to "bracket" (set aside) one's own lived experience during research, if the novel representations of the study is to be captured accurately during the research process, (Reiners, 2012) Martin Heidegger, a student of Husserl, was of the alternative view that it is not possible to simply bracket off one's experience, which he postulated would inevitably impact on an individual's perspective on the world, including the research process. Heidegger's interpretative phenomenology posits that the researcher is a person who not only interprets the research area in context, but is also interpreted by that context (Reiners, 2012).

Taken from the latter perspective, then, qualitative researchers then, may be seen as the "key research instrument "in qualitative research as they bring their own unique subjectivity to the research process.

All the research decisions and processes are filtered through his, her or their worldview, with their perspectives on the research question, the participants in the study, and the processes used to conduct the study all possibly influencing the findings of the study. Insight into the researcher orientation to the study topic, as well as an in-depth description of research processes and procedures selected to answer the research question can bring transparency to the research undertaking, noting measures taken by the researcher to ensure integrity of data collection, trustworthiness of the interpretation-of the data, and the credibility of the results and conclusions drawn from the research process.

Data collection and analysis processes outlined below for each objective of the study are compatible with the interpretive phenomenological approach of constant reflection and sense-making of the interaction between the researcher and study participants and between the researcher and the data, as the researcher attempts to intuit the meanings implicit in the data. This approach generally involves developing a sense of the data as a whole, then unpacking the data in detail to identify themes, and interpreting and synthesising the data as a particular understanding of the study phenomenon, reviewing the interpretation in terms of what it portrays relative to the research question and available literature and critically reflecting on the implications of the findings.

2.2 Researcher positionality and research assistants

Here, as the researcher for the study, I provide a brief introduction to myself, my orientation to and interest in to the topic, and what I perceive to be the impact my positionality brings to the study. I am an audiologist currently registered with the Health Professions Council of South Africa (HPCSA). I reside in Cape Town,in the Western Cape Province, where the study took place. I spent a year completing my community service at St Andrew's Hospital based in a rural area in another province, KwaZulu-Natal, South Africa. During that time, I was involved in diagnosing and managing paediatric and adult patients with hearing loss and multiple disabilities, including intellectual disability. The challenges faced when providing aural rehabilitation to D/deaf and hard-of-hearing patients with an intellectual disability inspired me to research this topic. My knowledge on aural rehabilitation and my experience in working as an audiologist with both children and adults with an intellectual disability and co-existing hearing loss stood me in good stead to conduct this research. I had received clinical training at schools for the D/deaf in Cape Town while I was completing my undergraduate degree. This background provided me with some knowledge with regards to the study sites.

I was able to fluently conduct interviews with the participants in English and isiXhosa. While I also understand basic SASL, my skills are not at a level that is suitable to interview sign language users independently. As this research study also included interviewing Deaf participants who are sign

language users, a SASL interpreter provided research assistance during the interviews. Since this study also included participants who communicated in Afrikaans the SASL interpreter selected was able to communicate and translate in English and Afrikaans as well. The SASL translator is recognized as an accredited SASL translator with the Deaf Federation of South Africa (DeafSA) in the Western Cape. DeafSA is a non-profit organization in South Africa. They conduct Deaf awareness and outreach programmes, as well as an early intervention programmes that provides psycho-social support services to Deaf individuals and their families, such as group therapy and life skills workshops. They also help Deaf individuals secure employment. They help with advocacy and language support in terms of interpreting SASL (DeafSA, 2018). The SASL interpreter currently works for a nongovernmental organisation, the Deaf Community of Cape Town (DCCT), and she freelances in her spare time. She has experience in interpreting interviews for Deaf individuals in Cape Town, especially children and adolescents in schools for D/deaf.

I was also assisted by a research assistant (VB) to code and co-analyse the data collected from the interviews. This research assistant is a Master's student at another South African university and is also an HPCSA registered audiologist who provides aural rehabilitation at a public hospital.

An experienced transcriber was recruited from the UCT Health Sciences writing lab to assist me with transcribing the two parent interviews.

Introduction to the scoping review

A preliminary overview of the literature on aural rehabilitation practices and tools was used to assess and manage D/deaf children and adolescents yielded very sparse literature which could usefully inform the current study. Scoping reviews are generally used as a systematic way to identify available evidence already produced through research on a particular topic (Munn et al, 2018). The purpose of this scoping review, therefore, was to review the current literature on aural rehabilitation practices and tools for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability (objective 1).

2.3 Method for the conduct of the scoping review

The scoping review framework of Arksey & O'Malley (2005) was used to guide the conduct of the review. This framework comprises 6 stages, specifically:

1. Identify the research question
2. Identify relevant literature
3. Select relevant studies

4. Extracting, mapping, and charting the data
5. Summarise, synthesize, and report the results
6. Integrate expert consultation

Arksey and O'Malley's stages for the conduct of a scoping review are elaborated below.

Stage 1: Identifying the research question

The research question for the scoping review was: What are the current aural rehabilitation practices and tools utilized with D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in low, middle, and high-income countries?

Stage 2: Identifying relevant studies

An appointment was made with the University of Cape Town Health Sciences Faculty librarian to refine the databases and Medical Subject Heading (MeSH) search terms to be used, to ensure that the most relevant studies were sourced.

a. Selecting databases

In consultation with the librarian, the following online databases were selected as appropriate databases to search for published peer-review journal articles relevant to the review: EBSCOhost (Academic Search Premier, Africa- Wide, MEDLINE, CINAHL, and Psych INFO), PubMed, Web of Science, and Scopus. MeSH terms or equivalent terms were used to search for the articles on these online databases.

b. Establishing search terms

The researcher and librarian refined the initial search terms and MeSH terms. Since aural rehabilitation implies the existence of a hearing loss, the following search terms were excluded: ''deaf'' OR '' Deaf'' OR ''hard of hearing'' OR ''hearing impairment'' OR ''hearing loss''. The following MeSH terms were used to search on PubMed and CINAHL:

- intellectual disability OR mental retardation AND
- child OR preschool OR child OR adolescent AND
- correction of hearing impairment OR hearing aids OR cochlear implants OR communication aids for disabled

The following search terms were used to search databases on EBSCOhost, Scopus, and Web of Science

- ''intellectual disability" OR ''mental retardation" AND

- ’children’’ OR ‘’adolescents’’ OR ‘’youth’’ OR ‘’child’’ OR ‘’teenager’’ AND
- ‘’aural rehabilitation’’ OR ‘’auditory training’’ OR ‘’communication training’’ AND
- ‘’ hearing aid’’ OR ‘’hearing devices’’ AND
- ‘’cochlear implant’’ OR ‘’cochlear implantation’’ AND
- ‘’practices’’ OR ‘’ strategies’’ OR ‘’approaches’’ OR ‘’tools’’ OR ‘’instruments’’ OR ‘’scales’’ OR ‘’questionnaires’’

c. Setting inclusion and exclusion criteria

The following parameters were set for the inclusion and exclusion of studies for the review.

Inclusion criteria	Exclusion criteria
Full-text qualitative, quantitative, and mixed method peer-reviewed studies focusing on	Studies that focus solely on aural rehabilitation practices and tools for D/deaf and hard-of-hearing
aural rehabilitation practices and tools used with D/deaf and hard-of-hearing children and adolescents with an intellectual disability. Studies that focused on aural rehabilitation practices and tools for children and adolescents with a disability, which disaggregated data for intellectual disability.	Studies on children and adolescents without an intellectual disability but which mentioned other disabilities were excluded, because practices and tools that are appropriate for that population may not be appropriate for D/deaf and hard-of-hearing children and adolescents with an intellectual disability. Studies on aural rehabilitation practices and tools used with D/deaf and hard-of-hearing adults with an intellectual disability were excluded because this study specifically focuses on a child and adolescents population. Grey literature was excluded because the current study was a time-limited mini-thesis which did not permit a comprehensive search which included grey literature.

Studies published in English.	Studies not published in English and full text were excluded.
Studies published from 1 January 1997 to 31 January 2022, without any restriction by country. This timeframe was used because most studies focusing on a holistic approach to aural rehabilitation date back to 1997 (Boothroyd, 2017).	Studies published before 1997 were excluded as they did not focus on a holistic approach to aural rehabilitation.

Stage 3: Process for identifying relevant studies for inclusion

After the main researcher (SM) searched all databases, five hundred and ninety-one articles were identified. There were four hundred and fifty-one articles left after duplicates were removed. SM and a research assistant (VB) screened the abstracts of the articles independently and then conferred to compare their lists. Forty articles were deemed relevant. Full-text articles were retrieved for all forty studies and were then read by both the researcher and research assistant. This was followed by a comparison of the independent lists, and finalisation of the list of relevant articles by consensus. Twelve articles met the inclusion criteria. The twelve articles were all retained after the full-text articles were re-checked to ascertain whether all articles that fully met the inclusion criteria were included. The reference lists of the twelve included articles were then reviewed. Seven further articles were sourced from a review of the reference lists of the twelve articles and reviewed for suitability for inclusion. Three of these met the criteria for inclusion. This scoping review therefore included fifteen articles.

Figure 3 below summarises the process followed to source and determine the included papers for review.

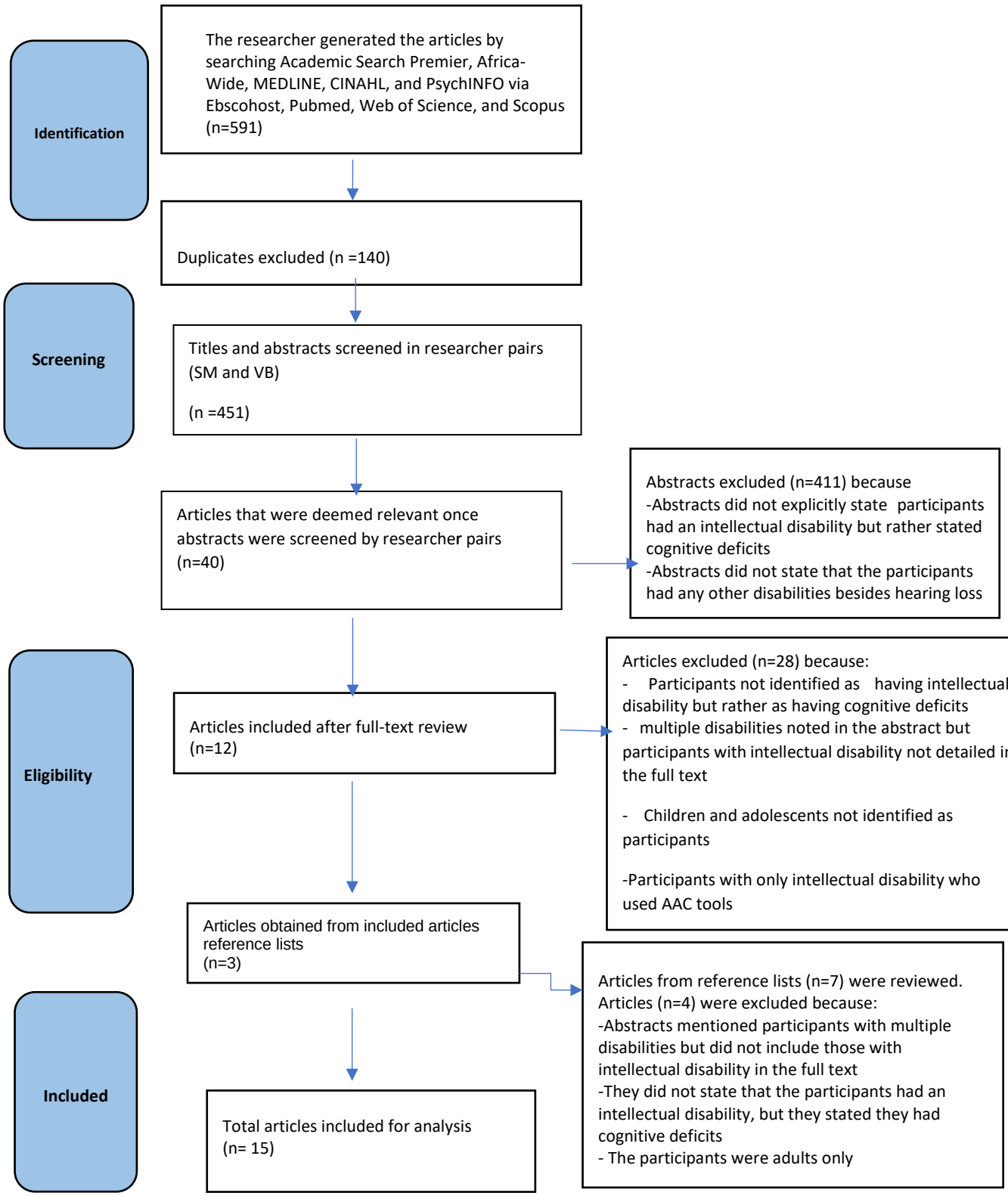

Figure 3 : Process for selection of included papers for review.

Stage 4: Extracting, mapping, and charting the data.

An excel data extraction form was developed to capture information on the author(s), title of the study, year of publication, location of the study, study population, aims, methodology, and important results of the study relevant to the research question set for the review. This included audiology practices, counselling, and tools used which are based on the Makhoba & Joseph (2016) framework of aural rehabilitation, and the personal and environmental factors as well as activity and participation components of the ICF. Other information that was captured included study outcomes and recommendations from the included studies.

The main researcher was also assisted by the research assistant (VB) in the analysis stages of the scoping review.

The main researcher (SM) and research assistant (VB) read through each of the articles several times to become acquainted with the content, and to identify data that answers the research question, using Makhoba and Joseph's (2016) framework of aural rehabilitation, specifically focusing on counselling, tools, and practices. The main researcher (SM) and the research assistant (VB) independently highlighted and coded relevant data to arrive at a list of core ideas related to the focus of the research question. SM and VB moved systematically from one article to the next, and hand-coded all articles. Hand coding was used because the small data base allowed for an intimate, detailed review of the dataset. Once a paper was reviewed and hand coded, these key ideas were extracted to the relevant codes in the data extraction sheet. SM and VB then compared coded data and discussed and resolved coding differences.

Stage 5: Summarise, synthesize, and report the results

a. Data summary and synthesis

The main researcher (SM) then sorted and combined the coded data in the data extraction sheet into themes related to counselling, tools, and practices based on Makhoba and Joseph's (2016) framework of aural rehabilitation as well as the ICF framework, but with room for additional themes. Original coded data across coded papers were combined with similar data coded for other papers, to arrive at a comprehensive overview of the data for a particular theme or subtheme. This is known as deductive coding which entails coding data based on preconceived themes you expect to find reflected in the data, based on a framework or theory (Nowell et al., 2017). The themes were reviewed and refined several times. One theme had three subthemes, and the theme tools were then divided into the three subthemes: hearing aids, cochlear implants, and Augmentative and Alternative Communication systems (AAC). One of the themes coded from the data which was not included in Makhoba and

Joseph's (2016) framework but was relevant to the research question was the availability of sensory management for D/deaf and hard-of-hearing children and adolescents with an intellectual disability.

b) Reporting of the results

The results of the scoping review are reported in chapter 3

Stage 6: Integrate expert consultation.

This stage is an optional stage for the Arksey and O'Malley framework, providing opportunity for the researchers to consult consumers of services (experts by experience) and other stakeholders (experts by profession or role) to suggest additional references, including peer reviewed literature which the search may not have sourced, or grey literature which may not be in the public domain but are relevant to the research focus. This optional stage was not included as part of the scoping review. However, the views of experts by experience (young adults and their caregivers) and experts by profession (audiologists) voiced their views on the research topic during the semi-structured interviews.

Introduction to the semi-structured interviews

This section of the chapter includes a description of the study setting, the study population, sampling methods, consent procedures, data collection methods, and data analysis methods used to explore Objectives 2-4 of the study. Objectives 2-4 focused on exploring the views of young adults with intellectual disability, their guardians, caregivers and audiologists on aural rehabilitation practices and tools utilized at public schools for the D/deaf. It also included a section on how research rigour was ensured, and the ethical considerations for this study.

2.4 Study sites

The study was conducted at public schools for the D/deaf in the Western Cape province of South Africa. Once the study was approved by the Faculty of Health Sciences' Human Research Ethics Committee (HREC) with protocol number 781/2021, a recruitment flyer (Appendix A) was sent to the Western Cape Department of Education asking for permission to conduct the study at schools for the D/deaf where there are D/deaf and hard-of-hearing participants with intellectual disability, and where there is an audiologist currently working who utilizes aural rehabilitation (Appendix J) (Western Cape Government, 2021). A letter of approval Appendix K was provided by the Western Cape Department

of Education. In the Western Cape, there are six schools for D/deaf and hard-of-hearing children and adolescents. Each of these schools currently employs at least one audiologist, and the schools utilize either an auditory or visual approach, with some utilizing total communication. Two of those schools are unable to accommodate D/deaf and hard-of-hearing students with a coexisting intellectual disability because they only offer the National Curriculum and Assessment Policy Statement (CAPS) curriculum, which is designed for students in grades R to 12 with typical intellectual abilities. Skills development is provided through the Differentiated National Curriculum and Assessment Policy Statement (dCAPS), which is for students with intellectual disability.

Children admitted to these schools are diagnostically within the mild to moderate range of intellectual disability. Children with actual severe to profound intellectual disability are currently still not formally included in the school system (Kruger, 2015). dCAPS focuses on vocational training, whereas the CAPS curriculum is the curriculum followed in mainstream schools. The table below describes each of the four schools according to students they accommodate, languages used, and curriculum followed.

Table 1: Characteristics of each school included in the study

	School A	School B	School C	School D
Description of students	Students between the ages of 3 to 20 years old, who are D/deaf and hard-of-hearing. This school also accommodates students who also have mild to Moderate intellectual disability.	D/deaf and hard-of-hearing Students from grade R up until they are 18 years old. This school accommodates students with an intellectual disability.	D/deaf students in pre-school and grades R to 12. This school Accommodates students with an intellectual disability.	Student from the age 3 to 18 years old, who are D/deaf and hard-of-hearing. This school accommodates students who have mild to moderate intellectual disability.

Languages used at the school	The medium of instruction is South African Sign Language (SASL), and Afrikaans and English are utilized for reading and writing.	This school offers English, and isiXhosa spoken language and SASL	This school offers the following languages: English, Afrikaans, and South African Sign Language	This school offers English, and isiXhosa spoken language and SASL
Curriculum followed	CAPS and dCAPS	CAPS and dCAPS	CAPS	dCAPS

Three of the four schools for the D/deaf who accommodate children with intellectual disability agreed to participate in this study. The fourth school informed the main researcher that they would be unable to participate in the study, citing time constraints.

2.5 Study population and sampling methods

D/deaf and hard-of-hearing young adults who are between the ages of 18 to 20 years old with a coexisting intellectual disability were recruited. This age group was chosen because most D/deaf and hard-of-hearing children and adolescents with an intellectual disability are identified and managed late. Thus, they might only provide sufficient information on their experiences of aural rehabilitation at a later stage of life. Young adults over the age of 18 were also recruited as it was felt that they would be able to reflect more on their experiences of aural rehabilitation across a wider lifespan than younger children and they would also be able to provide information on how aural rehabilitation has had an impact on their life post-school.

The school governing body and principal were asked to provide permission to recruit students through their school communication system. The principals of the schools were first contacted via email, and if no response was received, they were contacted telephonically. The following information was provided to the principal: the research topic, the purpose of the research study, the type of participants who would be recruited, and why they would be recruited. Informed consent forms, questionnaires, and a recruitment flyer were also sent to the principal. The principal worked with the school's audiologist to identify students who met the criteria. The principal then provided the students with the recruitment flyer and informed them that they could contact the researcher if they wanted more information or were interested in volunteering to be interviewed.

School A did not retain children 18 years and older, therefore young adults and their guardians could not be recruited from this school. However, the audiologist at the school was interviewed. School B did have D/deaf and hard-of-hearing children and adolescents with an intellectual disability which were included in this study but, very few were over 18 years old. School C had D/deaf and hard-of-hearing children and adolescents with an additional disability including an intellectual disability which were included in this study.

The recruitment flyer specified that the researcher would be interviewing the D/deaf or hard-of-hearing young adult with an intellectual disability and their parent/ guardian/caregiver. Potential participants expressed interest and agreed to take part in the study, informed the principal that they might be interested and were able to contact the researcher. Only young adults who expressed interest in the study and consented for their guardians and caregivers to be interviewed were recruited for interviewing. From the learners to whom the school provided the recruitment flyer, nine young adults met the inclusion criteria. Four agreed to participate in the study and gave permission to have their guardians and hostel caregivers recruited.

Audiologists

The audiologists were chosen using purposeful sampling to provide information on historical and current aural rehabilitation practices and tools used on D/deaf and hard-of-hearing children and adolescents with intellectual disability,. Purposeful sampling was chosen because these participants would most likely provide information that would answer and be relevant the research topic (Rendle et al., 2019). There was one audiologist at each school, and so three audiologists were interviewed. They were contacted telephonically and via email regarding the study and were informed that their participation was voluntary. Once they agreed to participate and gave informed consent, they were interviewed. During the interview, all the audiologists preferred to communicate in English.

(a) Deaf young adults with intellectual disability

Four Deaf young adults who are between the ages of 18 to 20 years old with a coexisting intellectual disability were interviewed. These young adults were all still currently receiving aural rehabilitation ensuring that the information gathered from the interviews with the participants would reflect their experience on recent aural rehabilitation practices. These participants were able to give informed consent to participate in the study and they understood that they could withdraw consent at any time. They were able to understand the aim, purpose, procedures, benefits, and risks of the research study. During the interview, they felt at ease communicating in SASL.

- Young adult 1 was a female who was 18 years old who identifies as Deaf. She was attending school C.
- Young adult 2 was a female who was 19 years old who identified as Deaf. She was attending school C.
- Young adult 3 was a male who was 18 years old who identifies as Deaf and he was attending school B.
- Young adult 4 was a male who was 20 years old who identified as Deaf, and he was attending school B.

These young adults were currently attending the 2 schools for the D/deaf in the Western Cape and lived at the hostel attached to their school. They reported that they usually went home during the weekends, or during the school holidays if their guardian stayed outside Cape Town. They were from low-income households

Three of the four participants had completed the Differentiated National Curriculum and Assessment Policy Statement (dCAPS). One young adult joined the school for the D/deaf after completing grade 11 at a mainstream school, following profound hearing loss at that time due to an accident. All the participants were currently doing vocational training at the schools for the D/deaf to study at the NID training centre once they have completed school. The NID training centre is a facility in Worcester in the Western Cape province that offers accredited training and work placements, as well as education and training services to Deaf and hard-of-hearing people with intellectual disability (NID Training, 2022).

(b) Guardians and caregivers of these young adults

A caregiver was defined as a person who provides direct care and support for individuals who are unable to look after themselves adequately due to a disability, illness, or age (Thompson et al., 2014). In terms of this study this included the caregivers who took care of these young adults at the hostels based at the school and their parents who were their guardians at home. For this study, this participant could have been a family member, caregiver, sibling, or parent who is the main caregiver of the young adult. It was required to be a person who spends a significant amount of time with the young adult. There was no cut-off age for the guardians or caregivers. Two hostel caregivers and two parents (of young adults 1 and 2) who currently reside in Cape Town were interviewed. This was on the condition that the young adult had given a written agreement for their participation. Young adults signed on the informed consent form that they agreed for the guardian or caregiver to be contacted to be interviewed. Two hostel-based caregivers were interviewed as part of the study because the young adults who agreed to have them interviewed said that they lived and spent most of their time in the

school's hostel. These young adults expressed that they felt more at ease having their hostel caregivers interviewed rather than family members, as they believed their hostel caregivers would be able to provide more information relevant to the research topic. Young adult 1 and 2 agreed to have one of their parents interviewed. These parents lived close to their school so that family contact was possible during term time.

The guardians or caregivers were able to provide information regarding their perceptions and experiences on aural rehabilitation practices and tools which were utilized on the young adults when they were children and adolescents.

- Caregiver 1 was a female. She identifies as a Deaf person and currently works at school A
- Caregiver 2 was a female. She does not have a hearing loss and currently works at school B
- Parent 1 of young adult one was based outside of the Western Cape but saw young adult 1 during school holidays and some weekends.
- Parent 2 of young adult two was based in Cape Town and saw young adult 2 during the weekends and school holidays.

They were able to give informed consent to participate in the study and they understood that they may withdraw consent at any time. They also understood the aim, purpose, procedures, benefits, and risks of the research study. During the interview, caregiver one felt at ease communicating in SASL, while caregiver two felt at ease communicating in English. The parents identified as members of the hearing community and they were interviewed in isiXhosa.

The study included a small number of participants, but in-depth interviews are conducted to obtain an in-depth understanding of the topic rather than a scoping of ideas. In qualitative research the final number of participants selected for interviews was also influenced by whether data saturation had been obtained (Saunders et al, 2018).

2.6 Data Collection

(a) Consent procedures

All the participants had to give informed consent to participate in the interviews and sign an informed consent form. The information on the consent form was explained by the researcher and the participants were given a chance to raise any concerns they might have before the interview started. The D/deaf and hard-of-hearing participants with an intellectual disability were asked to report their understanding of the information in the consent forms. This was done to ensure that they understood the information on the consent forms.

This information and the consent forms were presented in the participants' preferred language, which was English, isiXhosa and SASL. The consent forms (Appendix E for the audiologists, F for the young adults, and G for the caregivers and parents) contained information regarding the purpose of the study, the benefits, any potential harm, and where to contact the researcher for any additional information. The informed consent form was read to each potential participant**.** The young adults were also asked to confirm on their consent form that they are aware of and agree that their guardian or parent can be interviewed for additional information for the study. Since the participants were over the age of 18, they provided informed consent themselves.

Individuals with an intellectual disability are considered a vulnerable population. Extra care was taken to ensure that these participants had a clear understanding of the study's purpose and planned use of the findings. The young adults with an intellectual disability were asked key questions to ensure participants understood the nature of participating and to ensure that they are providing informed consent (Horner-Johnson and Bailey, 2013). The following questions asked were:

1. Please tell me, in your own words, what is this study about?

2. What will you be doing if you take part in this study?

3. Is there anything about the study that could harm you in any way if you were to take part?

4. When I say that your answers will be kept confidential, what does that mean to you?

5. What can you do if you start the study but don’t want to finish it?

The requirements for participation excluded the young adults who were unable to communicate their thoughts during the interview, and comment on their experience with aural rehabilitation. The study also excluded participants who might not be able to reflect on their experiences of aural rehabilitation. Since public schools that fall under Department of Education currently do not enroll any children with a severe to profound intellectual disability, as defined in the DSM-5 and ICD-11, none were included in this study. This was considered by the principal and audiologist in assisting with bringing the study to the attention of suitable young adults during recruitment and was again confirmed during the actual consent procedures. Suitability was determined by their ability to understand and respond to questions during the interviews. They understood that they could withdraw consent at any time before or during the interview.

(b) Interview schedules

Makhoba & Joseph's (2016) framework and the ICF framework were used as a guideline when developing the semi-structured questionnaires (Appendix B for the audiologists, C for the young adults, and D for the guardians and caregivers). The questionnaires were based on the three components of the Makhoba & Joseph (2016) framework as well as ICF framework and included : 1) questions regarding the health condition which was hearing loss and deafness, and questions regarding social factors related to their interactions with the hearing and deaf community, 2) activities and participation and how they have been impacted since they received aural rehabilitation and 3) environmental factors regarding their support and relationships as well as their attitudes. The questionnaires were used as a guideline for the interview. Semi-structured interviews were chosen because they allow the researcher to collect specific information about areas of enquiry. The open-ended format permitted exploration of the participants' experiences and perceptions about a range of subtopics within the overall research topic.

The purpose of these interviews was to determine (a) the experiences and perceptions of audiologists who utilized aural rehabilitation practices and tools at the schools for D/deaf, (b) the experiences of young adults who received aural rehabilitation, (c) guardians or caregivers of young adults' perceptions and experiences of aural rehabilitation practices and tools which were utilized on the young adults when they were children and adolescents.

The questionnaire also included a section on the most common met and unmet needs of aural rehabilitation that they might have, as well as their views on what might improve aural rehabilitation services for current and future learners. The audiologists were also asked about: 1) the challenges they face when providing aural rehabilitation, 2) the types of aural rehabilitation provided, and tools used, 3) whether they consider these learners to be benefitting from aural rehabilitation, 4) what provides these benefits, 5) problems experienced in providing these services and 6) what improvements may be brought to current aural rehabilitation practices.

The Centres for Disease Control and Prevention (CDC) guidelines mentioned that audiological services pose a medium to high risk for COVID-19 infection based on the proximity, test setup, and length of appointments. The consultation and test setup might have been adjusted to adhere to COVID-19 safety standards (Swanepoel & Hall, 2020). Therefore, these questionnaires also considered how experiences may have changed because of the COVID -19 pandemic.

The researcher had to build rapport, actively listen to the participants throughout the interviews, and had to be open to the participants' points of view. The interviews were recorded, and written notes were taken throughout the interviews. For audiologists and one caregiver who communicated in

spoken language, interviews were audio recorded. For the Deaf young adults and the one Deaf caregiver who communicated in SASL, video recordings were taken since sign language is a visual language that relies on facial expressions, fingerspelling as well as body gestures, and body language. A confidentiality agreement (Appendix H) was signed by the SASL interpreter who assisted during the interviews.

The main barrier to data collection was that when the researcher began conducting interviews, school vacation had just begun, so it took almost two months longer than planned to commence and complete data collection. The researcher organized the interviews for participates over a month while giving them an opportunity to decide the most convenient time and date for the interviews.

2.7 Data Management

Data collected with a voice recorder and the video camera was transferred to the researcher's laptop and temporarily saved in a secure file. When the researcher and the transcriber had completed the transcription process, the audio and video recordings on the laptop were deleted. Transcripts of the audio and video data were saved in a secure location within the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital. The identities of the participants were removed so that the independent researcher and the transcriber would not know who they are.

2.8 Data Analysis

Thematic analysis was used because it allowed the researcher to identify, analyse and report patterns within the data collected. The 6 phases of thematic analysis (Braun and Clark, 2006), used for the data analysis were as follows:

1. Familiarisation of the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Developing a report

Phase 1: familiarisation of the data

English interviews were transcribed verbatim by the main researcher and the researcher checked all the transcriptions several times. The interviews with Deaf participants which were done in SASL were interpreted into English by the SASL interpreter. The interviews conducted in isiXhosa were transcribed into English by a bilingual transcriber. Back translation of the isiXhosa interviews and of the SASL to English interviews was not done due to resource constraints for the study.

A part of this phase was to check the quality of the transcriptions where the researcher had reviewed the transcriptions against the recorded interviews to check for accuracy of transcriptions. All the transcriptions were loaded onto Nvivo which is a computer programme used for qualitative analysis. The researcher read through the data repeatedly, and actively searched the data to find meanings and patterns (Braun & Clarke, 2006).

Phase 2: generating initial codes

Preliminary codes based on three components of Makhoba & Joseph (2016) were generated by the researcher and research assistant. Additionally, codes based on the components of ICF were also generated. Familiarisation of the data in phase 1 then informed the main researcher's generation of additional codes, with help from the research assistant. The researcher and research assistant independently read a subset of the transcripts and derived codes. They then compared the codes derived and discussed and resolved differences in coding to arrive at a preliminary coding frame for the study. The researcher and research assistant then coded two of the interviews (interview of audiologist 1 and young adult 1) with the coding frame, to assess consistency in using the coding frame. They compared and adjusted the codes accordingly. The remaining transcripts were coded by the main researcher.

Phase 3: searching for themes

This was done by the primary researcher once a list of codes was gathered from the data set. The initial codes were sorted and combined into themes as well as sub-theme. During this process some of the initial codes were merged with other codes, while additional codes not derived in the previous phase were added (Braun & Clarke, 2006).

Phases 4 & 5: reviewing and naming themes

Themes had to have internal homogeneity and external heterogeneity. This means that data in these themes could not fall in between two themes and could not fit in more than one theme. The

outcome of the refinement of the themes was a clearly defined "thematic map" of data that reflected the core meanings in relation to the research question and objectives set for the study (Braun & Clarke, 2006). The main coding frame is listed in Appendix I.

Phase 6: developing a report

A narrative description of the themes and sub-themes was done. The researcher wrote up the themes, then returned to the write-up to read each of the themes and their elaboration in the write up.

2.9 Research rigour

Since this was a qualitative study, dependability, credibility, transferability, and confirmability were considered.

a) Credibility

Credibility relates to whether the study's results represent the data collected from the participants, and if the interpretation of the data is correct. At the end of the interviews, the researcher shared her interpretation of the information provided by participants during the interview. The participants then had a chance to communicate if the interpretation was correct or not.

Credibility was ensured through the triangulation of sources. Three different groups were interviewed: 1) audiologists, 2) Deaf young adults with an intellectual disability and 3) their guardians and caregivers. Triangulation of sources reduces bias in research (Anney, 2014).

b) Transferability

Transferability is the degree to which the results of the study can be applied or transferred to other contexts. The write-up of this study included a thick description of the participants, sampling methods, location, data collection method, and results. This can allow other researchers to make a judgment on whether the results may be appropriately transferred to their setting (Anney, 2014).

c) Dependability

Dependability relates to whether the results of the study are consistent and repeatable. Another researcher evaluating the data should have similar findings, interpretations, and conclusions. As detailed above under the section on data analysis, a research assistant co- analysed a portion of the data separately. The results of the researcher and the research assistant were compared, and if any inconsistencies arose, they were addressed to improve dependability (Anney 2014).

d) Confirmability

Confirmability is the degree to which the research findings can be confirmed by another researcher. This is done to ensure that the results are derived from the data. An audit trail was done by the researcher by writing details of the data collection, analysis, and interpretation. This also included a record of what topics stood out during data collection, thoughts on coding, and an explanation of the themes used. This also relates to the preservation of the raw data and written notes that were taken during the interviews as outlined in the data management plan (Anney, 2014).

2.10 Ethical considerations

Ethical considerations included getting the informed consent of the participants, maintaining autonomy, beneficence, non-maleficence, and confidentiality as well as ensuring that all participants understand that their participation is completely voluntary. This was to maintain and follow the principles enshrined in the Declaration of Helsinki and the Nuremberg Code (Reid et al., 2018). Ethical approval (Appendix L) was obtained from the University of Cape Town's Faculty of Health Sciences' Human Research Ethics Committee (HREC. 781/2021) in Appendix J since the study included human participants.

a) Autonomy

Autonomy is defined as the ability to make decisions for oneself and give informed consent. For the participants to give informed consent they had to be aware of and comprehend the purpose of the study, the procedure to be followed, their contribution to the study, any potential risks, any advantages that come from participation, as well as how their confidentiality will be maintained. A part of maintaining autonomy is ensuring that participants know that they have a right to withdraw consent at any stage of the interview and have a right to free speech (Varkey, 2020). All participants who gave informed consent to participate in the study had to sign a consent form. For the young adults with an intellectual disability, additional questioning was done after reading the consent forms, to ensure they understood the contents.

b) Beneficence

Beneficence is defined as an obligation of the researcher to act for the benefit of the participants (Varkey, 2020). Although there is no direct benefit of participation, this study allowed participants to reflect on their experiences, this increased self-awareness and gave the participants a chance to share their own opinions on aural rehabilitation practices and tools utilized on D/deaf and hard-of-hearing children and adolescents with an intellectual disability.

c) Non-maleficence

Non-maleficence is an obligation of the researcher to not harm the participants (Varkey, 2020). There was no risk of physical and emotional harm envisaged for participating in this study, and no risks were noted during the study.

d) Confidentiality

Confidentiality involves keeping personal information, such as the names of the participants, private (Varkey, 2020). The names of the schools were not mentioned in this thesis because each school has only one audiologist and including the names of the schools would jeopardise confidentiality and anonymity of the audiologists. After the transcription process, the recordings were destroyed. Transcripts were only accessible to the supervisor, transcriber and the main researcher, and identifying data was removed from the transcripts before coding so that the independent research assistant and transcriber did not know the identities of the participants. All the transcripts will be kept safe and secure for five years in a locked filing system in the Department of Psychiatry and Mental Health at the Neuroscience Centre, Groote Schuur Hospital.

e) Justice

Justice in ethics is defined as equity and fairness in treatment. This means all participants were treated equally and had a chance to participate in the study (Varkey, 2020). Since the study made use of Deaf participants, there was a SASL interpreter present throughout their interviews. This ensured that Deaf participants were able to communicate during the interviews and had a fair chance to participate and voice their views freely during in the study.

Chapter three: Results of the scoping review

This chapter reports on the finding of the scoping review of literature on aural rehabilitation practices and tools utilized on D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability and discusses these findings as they relate to objective 1 of the study.

Table 2 below summarises the included studies (n=15) by the author(s), date, topic, population, aim, methodology, and findings on audiology practices counselling and tools, study outcomes, and recommendations as well as the availability of sensory management for D/deaf and hard-of-hearing children and adolescents with an intellectual disability.

Author, year of publication, and title of the study	Location of study	Study population tools utilized	Aim the study	Methodology	Audiology practices and	Important results of the study	Study outcomes/ recommendations
Bruce & Borders, (2015) Communication and Language in Learners Who Are Deaf and Hard of Hearing with Disabilities: Theories, Research, and Practice	United States of America (USA)	Children and youth with an h intellectual disability	Identify aural rehabilitation practices and tools for Deaf and hard-of-hearing children with additional disabilities	Systematic review	**Tools**: cochlear implants & hearing aids, unaided AAC i.e., gestures and signs, aided AAC i.e., s line drawings, objects, picture representations & a speech-generating device (SGD) **Practices**: communication partner training **Counselling** : not noted	Using these tools and interventions improved participants' communication and language outcomes.	**Tools:** Early detection and interventions like hearing aids and cochlear implants should be recommended for these children as it enables speech and language development. AAC should be recommended as AAC supports the acquisition of speech and Sign Language development **Practices:** It is recommended that communication strategies should be provided to the child, their peers, and family members as well as guardians because when communication improves there will be a decrease in disruptive behaviours and frustration that usually occurs when appropriate communication methods are absent. **Counselling:** not noted **Availability of sensory management**: not noted
Cupples et al. (2013) Outcomes of 3-Year-Old Children with Hearing Loss and Different Types of Additional Disabilities	Australia	119 three year old children with hearing loss and additional disabilities, as well as their caregivers. 41 of these children had an intellectual disability	To provide detailed information about the language outcomes of D/deaf or hard-of-hearing children with hearing loss and other disabilities, including intellectual disability	Population-based longitudinal study	**Tools:** cochlear implants and hearing aids, subjective outcome measures such as the Parent Evaluation Aural/Oral Performance of Children (PEACH), Speech Intelligibility Rating (SIR), and Child Development Inventory (CDI) **Practices:** not noted **Counselling:** not noted	Poorer language outcomes were achieved by children with an intellectual disability. Poorer language outcomes are associated with increased cognitive deficits. Despite this, children with an intellectual disability who received cochlear implants or who were fitted with hearing aids did show improved speech and language skills.	**Tools**: deaf children with an intellectual disability can benefit from cochlear implants and hearing aids and should not be excluded from receiving the assistive technology. Subjective outcome measures can be used to determine auditory and language outcomes for this population. Future research for children with hearing loss and intellectual disability should focus on language outcomes post-hearing aid fitting and cochlear implantation. **Practices and Counselling**: not noted **Availability of sensory management**: not noted

							Tools:
Cupples et al. (2018) Language development in deaf or hard-of-hearing children with additional disabilities: type matters!	Australia	67 children with hearing loss and additional disabilities. 15 of those children had an intellectual disability	Evaluate data on language development over 2 years from a large sample of D/deaf and hard-of-hearing children with various types of additional disabilities who were assessed at 3- and 5 years of age.	Population based longitudinal study	**Tools**: cochlear implants and hearing aids, objective outcome measures such as the Preschool Language Scale 4th edition (PSL-4), Peabody Picture Vocabulary Test 4th edition (PPVT-4), and Wechsler Non-verbal scale (WNV). **Practices**: not noted **Counselling**: not noted	Children with hearing loss and additional disabilities, including an intellectual disability, had slower progress in their development of language than children with a hearing loss without an additional disability. This is due to cognitive deficits associated with an intellectual disability.	**Tools:** Children with a hearing loss and an intellectual disability who were fitted with cochlear implants and hearing aids had improved speech and language outcomes, although outcomes were poorer than children who had only had a hearing loss and no additional disability. This study recommended that additional support in the form of additional services should be provided by a multidisciplinary team after fitting of hearing aids and cochlear implants, to maximize language outcomes. **Practices and Counselling**: not noted **Availability of sensory management**: not noted
Daneshi & Hassanzadeh (2006) Cochlear implantation in prelingually deaf persons with additional disability.	Iran	Prelingually deaf children with an additional disability. 13 out of the 60 deaf children also had an intellectual disability	Identify the number of participants using a cochlear implant with an additional disability as well as report their development of auditory perception	Retrospective study	**Tools:** Cochlear implants and objective outcome measures Persian auditory perception test **Practices**: not noted **Counselling:** not noted	Prelingually deaf children with mild to moderate intellectual disability showed significant improvement in auditory perception.	deaf children with an intellectual disability require specialized aural rehabilitation. They should also receive services from a multidisciplinary team. Parents/ caregivers should be included in aural rehabilitation to maximize speech and auditory development. **Practices and Counselling**: not noted **Availability of sensory management**: not noted
Davis et al. (2009) Aided AAC Systems Among Individuals with Hearing Loss and Disabilities.	USA	32 Participants with hearing loss, including children with additional disabilities. 31 participants had an intellectual disability.	Review existing literature on the use of aided AAC systems among people with hearing loss who have one or more additional disabilities.	Systematic review	**Tools:** Aided AAC such as picture dictionaries, tokens, SDG, communication boards, picture break, and vibrating switch. **Practices:** not noted **Counselling:** not noted	The results suggest that aided AAC devices are effective tools that can be used during communication interventions for individuals with hearing loss who also have additional disabilities	**Tools:** AAC devices should be considered first and foremost rather than being the last option in early childhood intervention. AAC will allow children to develop language skills that will lay the groundwork for more advanced language and learning skills. **Practices and Counselling**: not noted **Availability of sensory management**: not noted

Friedman & McNamara (2018) Home- and -Community Based Speech, Language, and Hearing Services for People with Intellectual and Developmental Disabilities.	USA	Participants with a hearing loss and intellectual disability/ developmental disability (DD)/ autism spectrum disorder (ASD)	Evaluate how speech, language and hearing services were provided to people with IDD across the country, specifically in the fiscal year 2015 Medicaid Home and Community Based Services (HCBS) 1915 (c) waivers	Retrospective study	**Tools:** Cochlear implants, hearing aids, AAC aided and unaided **Practices:** communication intervention as communication partner training **Counselling:** not noted	There is a clear need for appropriate SLH services for people with IDD but funding for SLH services through HCBS waivers was insufficient reimbursement for rates and services.	**Tools & Practices:** There is a need to improve access to appropriate SLH services for people with IDD. This population does benefit from receiving aural rehabilitation. Aural rehabilitation services led to an improvement in speech and language development as well as reduced disruptive behaviour associated with maladaptive communication strategies. **Counselling**: not noted **Availability of sensory management**: not noted
Filipo et al. (2004) Cochlear Implants in Special Cases: Deafness in the Presence of Disabilities and/or Associated Problems	Italy	8 out of 21 deaf children with additional disabilities. 5 out of those 8 deaf children had a mild to moderate intellectual disability. The other three deaf children had visual impairment or autism spectrum disorder (ASD) as an additional disability.	To create a reference model that highlights the attitude, requirements, and resources required to deal with deafness and additional disabilities	Qualitative study	**Tools:** Cochlear implants. **Practice:** communication intervention as auditory training **Counselling:** psychosocial adjustment and informational counselling	There was an improvement in attention span and listening skills for deaf children with a coexisting intellectual disability, although the progress was slow. Cochlear implants can improve the quality of life of deaf children with intellectual disability by improving their listening and communication skills.	**Tools & Practices**: The study recommended all services should be done in the centre, ideally to ensure that auditory training and speech therapy is conducted as soon as possible post cochlear implantation. This allows meeting of the special needs of these children, as well as allowing the possibility of acting immediately if the cochlear implant malfunctions. **Counselling:** Families of these children should be included in counselling. The study emphasized that the families should understand the information shared during counselling and be involved decision making regarding interventions provided to these children. **Availability of sensory management**: not noted

							Tools:
Fukuda et al. (2003) Language development of a multiply handicapped child after cochlear implantation	Japan	A 10-year-old deaf child with profound hearing loss and moderate intellectual disability	To describe the language development of a deaf child with profound hearing loss and moderate intellectual disability following cochlear implantation	Case study	**Tools:** hearing aids and cochlear implant, objective outcome measure. A monosyllable speech perception test battery **Practice:** Auditory training **Counselling:** informational counselling	Post cochlear implantation the deaf child showed improved oral and auditory development. He did not rely on visual modes alone to communicate.	**Tools & Practice:** a deaf child had shown minimal benefit from bilateral hearing aids, but once he received cochlear implants, speech therapy, and auditory training he showed improved auditory and oral development. Deaf children with intellectual disability should not be excluded from cochlear implantation. **Counselling:** To assist family members in making decisions on interventions provided to the child, detailed information on the auditory, language and speech development of a deaf child with an intellectual disability is required. **Availability of sensory management:** At the time this study was conducted deaf children with an intellectual disability were not usually considered for cochlear implantation, and there was very little research on language outcomes for this population. The results of this study support that this population should not be excluded from cochlear implantation as it does lead to improved language outcomes.

Kaga et al. (2007) Changes in auditory behaviours of multiply handicapped children with deafnessafter hearing aid fitting.	Japan	28 deaf children and 5 deaf infants. The 5 deaf infants had no additional disabilities, whereas 7 out of the 28 deaf children had mild to severe intellectual disability	Compare the development of auditory behaviours after the fitting of hearing aids in deaf children without additional disability issues versus deaf children with additional disabilities.	comparative study	**Tools:** Hearing aids **Practices:** not noted **Counselling:** not noted	Participants with mild and moderate intellectual disability showed improved speech and language development, but to a lesser extent than deaf children without an intellectual disability. Despite being fitted with hearing aids, some deaf children with severe intellectual disability either showed delays in the development of auditory abilities, no change in auditory behaviours, or were unable to wear hearing aids	**Tools:** This study emphasized the importance of early diagnosis of hearing loss and early intervention through hearing aids in deaf children with an intellectual disability, to ensure the development of their language or auditory skills. Hearing aids are ineffective or not used by some deaf children with severe intellectual disability. **Availability of sensory management:** Children with severe intellectual disability were often not considered for hearing aid fittings. The results suggest that they should not be excluded as some of these children did develop auditory skills. Careful hearing aid fitting is encouraged for deaf children. **Practices and Counselling**: not noted
Kunst et al. (2006) Rehabilitation of patients with conductive hearing loss and moderate mental retardation using a bone-anchored hearing aid.	Netherlands	22 Participants, including children with congenital moderate intellectual disability and conductive or mixed hearing loss (n=8)	Evaluate if the BAHA is an effective management option for participants with moderate intellectual disability and see if the indications for BAHA use can be expanded.	Retrospective clinical evaluation	**Tools:** bone-anchored hearing aid (BAHA) **Practice**: not noted **Counselling:** information counselling	Participants showed improved speech recognition scores after fitting BAHA, they did not have any difficulties handling the BAHA and the results showed that it can positively impact their schooling.	**Tools:** A soft band BAHA would be beneficial and should be considered first for very young children for whom surgical intervention such as BAHA might not be an option. Since participants with moderate intellectual disability show improvement in quality of life and overall communication skills, they should not be part of the exclusion criteria but instead carefully considered. **Counselling:** Participants' caregivers were trained and tasked with inspecting and maintaining the BAHA system. The yearly check-up should be used to provide additional information to caregivers about how to handle and maintain the BAHA. This was useful in this study, and it contributed to the success of BAHA. Due to this counselling, the participants were able to use and maintain the BAHAs. **Availability of sensory management:** Before this study, this population was excluded from receiving BAHAs as there were concerns that the caregivers and the participants would not be able to cope with using and maintaining the BAHA. Recommendations were that this population should not be excluded as caregivers and participants were able to maintain and handle BAHAs with very little or no additional issues. **Practices:** not noted

					Tools:		**Tools:**
Lee, Jeong & Kim (2013). AAC intervention using a VOCA for deaf children with multiple disabilities Determine the effectiveness of AAC intervention using a VOCA in improving speech perception, speech production, receptive vocabulary skills, and communicative behaviours in children with additional disabilities following cochlear implantation Comparative voice output communication aid (VOCA) which is aided by AAC,	South Korea	10 deaf children with an intellectual disability who received cochlear implantation. Cochlear implants study & Objective outcome measures: monosyllabic word tests were used to determine speech perception scores;	Assessment of Phon	ology & Articulation for Children (APAC) was used to determine speech production scores and PPVT Korean version was used to determine receptive language scores. **Practices:** not noted **Counselling**: informational counselling During AAC intervention, five deaf children with intellectual disability were able to learn to use the VOCA to express their communicative intentions, compared to	the other five deaf children with an intellectual disability in the control group who did not receive VOCA. VOCA is recommended as an effective AAC for improving communication skills for deaf children with intellectual disability who had very limited verbal communication skills following cochlear implantation. **Counselling:** VOCA training began with teaching these children how to operate the device, which	made it easier for them to use the VOCA. Children learned symbols by requesting a preferred object by pointing to pictures affixed to the VOCA. They recommended that the parents of these children should be encouraged and trained to use VOCA. The parents of these children were encouraged to prompt the child to use VOCA by either demonstrating or imitating how to use VOCA and giving physical guidance. This aided the development of communication skills. **Practices:** not noted **Availability of sensory management**: not noted
Sakai, Watanabe & Kaga (2002). Auditory brainstem responses and usefulness of hearing aids in hearing impaired children with Cornelia de Lange syndrome.	Japan	13 deaf children and infants with Cornelia de Lange syndrome, and severe intellectual disability	(a) Determine the degree of hearing loss in participants with Cornelia de Lange syndrome (CDLS) by measuring their Auditory brainstem evoked response (ABR) and (b) determine how hearing aids and auditory training can affect auditory and speech development in these participants.	Explorative study	**Tools:** Hearing aids **Practice:** communication intervention as auditory training **Counselling:** not noted	Only 5 of the 13 children were successfully fitted with hearing aids and received auditory training. 3 of the children with severe intellectual disability demonstrated improved auditory development, including improved sound localization and increased awareness of environmental sounds. Due to the severity of their cognitive deficits, they were not able to develop language skills	**Tools & Practices:** The study recommended that fitting hearing aids followed by auditory training might be beneficial for auditory development even though it does not lead to the development of language and speech. It can still improve the quality of life for children with severe intellectual disability. **Availability of sensory management**: Children with intellectual disability are considered a difficult to test population, which is one of the reasons sensory management is not accessible. However, with objective tests like the Auditory Brainstem Response (ABR) test it is possible to obtain hearing levels for this population and provide sensory management. **Counselling** : not noted

					Tools:		**Tools:**
Tucker Cohen et al. (2001) Use of picture dictionaries to promote written communication by students with hearing and cognitive impairments.	USA	3 students who have hearing loss and a mild to borderline intellectual disability	Determine the usefulness of using picture dictionaries for Deaf students with mild intellectual disability	Multiple baseline probe design	Aided AAC as picture dictionaries **Practice:** none noted **Counselling:** none noted	Picture dictionaries are an effective form of expressive communication for students who a hearing loss and an intellectual disability	These AAC tools should be recommended to other students with hearing loss and an intellectual disability because this mode of communication was easily understood by communication partners, and it allowed students to communicate effectively across a variety of social gatherings. **Practices and Counselling**: not noted **Availability of sensory management**: not noted
Yamazaki et al. (2012) Cochlear implantation in children with congenital cytomegalovirus infection accompanied by psycho-neurological disorders.	Japan	25 deaf children who received a cochlear implant and 11 children who had hearing loss due to congenital cytomegalovirus (CMV), with most of these children also having an intellectual disability (n=6), while the other 14 children had congenital hearing loss	To investigate the impact of congenital cytomegalovirus (CMV) -related psychoneurological disorders on the language outcomes post cochlear implantation	Retrospective review	**Tools:** cochlear implants **Practice:** not noted **Counselling**: not noted	Cochlear implantation was an effective management plan for deaf children with CMV infection, but their language outcomes were frequently poorer.	**Tools:** The evaluation of cognitive development and autistic tendencies may be useful in predicting language outcomes after cochlear implantation **Practices and Counselling**: not noted **Availability of sensory management**: not noted

Youm et al. (2013)	South Korea	28 prelingually deaf children, 14 with an intellectual disability after cochlear implantation. 14 with no additional disability (control group)	The auditory and speech performance of children with an intellectual disability and	Evaluate the auditory and speech abilities of 14 young deaf children with intellectual disability post cochlear implantation	Retrospective study **Tools:** Categories of Auditory Performance (CAP) score and monosyllabic word tests **Practices:** not noted **Counselling:** informational and psychosocial adjustment counselling	After cochlear implantation, deaf children with intellectual disability showed improvement in auditory perception and speech production. Furthermore, the communication mode shifted from nonverbal to vocalizations or oral communication **Tools: d**eaf children with an intellectual disability made improvements in their auditory perception and speech development. Intellectual disability in children should not be regarded as a contraindication to cochlear implantation **Counselling**: This study recommended that counselling should also aim to assess the acceptance of the hearing loss diagnosis and cooperation with the suggested management plan, provide support when necessary, and provide a clear picture of the child's capabilities, limitations, and benefits of the cochlear implant **Availability of sensory management:** Sensory management, such as cochlear implants, can help deaf children with intellectual disability develop speech, language, and auditory skills. They recommended that deaf children with other disabilities, such as intellectual disability, should not be excluded from receiving cochlear implants. **Practices:** not noted

Table 2: data extraction table with included studies

3.1 Characteristics of included studies

Although the sourced articles (n=451) demonstrated that there is a fair amount of literature on aural rehabilitation practices and tools used on D/deaf and hard-of-hearing children as well as and adolescents without an intellectual disability, there were very few studies that focused on D/deaf and hard-of-hearing children and adolescents who had an intellectual disability, with only fifteen peer-reviewed articles focusing on aural rehabilitation practices and tools used on deaf and hard-of-hearing children and adolescents with intellectual disability. Between 2000 and 2010, eight articles were published, and between 2011 and 2018, seven articles were published. There were no articles found which were published between 2019 and 2022. There were three qualitative studies, eleven quantitative studies, and one mixed methods study. Most of the articles were sourced from Web of Science, followed by PubMed and CINAHL. There were no studies published in low- and middle-income countries. Only one study, by Daneshi and Hassanzadeh (2006), was conducted in Iran, an upper middle-income country, with the rest being conducted in high-income countries. There were no studies found that were conducted in Africa or SA.

3.2 Key themes

The data from the articles are discussed under four themes: counselling, tools, practices, and availability of sensory management.

(a) Tools

Almost two thirds of the authors included in this scoping review (Sakai, Watanabe & Kaga, 2002,

Fukuda et al., 2003, Kunst et al., 2006, Kaga et al., 2007, Yamazaki et al., 2012, Cupples et al., 2013, Youm et al., 2013, Cupples et al., 2018 and Friedman & McNamara, 2018) reported that the most common sensory management tools used on deaf and hard-of-hearing children and adolescents with an intellectual disability were cochlear implants and hearing aids. The participants included in these studies were deaf and hard-of-hearing children and adolescents, with a mild to severe intellectual disability.

According to the research of Cupples et al., 2013, Youm et al., 2013, and Friedman & McNamara, 2018, the main factors influencing speech and language outcomes are the degree of hearing loss, the age at which the child receives the sensory management, the severity of the intellectual disability, the type of sensory management used, and the use of Augmentative and Alternative Communication systems (AAC). The benefit of aural rehabilitation in deaf and hard-of-hearing children and adolescents with an intellectual disability can be determined using subjective and outcome measures (Fukuda et al., 2003;

Daneshi & Hassanzadeh, 2006; Cupples et al., 2013; Lee, Jeong & Kim, 2013; Cupples et al., 2018). Scales and checklists such as the Parent Evaluation Aural/Oral Performance of Children (PEACH), Speech Intelligibility Rating (SIR), and Child Development Inventory (CDI) can be used to determine subjective language, auditory, and speech outcomes (Cupples et al., 2013). These outcomes can also be determined objectively using scales, tests, and assessments like the Preschool Language Scale 4th edition (PSL-4), Peabody Picture Vocabulary Test 4th edition (PPVT4) and Wechsler Nonverbal scale (WNV) and the Assessment of Phonology & Articulation for Children (APAC) (Fukuda et al., 2003; Daneshi & Hassanzadeh, 2006; Lee, Jeong & Kim, 2013; Cupples et al., 2018).

Sub-theme one: hearing aids

Almost half the authors included in this scoping review (Sakai, Watanabe & Kaga, 2002, Kunst et al., 2006, Kaga et al., 2007, Cupples et al, 2013, Cupples et al., 2018 and Friedman & McNamara, 2018) reported that sensory management in the form of hearing aids is known to improve speech and language outcomes as well as overall quality of life at home and at school for deaf and hard-of-hearing children and adolescents with an intellectual disability. When hearing aids are used as a sensory management for this population, the degree of hearing loss and the severity of intellectual disability affects speech and language outcomes (Cupples et al, 2013; Cupples et al., 2018).

Cupples et al., 2013 conducted a population-based longitudinal study in Australia on 119 three-year-old children with hearing loss and additional disabilities, including an intellectual disability (n=41), with the goal of providing detailed information about these children's language outcomes. They discovered that, while the performance of deaf and hard-of-hearing children with an intellectual disability is dependent on the severity of the intellectual disability, severe levels of hearing loss were also linked to lower receptive vocabulary scores and poorer language outcomes. They also recommended providing additional support for children with an intellectual disability to optimize language outcomes, this support should vary and will be dependent on the establishment of a multidisciplinary team with specialist knowledge of the specific disability type (Cupples et al., 2013).

According to the literature of two thirds of the authors which included Sakai, Watanabe, and Kaga,

2002, Kunst et al., 2006, Kaga et al., 2007, Cupples et al., 2013, Youm et al, 2013, and Friedman & McNamara, 2018, there is a negative correlation between cognitive deficits, speech, and language outcomes. Cognitive deficits make it difficult for these children to process, interpret, analyse, and organize auditory information (Lee, Jeong & Kim, 2013). Sakai, Watanabe, and Kaga (2002) conducted an exploratory study in Japan on children (n=13) with Cornelia de Lange syndrome (CDLS) and severe intellectual disability who received sensory management in the form of hearing aids. Cornelia de Lange

syndrome (CDLS) is a genetic disorder characterized by distinct facial features, intellectual and developmental disability, hearing loss, congenital heart deficits, and growth delays. Five of the 13 children were successfully fitted with hearing aids and received auditory training, while 3 of the children with severe intellectual disability demonstrated improved auditory development. This led to increased social interactions, thus improving the quality of life for the children and their caregivers. Due to the severity of their cognitive deficits, the children were not able to develop language skills (Sakai, Watanabe & Kaga, 2002).

Sub-theme two: cochlear implants

According to the findings of a few authors which included Fukuda et al., 2003, Yamazaki et al., 2012, Cupples et al., 2013, and Youm et al., 2013, cochlear implants are a viable option for deaf children with an intellectual disability who have received little to no benefit from hearing aids due to the severity of their hearing loss. Although the severity of the intellectual disability also affects speech and language outcomes in deaf children with an intellectual disability who were fitted with cochlear implants, improved speech, language, or auditory development is observed following cochlear implantation (Fukuda et al., 2003; Yamazaki et al., 2012; Cupples et al., 2013; Youm et al., 2013). Cupples et al., (2013) and Youm et al., (2013) both reported that deaf children with mild intellectual disability had improved auditory perception and language acquisition after cochlear implantation, with some auditory and language outcomes comparable to deaf children without an additional disability.

Deaf children with moderate intellectual disability had limited gain after cochlear implantation, made very slow progress and remained in the very early stages of auditory, speech, and language development due to their poor cognitive abilities (Cupples et al., 2013; Youm et al., 2013). Yamazaki et al. (2012) conducted a retrospective study in Japan on deaf children who received a cochlear implant (n=25). Eleven deaf children had hearing loss due to congenital cytomegalovirus (CMV) and six of those eleven deaf children also had an intellectual disability. The control group was fourteen deaf children who had congenital hearing loss. Their research found that , while cochlear implantation was an effective management strategy for deaf children with CMV infection and an intellectual disability, their language outcomes were frequently poorer than those of deaf children with congenital hearing loss without an additional disability due to cognitive deficits associated with an intellectual disability (Yamazaki et al., 2012).

Sub-theme three: Augmentative and Alternative Communication systems (AAC)

Aided AAC devices should be prioritised in aural rehabilitation because they assist deaf and hard-of-hearing children with an intellectual disability in developing language skills through development of

expressive language as well as laying the groundwork for language and learning skills (Tucker Cohen et al., 2001; Davis et al., 2009; Lee, Jeong and Kim, 2013). Lee, Jeong, and Kim (2013) conducted a comparative study on 10 deaf children with intellectual disability who received a cochlear implant in South Korea. Five of the ten deaf children with an intellectual disability used a voice output communication aid (VOCA), while the other five did not. According to their findings, VOCA was an effective aid in improving expressive language and reducing challenging behaviours in deaf children with intellectual disability. Their research suggested that the parents of these children be counselled, encouraged, and trained to use VOCA. Parents of these children were encouraged to prompt their children to use VOCA by demonstrating how to use VOCA and providing physical guidance. This aided in the development of communication skills (Lee, Jeong and Kim, 2013). Their study highlighted that VOCA could be more effective than manual signs in families where communication partners of deaf children with an intellectual disability cannot understand manual signs (Lee, Jeong & Kim, 2013). It suggests that the VOCA would be useful for parents who do not understand Sign Language and have limited means of communicating with their children. A multiple baseline probe design study was conducted in the USA by Tucker Cohen et al. (2001) on 3 students with hearing loss and a mild intellectual disability to borderline intellectual disability. These students were provided picture dictionaries, which is an AAC system that can improve expressive language. They found that picture dictionaries were easily understood by communication partners, and it allowed students to communicate effectively in a variety of social settings (Tucker, Cohen et al., 2001). These pictures vocabularies have been developed for a USA context. If they were to be used in SA, the vocabulary would need to be adapted for our local context.

(b)Counselling

According to a few of the authors which included Filipo et al., 2004, Kunst et al., 2006 and Youm et al., 2013 counselling is beneficial for deaf and hard-of-hearing children and adolescents with an intellectual disability and their family members. The informational and psychosocial adjustment provided to this population and their family members gave them a better understanding of hearing loss and how it impacts their daily lives. Three of the articles (Filipo et al., 2004, Kunst et al., 2006 and Youm et al., 2013) noted that counselling for deaf children with an intellectual disability and their parents should aim to share information about the hearing loss diagnosis, assess cooperation to the suggested management plan, provide support when needed, and provide a clear picture of the child's capabilities, limitations, and benefits of the cochlear implant, allowing them to make an informed decision about the aural rehabilitation plan. A qualitative study by Filipo et al (2004) on 21 deaf children in Italy, 5 of whom had mild to moderate intellectual disability, indicated that counselling

should focus on providing information to the family members of deaf children on the diagnosis of hearing loss and the management plan (Filipo et al., 2004). When caregivers or parents are provided with practical counselling, such as information on how to use and maintain a hearing aid, it increases the likelihood of having improved speech and language outcomes (Kunst et al., 2006). Information provided during counselling can also aid in the development of realistic expectations. However, the benefit and performance after cochlear implantation, among deaf children with additional disabilities such as intellectual disability, differs according to the severity of the intellectual disability. This difference makes it harder to predict educational and developmental outcomes, thus making it more difficult to engage caregivers or parents with any concerns about future outcomes and expectations from aural rehabilitation (Youm et al., 2013).

(C) Practices

According to several authors which included Sakai, Watanabe & Kaga, 2002, Fukuda et al., 2003, Filipo et al., 2004, Bruce & Borders, 2015, and Friedman & McNamara, 2018 the most common communication interventions provided to deaf and hard-of-hearing children with intellectual disability were communication partner training and auditory training. The Bruce & Borders (2015) and Friedman & McNamara (2018) studies conducted in USA recommended that communication strategies should be provided to the child, their peers, and their family members during communication partner training. They found that when communication improves there is a decrease in disruptive behaviours and frustration that usually occurs when appropriate communication methods are absent. Auditory training is usually done post cochlear implantation and after hearing aid fitting. Auditory training focuses on a wide range of auditory skills such as detection, discrimination, identification, and comprehension (Olson, 2015). Fukuda et al., (2003) conducted a case study in Japan on a 10-year-old deaf child with profound hearing loss and moderate intellectual disability who received a cochlear implant. They highlighted that a deaf child with moderate intellectual disability had shown minimal benefit from bilateral hearing aids. However, once the child had received cochlear implants, speech therapy, and auditory training, he showed improved auditory and oral development (Fukuda et al., 2003).

(d)Availability of sensory management

According to several authors (Sakai, Watanabe, and Kaga, 2002; Fukuda et al., 2003; Kunst et al., 2006; Youm et al., 2013), deaf and hard-of-hearing children with an intellectual disability were previously excluded from receiving cochlear implants and bone-anchored hearing aids (BAHA) but they found

that these children can benefit from BAHA and cochlear implants, with improved speech, auditory or language outcomes. The articles note that, although their outcomes are generally poorer than deaf children without an additional disability, they should not be excluded from receiving such interventions. A retrospective clinical evaluation study conducted in the Netherlands by Kunst et al. 2006 focused on 22 participants with moderate intellectual disability who had a conductive or mixed hearing loss and were fitted with BAHAs. The bone-anchored hearing aids (BAHA) were developed as an alternative surgical option for patients with moderate-to-severe conductive or mixed hearing loss who are unable to be fitted with conventional behind-the-ear (BTE) hearing aids. They highlighted that prior to their study, children with a moderate intellectual disability and conductive or mixed hearing loss were excluded from receiving BAHAs. Health professionals doubted their ability to benefit from the BAHA and were concerned that their caregivers might not be able to cope with maintaining the device. Research findings were that these individuals and their caregivers could use and maintain the device as well as deaf children without an intellectual disability would do (Kunst et al., 2006). Their study recommended that these children, accompanied by their caregivers, have regular check-ups to prevent skin reactions that could jeopardize the success of the BAHA implantation, as well as yearly check-ins to improve caregivers' ability to handle and maintain the BAHA (Kunst et al., 2006). A retrospective study done in South Korea by Youm et al., (2013) made use of 28 prelingually deaf children, 14 with an intellectual disability and 14 with no additional disability (control group). Their study reported that when cochlear implants were first introduced, deaf children with additional disabilities, such as intellectual disability, were frequently not considered for cochlear implantation. This was due to concerns that these deaf children would not be able to process, analyse, and organize auditory information to the degree that deaf children without an additional disability would. Similarly, according to research conducted by Fukuda et al., (2003) and Youm et al., (2013), deaf children with an additional disability, such as an intellectual disability, should not be excluded from cochlear implant candidacy as these children showed improved language and speech outcomes post cochlear implantation.

Aural rehabilitation provided to deaf and hard-of-hearing children and adolescents with an intellectual disability helped to improve their academic performance. Improved hearing abilities and access to auditory stimuli improved incidental learning and access to information. These aural rehabilitation practices and tools led to improved speech, language, and auditory development. This in turn led to increased social interactions and participation at home, in their community and at school, as well as improving relationships with peers and family members. Aural rehabilitation that focuses on support from family members was associated with improved speech, language, and auditory outcomes for this population. The environment at home and at school has a significant role on outcome. A positive

supportive environment that accommodates these children is necessary to achieve maximum outcomes (Cupples et al., 2013; Cupples et al., 2018; Sakai, Watanabe, and Kaga, 2002; Fukuda et al., 2003; Kunst et al., 2006; Youm et al., 2013). The section below will discuss, expert consultation received while conducting this scoping review, a discussion of this scoping review and the implications of these findings of this scoping review as well as recommendations for future research.

Stage 6: Expert consultation

For this master's study, due to time and resource constraints expert consultation was limited to sessions with the supervisors.

3.3 Discussion of the scoping review

According to the findings of this scoping review, there are aural rehabilitation tools available for D/deaf and hard-of-hearing children and adolescents with an intellectual disability. This includes hearing aids, cochlear implants, and AAC systems. Communication partner and auditory training are most often used as aural rehabilitation practices for deaf children with a hearing loss and intellectual disability, globally and in SA. Although the studies included in this scoping review (except for one study) were conducted in high-income countries, the aural rehabilitation practices and tools discussed in this review are currently utilized in SA. However, as noted in the introduction, lack of funding and staff in SA might inhibit these aural rehabilitation practices and tools from being utilized optimally (Rutherford & Petersen, 2018; Makhoba & Joseph, 2016).

The findings of this scoping review also show that speech, language, and auditory outcomes of deaf and hard-of-hearing children and adolescents with an intellectual disability are generally poorer than those of D/deaf and hard-of-hearing children and adolescents who do not have an additional disability. The severity of the intellectual disability also has a significant impact on outcomes. The speech, auditory or language outcomes for D/deaf and hard-of-hearing children and adolescents with a profound intellectual disability were not discussed in any of the articles in this scoping review. This is important as the outcomes may be different from children and adolescents with a mild to severe intellectual disability, which were including in this scoping review (Holk & Kirk, 2004). Bertinni et al. (2018) conducted a study in Italy on 23 children after cochlear implantation, with 10 of these children having mild to severe intellectual disability. Their study recommendations are consistent with the findings of this scoping review. They recommended that, regardless of the severity of the intellectual

disability, aural rehabilitation in the form of cochlear implants should be considered, because it leads to improved auditory and communication skills, as well as increased social interactions and participation at home and school (Bertinni et al., 2018). Based on this scoping review, informational and psychosocial adjustment counselling is currently recommended for these children and their family members, as including the family members can improve speech, auditory and language outcomes. It can give them a chance to engage in aural rehabilitation, which will ultimately improve the relationships and the social interactions between them and the child. The emerging theme of this review was the lack of availability of sensory management, particularly for cochlear implants and BAHAs which require surgery, despite research indicating that deaf children with an intellectual disability can benefit from it. Hamazavi et al., (2000) conducted a study in Austria with 10 deaf children with an additional disability, including those with intellectual disability (n=6) who were fitted with cochlear implants. Their findings also indicated that deaf children with intellectual disability who received cochlear implants had better speech and language outcomes. Furthermore, their research discovered that parental involvement during aural rehabilitation is associated with significant improvements in speech and language outcomes. Their findings advocated for a family-centred approach to aural rehabilitation for deaf children with an intellectual disability (Hamazavi et al., 2000).

The implications of this scoping review are clear. Based on the numerous factors that influence the outcomes of aural rehabilitation, each management plan should be individualized and tailored to the child's specific needs. Aural rehabilitation practices and counselling should also be more family centred. When parents and other family members participate in sessions, the speech and language outcomes improve because they can practice the communication strategies provided at home with their child. Furthermore, deaf and hard-of-hearing children and adolescents with intellectual disability should not be excluded from receiving cochlear implants and should rather be more widely available to them as research has shown significant improvements with implantation.

3.4 Recommendations for future research

This review highlights the need for five key areas of research to improve the field for children and adolescents with co-occurring intellectual and hearing disability.

First, the studies reported in this scoping review found that when deaf and hard-of-hearing children and adolescents with a mild, moderate, or severe intellectual disability receive aural rehabilitation they showed improved speech, language, or auditory outcomes. This suggests that it may be beneficial for future research to concentrate on aural rehabilitation practices and tools for deaf and hard-of-hearing children and adolescents with profound intellectual disability, as well as auditory, speech, and language outcomes for these children (Holt and Kirk,2004).

Second, most studies concentrated on the sensory management component of aural rehabilitation rather than the other two components. In this scoping review, there were few studies that focused on other aspects of a comprehensive service required for providing holistic and contextually relevant aural rehabilitation, such as informational and psychosocial adjustment counselling, as well as communication interventions (Makhoba & Joseph, 2016). The other two components of aural rehabilitation should therefore be included more explicitly in the focus of future research on aural rehabilitation for this population.

Third, most of the studies focused on aural rehabilitation practices and tools for deaf and hard-of-hearing children with an intellectual disability who communicate orally with very little focus aural rehabilitation practices and tools for Deaf children with an intellectual disability. More research should be done which focuses implications of these aural rehabilitation practices and tools on sign language development and on aural rehabilitation practices and tools that aim to meet the needs of culturally Deaf children and their families, especially since they rely on sign language instead of spoken language to communicate (Health Profession Council of South Africa, 2019).

Four, there is a continuing need to understand how aural rehabilitation tools such as cochlear implants, hearing aids, and AAC systems can support both D/deaf and hard-of-hearing children with additional disabilities such as an intellectual disability, in receptive and expressive communication across communication modes. This can be used as evidence-based practice, and it will improve access to and receptivity of Deaf families to aural rehabilitation for D/deaf and hard-of-hearing children with an intellectual disability (Health Profession Council of South Africa, 2019; Nelson & Bruce, 2019).

Lastly, this scoping review found no studies conducted in Africa or South Africa. Future research, such as the current study, should be conducted in this context to determine how SA's rich linguistic diversity is accommodated in these aural rehabilitation practices (Kathard et al., 2007).

32.5 Conclusion

This scoping review highlighted current aural rehabilitation practices and tools used on deaf and hard-of-hearing children and adolescents with an intellectual disability, as well as the need to improve these practices and tools. Some of the practices and tools described in this scoping review are already being implemented in South Africa. These findings may not be applicable to children and adolescents with profound intellectual disability because they were not included in this review. The studies in this scoping review provided a solid overview of the factors that influence speech, auditory, and language outcomes for this population, which will help guide the rest of the study.

Chapter four: Results of the semi-structured interviews

Introduction

This chapter reports on the findings of the semi-structured interviews conducted with participants in this study, specifically audiologists (objective 2), young Deaf adults with intellectual disability (objective 3) and caregivers as well as parents (objective 4).

The analysis of the interview data is first reported in terms of the three components of Makhoba and Joseph's (2016) framework of aural rehabilitation, data related to the components of the ICF framework are embedded in the reporting of the findings across these three areas, where they emerged. Theme 4 relates more particularly to environmental considerations of the ICF framework. The themes reported on are counselling, tools, practices, and accessibility of audiology services.

These themes are elaborated below, with quotations to illustrate participants' firsthand experiences and perceptions of the issues raised.

Description of personal characteristics of the participants

- Young adult 1 developed bilateral profound hearing loss at the age of 16 to 17 after a brain injury from a car accident and is currently pursuing vocational training in sewing.
- Young adult 2 was born and raised in Cape Town. She was diagnosed with hearing loss at the age of 4 to 5. She has a profound hearing loss in one ear and a slight hearing loss in the other ear. She will be going to the National Institute of the Deaf (NID) training centre in Worcester to get a certificate in culinary arts next year.
- Young adult 3 was born in the Eastern Cape Province but raised in Cape Town. He was diagnosed with progressive hearing loss at a young age after being sick for a while, and currently has a profound bilateral hearing loss. He is pursuing vocational training in furniture making. He had previously attended two other schools for the D/deaf in the Western Cape Province.

- Young adult 4 was born Deaf, has a profound hearing loss bilaterally and is now pursuing vocational training in pottery.

All of the young adults communicated in SASL.

- Caregiver 1 worked at another school which was included in this study, and she studied at the NID College for five years. She started as an assistant teacher at school A and then started working as the hostel caregiver. She has been working as a caregiver there for 13 years.
- Caregiver 2 has been working at the school for 23 years. She started working at the kitchen in School B kitchen before working at the hostel, and spends most of her time with the young adults
- Parent 1 of young adult 1 was based outside of the Western Cape, but she sees the young adult 1 during school holidays and some weekends. She is currently unemployed but spends most of her time taking care of her other children.
- Parent 2 of young adult 2 was based in Cape Town and sees young adult 2 during the weekends and school holidays. She is also currently unemployed but is looking for work. Both parents are fluent in English and isiXhosa but preferred to communicate in isiXhosa.

The audiologists had an extensive experience in pediatric diagnostic audiology and aural rehabilitation, as well as working with children and adolescents with an intellectual disability ranging from about 5 to more than 20 years. They were all raised in the Western Cape. They preferred to communicate in English, but they could also communicate in Afrikaans.

Themes

(a) Theme one: Counselling

This theme represents the participants' views and experiences with informational and psychosocial adjustment counselling, as well as the impact it has on the outcomes of aural rehabilitation. According to the audiologists in this study, although counselling is provided, it is primarily done with the parents. Audiologist 2 and 3 both reported that the majority of initial information and psychosocial counselling happens with the audiologist at the hospital. The baseline audiological diagnostic assessment is done at the hospital, and they are fitted with hearing aids and cochlear implants there. They also found that sometimes additional informational counselling was needed and was provided in the follow-up sessions at the school with the audiologist. These sessions involved explaining the diagnostic

assessment results to the caregivers and parents and explaining what gains or benefits the hearing aids provide.

Interviewer: *''Do you provide informational and psychosocial adjustment counselling?''*…Audiologist 2: *''When the learner is placed at school A, the diagnosis and counselling already happened at the place of diagnosis which is normally a hospital. I am available for follow up sessions e.g., explaining the audiogram to the guardian, explaining what the learner can detect with hearing aids''.*

Interviewer: *''Do you provide informational and psychosocial adjustment counselling?''...*Audiologist 3: *'' I orient them, when necessary, on how to maintain and use the hearing aids or cochlear implants. I let them know the purpose of doing their audiograms annually.''*

Audiologist 2 and 3 stated that informational and psychosocial adjustment counselling was beneficial as it gives them the opportunity to understand the diagnosis and aural rehabilitation process. It also gives parents or caregivers the feeling that they could participate in decision making. They highlighted the valued role of parenting since they play a significant role in the child's wellbeing.

Interviewer: *''What impact do you feel informational and psychosocial adjustment counselling has on the lives of D/deaf and hard-of-hearing children/ adolescents and their guardians?''...* Audiologist 2: *''Guardians get a chance to understand what the diagnosis of deafness means.''*

Interviewer: *"What impact do you feel informational and psychosocial adjustment counselling has on the lives of D/deaf and hard-of-hearing children/ adolescents and their guardians?"...* Audiologist 3: *"I think they get an opportunity to understand what the diagnosis means and the management plan. I think it helps them cope better with the hearing aids or cochlear implants."*

When children are between the ages of 10 to 14 years old and start attending school, they receive informational counselling from the audiologist on topics such as how to use and maintain the hearing aid or cochlear implant, the purpose of the device, and the importance of annual audiograms. Audiologist 1 reported that once they can comprehend instructions and request assistance independently, they frequently inquire about how to use and maintain the device, and their audiological assessment results. It is necessary to provide them with this information in the form of informational counselling.

Interviewer: *''And in terms of counselling, do you provide them with any counselling? Do they require any counselling? ''* … Audiologist 1: "*Once you know the learners are about 10- 13 years old. They start having more questions because when they're younger, you deal with the parents and you try to explain to the children, but you don't really focus on them so much, which is a bit of a flaw in the way that we manage things, but, I found it quite beneficial to actually sit down with the learners when they're in*

that age range between, say, 10 and 14. Counsel them on what exactly is a hearing loss, what it means for them and what is an audiogram, what does it tell us about them and why do we keep doing hearing tests once a year, why do we keep bringing the hearing aids in for adjustments, that sort of thing. I do that with that age range. Then with the older learners and I do quite a bit for the school leavers. Towards the end of the year when they're leaving. I do a lot of preparation. How to access audiological services once they're outside of the school, sort of to prepare them to be independent and manage their devices on their own, so I do offer that sort of counselling. Then obviously across the board to support their parents.''

All the audiologists emphasized that the benefits of counselling can be limited with this population. This is due to associated cognitive deficits which impacts their abilities to comprehend language, regardless of the mode of communication. Audiologist 1 stressed that while counselling is beneficial, it is far less beneficial than for D/deaf and hard-of-hearing children who do not have an additional disability. They frequently require information to be presented concisely and shared repeatedly, and even then, it is not always clear that they have understood everything.

Interviewer: *''How do you feel about the information that you shared during counselling it? Do you feel like it has an impact on them?*"... Audiologist 1: *''With certain learners, yes but sometimes I do struggle. With our learners who do have ID. They mainly don't really understand. You've got to really break it down and sometimes it takes a lot of repetition. Even then, I'm not always entirely sure that, yeah, my counselling is effective, and there are one or two learners that I do worry about. You know, when they do leave the school, I'm like how they are going to be able to cope independently and not all of them can, and there are a few that, no matter how much counselling they get, they require very high levels of support, so they won't ever be able to, you know, do things independently.''*

Young adult 1 and 2, the two parents and caregiver 1 highlighted that the information provided during counselling is not always enough, or it is not always provided to them. Some of the young adults stated that they did not receive clear information regarding their diagnosis or how to use the hearing aids at the hospital, and the information was only shared with the parents.

Interviewer: *''Did you receive any information about the hearing aid/cochlear implant before you were fitted with the hearing aid/cochlear implant?''*... Young adult 1: *''they shared the information with my mother, my mother couldn't explain it to me, but they showed me how to use it,''*

Interviewer: *''Did you receive any information about the hearing aid/cochlear implant before you were fitted with the hearing aid/cochlear implant?''...* Young adult 2: *''I could not understand or communicate with the audiologist, they did not understand sign language but later they showed me how to use my hearing aids.''*

Interviewer*: ''Do you think that the information they do share do you feel like it is enough or not enough?''*...Caregiver 1*: ''No, it's not enough.''*

Interviewer: ''Do you think that the information they do share do you feel like it is enough or not enough?''...Parent 1: ''No, it was not enough when we found out my child's hearing loss, I did not completely understand how that would affect their life.''

Interviewer: ''Do you think that the information they do share do you feel like it is enough or not enough?''...Parent 2: ''No, it's not enough and also, I did not understand all of the information shared because they were speaking to me in English.''

The four young adults who communicate mainly through sign language noted a language barrier when communicating with most of the audiologists. Based on their experiences, the majority of audiologists they have encountered could not communicate in sign language fluently, and very few had a SASL interpreter to assist them. This also limits the benefits of counselling because it is difficult to share information when there is a language barrier.

Interviewer: *''Did you receive any information about the hearing aid/cochlear implant before you were fitted with the hearing aid/cochlear implant?''…* Young adult 2: ''I *could not understand or communicate with the audiologist, they did not understand sign language but later they showed me how to use my hearing aids''*

Interviewer: ''So, you said they always had an interpreter, so you did not have problems communicating with them'' … Young adult 4:''No, I did not''

Additionally, young adults, parents and caregivers were asked to reflect on their understanding of deafness, which they would have acquired from the information counselling they received from the audiologist.

Interviewer: *''Can you tell me a little bit about what you know about your deafness/ hearing loss?''*...Young adult 1: *''Hearing loss is when you cannot hear well, and you have problems communicating with others.''*

Interviewer: *''Can you tell me about what you know about hearing loss or deafness?''* ...Young adult 3*: ''I remember when I was a child with my friends, I could not hear anything, and my mom took me to hospital. That is when I heard about my hearing loss…I cannot hear anything, but I can feel vibrations''*

Interviewer: ''*What do you understand about deafness or hearing loss?''*… Caregiver 1: ''*So you do get different degrees of deafness and hearing loss so deafness is when someone is profoundly deaf, when someone is born hearing or they lose their hearing at a later stage that's why you would call hard-of-*

hearing and there are other people who can speak very well, there are other people who cannot speak they sign…some of them can lip-read so each one is different so I think it's all part of that''

Interviewer: *''Can you tell me what you understand by deafness or hearing loss?''…*Caregiver 2: *''They have partial hearing and a speech problem they communicate using sign language or they can lip-read''*

Interviewer*: ''What do you understand about deafness or hearing loss?''… Parent 1: 'It is when your child cannot hear properly, and they use sign language''*

According to the participants, informational and psychosocial adjustment is being provided, however, due to language barriers and cognitive deficits associated with an intellectual disability, and language barriers which negatively impacts language comprehension, some of the information is not being shared adequately. Students who were prelingually Deaf versus those who were post lingually Deaf had better language outcomes in relation to development of SASL thus found communicating easier. The benefits are more limited than they would be for deaf and hard-of-hearing children without an intellectual disability, and those caregivers who can communicate using spoken language. Likewise, when providing counselling to the parent, language barriers can be an issue. This is especially important since two of the parents preferred to communicate in a language the audiologist does not understand.

(b) Theme two: tools

This theme represents the participants' views and experiences on the tools utilized on this population. This included hearing aids and cochlear implants, as well as objective outcome measures which included any scales, questionnaires and checklists which are used to assess language and speech outcomes. This theme also represents the participants' views on the impact these tools have for this population.

Sub-theme one: hearing aids

All the young adults and the parents shared that hearings aids provided minimal benefit since they could not hear speech sounds, or they could barely hear speech with them. Hearing aids also did not provide much benefit to young adults because they communicated in sign language, with occasional lip-reading.

Interviewer: *''Can you please tell me how the hearing aid helped or not helped you to communicate with other people when you were a child or teenager''*…. Young adult 1: *''It didn't really help me, as I am Deaf, so I communicate using sign language.''*

Interviewer: *''Can you please tell me how the hearing aid helped or not helped you to communicate with other people when you were a child or teenager''*… Young adult 2: *''It didn't really help me, as I am Deaf, so I communicate using sign language. I can hear something in the one ear but it's difficult to listen to someone far away or to hear everything with that ear. Sometimes I get ear infections.''*

Interviewer: ''Can you please tell me how the hearing aid helped or not helped the young adult communicate with other people when they were a child or teenager''…. Parent 1: ''It didn't really help them since they communicate with others using sign language or manual signs. Even at home that's how they communicate with other people.''

Audiologist 1 reported that any improvement post hearing aid fitting, including speech and language outcomes and academic performance, is influenced by the severity of the intellectual disability.

Interviewer: *''Do you notice from children and adolescents with ID? Is there any improvement in their communication or quality of life after they received like a hearing aid or cochlear implant?''*…
Audiologist 1: *''Definitely, but also sometimes not so much. I'm sure you know with intellectual disability, it's such a broad spectrum. We've got some kids that thrive with amplification, and it really benefits them, and it helps their speech, and it really helps their learning.''*

Audiologists 3 reported that the benefit of hearing aids is influenced not only by the severity of the intellectual disability, but also by the degree of hearing loss. The more severe the hearing loss is, the poorer speech and language outcomes are.

Interviewer:*'' What impact do the amplification devices have on their communication and their quality of life?''….* Audiologist 3*: ''It improves spoken language for those with those with a mild to moderate hearing loss and for those with a profound hearing loss it makes them aware of environmental sounds. So, it depends on the degree of the hearing loss and the severity of the intellectual disability.''*

Sub-theme two: cochlear implants

The young adults who were interviewed could not provide information on their experiences with cochlear implants since they did not receive them, but they did understand what cochlear implants do. Caregiver 1 reported that some of the children she cares for struggled with cochlear implants because they are expensive to maintain. Due to the strict eligibility criteria and high cost of cochlear implants, no young adults received an implant, even under public healthcare.

Caregiver 1: *Now I see a lot of parents who are letting the children use cochlear implants and we hear a lot of complaints about it''*…Interviewer: *''What complaints do you usually hear?''*…Caregiver 1*: ''Yes you know some of the stuff like its expensive"*

According to audiologist 1, even with early detection and intervention, young deaf and hard-of-hearing children who receive a cochlear implant do not always have improved speech and language outcomes. The severity of an intellectual disability influences speech and language outcomes.

Interviewer: *"Is there any improvement in their communication or quality of life after they received like a hearing aid or cochlear implant?''* Audiologist 1: *"We've got a small boy, about five, and he had a cochlear implant since he was two and he's just not developing any speech. He's not developing any sign language like there's just no difference with him. Yes, it definitely does help some of the learners especially the hard-of-hearing learners.''*

Sub-theme three: scales, checklists, and questionnaires

The audiologists stated that scales checklists and questionnaires which are available are unsuitable and contextually inappropriate because they were not standardized for our South African context. As a result, these instruments were not recommended for good clinical practice by the audiologists. At best, the audiologists stated that some of questionnaires, scales and checklists could be used as a guide for therapy sessions.

Interviewer: *''In terms of aural rehabilitation tools, do you feel like there are any tools and resources that are suitable for them?"*… Audiologist 1: *''No, not really. Even when we're not talking about such a specific population such as ID, I find that the tools that are available are not necessarily relevant in our context. So, I tend to not use them. I don't find them useful. I go off script and find my own way to do things or just use them very informally as like rough guides.''*

Interviewer: *''Why do you feel like they're not relevant for our context?''* … Audiologist 1: *''So it's a bit of a tricky one because in South Africa, where we're quite behind and what we are able to offer like the services that we are delivering. It's not really good practical standard practice. Globally, in a first world country where all these schools are developed, they have so much more resources. Our children are identified much later, they'll have a tool that generally would be used overseas for, like kids under the age of three but our children mostly only get fitted, after six. They're not age appropriate, and they don't really match the level of service that we offer here in South Africa.''*

Interviewer: *''Do you feel that the aural rehabilitation tools and resources are suitable for D/deaf and hard-of-hearing children and adolescents with an intellectual disability?''…* Audiologist 2: *''No, most resources are standardised on a hearing population with normal intellectual abilities.''*

In summary, audiologists interviewed agree that tools exist, but they are not always appropriate or useful. Deaf young adults with an intellectual disability, their parents and caregivers included in this study reported that they benefit from hearing aids only minimally and communicate mainly using sign language. The audiologists reported that children with an intellectual disability who have a less severe hearing loss benefit more from hearing aids. Audiologists also noted that although cochlear implants are available, they are not readily accessible, and many children do not meet the full criteria for cochlear implant candidacy. In the case of checklists, questionnaires, and scales that can be used to assess speech and language outcomes, academic performance, and quality of life following the fitting of hearing aids and cochlear implants, they are available but are not appropriate in our South African context. South Africans has eleven official languages for communication, making the tests normed and verified on English speakers only largely unsuitable. Also, the age that deafness is identified in South Africa is later than in high income countries. The age norms for questionnaires, scales, checklists, and assessments are thus not suitable for use in South Africa.

(C) Theme three: Practices

The theme of practices covered communication intervention, which includes all other communication strategies and training aimed at improving communication and quality of life for this population. This theme also represents the impact of communication intervention for this population.

Due to her case load, audiologist 2 stated that communication intervention is not always possible. All the audiologists work alone and see large numbers of children. As a result, audiologist 2 stated that it is extremely difficult to meet all their needs.

Interviewer: *''Do you encounter any challenges when treating patients with a hearing and intellectual disability?*"...Audiologist 2: ''*Yes, they find it difficult to understand the instructions for testing, they find it difficult communicate their needs, they find it difficult to indicate that there is a problem with the hearing aid, sometimes they find it difficult to wear the hearing aid, they find it difficult to obtain funding to buy hearing aids plus there is a huge case load of 177: 1 so it's impossible to service everyone's needs''*

Audiologist 1 and audiologist 3 reported that a larger budget would help, because some of the communication intervention tools require funding to purchase. It will also allow for another audiologist to be employed to reduce the workload and allow more time to do communication intervention or therapy. Audiologist 3 also reported that the school has a speech therapist who helps with speech and language assessments and interventions, as this falls within their scope of practice.

Interviewer: *''Please elaborate on the types of communication interventions you provide''* …Audiologist 3*: ''We do have a speech therapist working at the school she provides speech and language therapy. There isn't much time to provide in depth communication interventions besides auditory training for those who use cochlear implants or those who communicate with spoken language. Most of the learners prefer to communicate in sign language.''*

Interviewer: ''*What do you think can be done to improve aural rehabilitation practices and tools for individuals of hearing and intellectual disability in our context?''…* Audiologist 1:
"It is very difficult when you are one audiologist at a school with over 100 learners. I feel like if there was an extra person, the testing would be done so much quicker, and the fittings would be done so much quicker and there would be so much more time for actual therapy''

In terms of participation impact, audiologist 2 also stated that the severity of the intellectual disability influences speech and language outcomes as well as overall improvements in quality of life and communication. The severity of an intellectual disability is related to cognitive abilities.

Interviewer: ''*What impact do you feel communication intervention has on the children and adolescents' participation in school and their overall quality of life?''*... Audiologist 2*: ''In some cases, it is a contributing factor to enhanced quality of life. The severity of the intellectual disability plays a role in the effectiveness of the communication intervention.''*

Hostel caregiver 2 and two of the parents highlighted that progress for this population is usually slow and usually less than D/deaf and hard-of-hearing children without an additional disability.

Interviewer: *''Do you feel like the sessions with the audiologist are helping or not helping them?''...* Caregiver 2: ''*It's a process. Everything doesn't change overnight, but with practice and talking or signing and interacting with other children there is progress''*

Interviewer: ''Do you feel like the sessions with the audiologist are helping or not helping them?''...Parent 1:''They did but I think the audiologist needs to work more closely with us together maybe that would help because the caregivers at the hostel and the parents know a lot more about the child''

Young adult 1 and young adult 2 also stated that while therapy sessions are sometimes available and the impact of these therapy sessions at home and at school which focuses activities and participation. They are not always easy to do due to a communication barrier.

Interviewer: ''*How have the sessions with the audiologist helped or not helped you to take part in activities at school and home when you were a child or teenager?*''… Young adult 1: ''*Sessions with the*

audiologist did not help me take part in activities at school or at home…because I communicate in sign language''

Interviewer: *''What do you think can be done to make the sessions you received from the audiologist better for children and teenagers with hearing loss and intellectual disability?*"...Young adult 2: *''If they understood sign language it would easier to communicate with them''*

In summary, the participants all agree that communication intervention training for the D/deaf is underutilized in schools for D/deaf. Audiologists cited time constraints, budget constraints, and a lack of additional staff as reasons, whereas young adults cited language barriers as a barrier to expressing their needs, which ultimately limits their ability to express a need for communication intervention. Furthermore, the caregivers and the parents were of the view that when communication intervention is provided, it resulted in progress in terms of speech and language development as well as improved academic performance. However, progress was at a slower rate and more limited than would be expected for Deaf individuals without an additional disability.

(d)Theme four: accessibility of audiology services

This theme represents the accessibility of audiology services and the impact it has on this population. Audiologist 1 highlighted that there are tools such as hearing aids and cochlear implants, and diagnostic assessments available for D/deaf and hard-of-hearing children and adolescents with an intellectual disability. In a South African context, however, special needs schools are the responsibility of the Department of Education. Provision of cochlear implants and hearing aids is the responsibility of the Department of Health. The quality of audiology services provided is also not consistent and is dependent on the catchment area hospital to which the child is referred. Children are diagnosed and fitted with amplification devices in hospitals before they start school.

Interviewer: *'' …And didn't these children come to the school with the hearing aids?''…* Audiologist 1: *''. For them to be admitted to a school, they have to be diagnosed with a hearing loss… Then usually they get fitted by the Department of Health because the Department of Education doesn't have a budget and that is another big challenge for me providing services is that the Department of Education doesn't make provision or doesn't budget for therapy services other than to pay our salaries. So, any resources that I need…, we have to go through the Department of Health… according to their catchment area, and then once they start attending school, I then take over the management. It works differently with different hospitals, some like a hospital like Red Cross. If I have a patient that falls under them if they need new hearing aids or something, if it breaks and they need to be replaced then Red*

Cross will send the hearing aids to the school and I will do the fitting at school so that the child doesn't have to miss any days of school. But other hospitals like Tygerberg and Groote Schuur fits themselves… it's sort of just depends on the hospital.''

The two caregivers supported this. They stated that hearing aids are expensive, and if someone loses it, they will usually be unable to afford a new one. Also, the waiting period for an appointment at the hospital is quite long.

Interviewer: *''I know that some of the children have hearing aids and cochlear implants when they come to you, do you receive information about them from the audiologist?''*... Caregiver 2: *''I never knew that hearing aid is so expensive afterwards I found the value of it…''*

Interviewer*: ''Do you think that the information they do share do you feel like it is enough?'' … Caregiver 1:'' No, it's not enough but then when the children lose the hearing aids you have to request for them to get them again or someone to sponsor them so… the children have to go back to hospital to fetch the hearing aid again …and you have to wait very long and sometimes you wait up till 6 months to get an appointment and here at school they don't have hearing aids which they can just give to the children''*

These participants emphasized that, while audiology services (including aural rehabilitation) are available in our context, they are not always as easily accessible as they should be. They are also not always affordable. It is also clear that, while audiology services are available through hospitals, not all hospitals provide the same level of service.

Chapter five: Discussion

5.1 Introduction

The study aimed to provide qualitative insight into the experiences and perceptions of audiologists, D/deaf and hard-of-hearing young adults with an intellectual disability, as well as their caregivers and guardians, of aural rehabilitation practices and tools used in schools for the D/deaf. The study emphasized various aspects of aural rehabilitation, including factors that influence this population's speech and language outcomes. These factors include age of the child, severity of the intellectual disability and hearing loss as well as type of sensory management used (Meinzen-Derr, Wiley, Grether & Choo, 2009; Meinzen-Derr, Wiley, Grether & Choo, 2011). Most of the study's findings agree with the literature from the scoping review. While aural rehabilitation practices and tools such as communication intervention, counselling and sensory management can be implemented on D/deaf and hard-of-hearing children and adolescents with an intellectual disability, their outcomes are generally poorer than D/deaf and hard-of-hearing children and adolescents without an additional disability (Meinzen-Derr, Wiley, Grether & Choo, 2011). This implies that the speech, auditory and language development may be poorer for this population compared to D/deaf and hard-of-hearing children and adolescents without an additional disability. This discussion will firstly summarise key findings, then elaborate on the implications of the study for local service development, note the limitations of the study, make recommendations which emerge from the study's findings and then include a brief summative conclusion to the study.

a) Counselling

According to the audiologists who took part in this study, there is a clear benefit to providing counselling to D/deaf children or adolescents, as well as their caregivers and parents. This is in keeping with the literature which notes that counselling enables parents to make well-informed decisions about their children's' management plan and increases the likelihood of parents participating in aural rehabilitation (Wiseman & Warner-Czyz, 2018). The findings of the interviews suggest that when providing counselling to D/deaf children and adolescents with an intellectual disability there are two factors that impact the effectiveness: 1) the severity of the intellectual disability and 2) language barriers. One Deaf caregiver, two parents and all four Deaf young adults in this study reported that a language barrier has a significant impact on effectiveness. Language barriers made it increasingly difficult to share information and communicate with the audiologists. The stakeholders' views concur

with the findings of the scoping review which holds that cognitive abilities influence one's ability to comprehend language. The severity of an intellectual disability can also have a negative impact on the effectiveness of counselling (Luft, 2022). Successful communication between both parties is essential for effective patient-provider interactions (Penn, 2007). This implies that to mitigate such challenges, it is recommended that healthcare professionals have access to the services of a trained interpreter who is familiar with the culture and context and is bound by confidentiality (Weiner & Rivera, 2004). The Health Professions Council of South Africa (2019) notes that increasing SASL fluency is also recommended for audiologists, especially those who work close to Deaf people as in the case of educational audiologists at schools for the D/deaf (Health Profession Council of South Africa, 2019).

b) Aural rehabilitation tools

According to the literature in the scoping review, aural rehabilitation tools were divided according to cochlear implants, hearing aids, AAC systems and subjective outcome measures in the form of checklists, scales, and questionnaires. However, in the interviews, not all the tools which emerged from the scoping review were mentioned or found relevant by the audiologists interviewed in this study. The literature in the scoping review did not agree with the data collected from the interviews. Interviews highlighted that the scales, questionnaires, and checklists used to determine speech and language outcomes are irrelevant and inappropriate for this context. The participants in this study discussed all the tools except AAC systems, which was discussed in the literature in the scoping review.

Sub-theme one: hearing aids

The scoping review and the interviews highlight that the severity of the intellectual disability and level of hearing loss has a significant impact on speech and language outcomes post fitting of hearing aids for this population (Luft, 2022). This implies that that sensory management in the form of hearing aids alone is not enough to improve speech or language development, and additional tools such as AAC systems will be required for this population to develop spoken language (Nelson & Bruce, 2019).

Sub-theme two: cochlear implants

Both the scoping review and interviews with the audiologists supports the view that deaf children and adolescents with an intellectual disability who have minimal to no benefit from hearing aids can receive significant benefit from cochlear implants, since it provides direct stimulation to the auditory nerve (Holt and Kirk, 2004). The severity of the intellectual disability has significant impact on speech and language outcomes post cochlear implantation (Luft, 2022). Audiologists in this study also noted that the more severe the intellectual disability, the poorer the speech and language outcomes likely for children, because cognitive deficits associated with an intellectual disability negatively impact

speech and language development. Cochlear implants may allow deaf children with an intellectual disability to not only develop speech and language, but it also improves behaviour and social skills, motor, and cognitive development. This leads to an improvement in overall quality of life for these children (Meinzen-Derr, Wiley, Grether & Choo, 2009; Wiseman & Warner-Czyz, 2018). However, in the study, none of the participants had access to cochlear implants because of the prohibitive cost of buying and maintaining them, and because public health and educational facilities have strict eligibility criteria for cochlear implantation services. In South Africa, audiology services are poorly resourced, and it is thus not possible to provide this population with these services (Makhoba & Joseph, 2016; Rutherford & Petersen, 2018).

Sub-theme three: AAC systems and subjective outcome measures

Checklists, scales, and questionnaires can be used as subjective outcome measures. However, the findings of the interviews suggests that these tools are not suitable for children with an intellectual disability, since they were standardized for children with typical intellectual abilities (Bagatto et al., 2011). Students with significant intellectual challenges such as students with an intellectual disability may necessitate more supportive communication options and devices, such as increased use of visual language and/or modalities which can be provided using AAC systems (Luft, 2022).

c) Communication intervention

The information gathered from interviews with all the participants indicate a lack of communication intervention for this population. All the young adults confirmed that they do not receive any audiology services besides diagnostic assessments, counselling, and sensory management. Audiologists highlighted lack of staff and budget as reasons for a lack of communication intervention with this population. The literature highlighted communication interventions which can be used on this population includes lip-reading, communication partner training and auditory training (Makhoba & Joseph, 2016). The literature in the scoping review indicates a need to emphasize communication intervention to improve the quality of aural rehabilitation provided to this population. However, once again, achieving this in a low-resourced setting with competing priorities and a limited fiscus, remains a challenge.

d) Accessibility and availability of audiology services

The scoping review also suggested that cochlear implants are not always readily available for deaf and hard-of-hearing children and adolescents with an intellectual disability, since there is skepticism on how much benefit they would receive from cochlear implantation. This was also evident in the data collected from the interviews. In SA, they are not considered for cochlear implantation due to not

meeting the full criteria. The requirements for financial criteria, which state that these children's families should be able to cover costs, make it difficult for this population to receive cochlear implants as many of them cannot afford this (Kerr et al., 2012). The South African public healthcare provides free hearing aids to children under the age of six, although availability is inconsistent (Khan, Joseph, & Adhikari, 2018).

The interviews make it clear that more funding is needed to make audiology services more accessible in SA for D/deaf and hard-of-hearing children and adolescents with an intellectual disability. A systematic review conducted in SA by Capri et al., (2018) highlighted that children with an intellectual disability are five times less likely to receive rehabilitation services than children with physical disabilities. This also goes against their right to access the best available healthcare without discrimination or exclusion resulting from their disability, as outlined in Article 25 of the UNCRPD (UNCRPD, 2006). Inadequate access to assistive devices is compounded by additional challenges such as healthcare budget, which prioritizes improving health outcomes such as life expectancy, and decreasing the burden of disease (Kerr, Tuomi, & Müller, 2012).

According to the interviews the participants still have access to audiology services provided by the audiologist at school as they are still completing vocational training, but there is a need for them to achieve independence by getting a job once they finish school. Once completed, they will register with the only accredited occupational training institution in Africa. Deaf students from South Africa enroll with the NID College, and on successful completion of their studies they receive accredited international certification in occupational training. Students receive training in specific trades, as well as training in communication and life skills which go together with technical training in the industry. This process ensures that the students are properly equipped to enter the open labour market with confidence. NID College boasts a 90% success rate in work placement. This training will enable them to get access to jobs and achieve independence, which will enable them to afford access to audiology services (NID, 2022).

Based on the information provided during the interviews by the Deaf students they currently do not feel as if they are benefiting as much from audiology services. They do feel as if they are benefiting in terms of being at school, having access to support in the form of their peers and having access to vocational training which will ultimately prepares them for the training they will be receiving at NID College. They believe that this will improve their quality of life. As highlighted by the caregivers and parents' Deaf children spend most of their time at the school. They struggle to communicate with people in the hearing community, including their family members. When they are at school, they have a sense of belonging, and the sign language taught at school enables them to communicate with

others. The audiologists highlighted that they do prepare D/deaf and hard-of-hearing students with an intellectual disability for life after school by providing them with information on accessing audiology services once they complete school.

5.2 Implications of the study

The first step toward effective aural rehabilitation is the government's adoption and implementation of relevant policies aimed specifically at managing hearing loss. Access to audiology services for D/deaf children with an intellectual disability is inherent in this (Beswick et al., 2021). Based on the data gathered from the interviews, here is a strong need for the Department of Health and Education in SA to collaborate more closely to improve accessibility of audiology services for this population.

It is very clear from the data collected during the interviews and the review of literature that aural rehabilitation for this population focuses mostly on the sensory management component. All three components must be included for aural rehabilitation to be effective and holistic, especially for D/deaf and hard-of-hearing children and adolescents with an intellectual disability (Boothroyd, 2007; Makhoba & Joseph, 2016). The findings of the interviews and the scoping review also implies that there is a need for the audiologists to improve their practices for this population. There is a clear need to advocate for communication intervention to be provided for this population and their families at school, rather than just sensory management. This should start with increasing funding and budgeting for more audiologists at each school for the D/deaf, to assist them to have sufficient time to deliver this more comprehensive service to these children. It can be argued that using budgetary constraints as a reason for holistic services not to be provided to this population in South Africa is a matter of political will. To train and employ audiologists who do not have the basic ability to communicate effectively with the children and their guardians is an inefficient use of this resource, and of the investment made in training this cadre of health/education workers in the first place.

Lack of political will is reflected in a lack of implementation of policies, even with legal proceedings. The Western Cape Forum of Intellectual Disability filed a case in the Western Cape High Court against the Government of the Republic of South Africa and the Government of the Province of Western Cape which highlighted the challenges of the D/deaf and hard-of-hearing population with intellectual disability and placed it on the policy agenda. However, appropriate, and adequate implementation of the court ruling and the policy document that subsequently came out of this process, is still sorely lacking.

There should be more sign language classes made available to teachers, and caregivers to reduce communication barriers when working and communicating with Deaf children, adolescents, and young adults at the schools for the D/deaf. Although organizations such as DeafSA offer sign language classes

for parents of these students there is still a need to encourage and motivate parents to take these classes. Deaf students are mostly born to hearing parents, and there is a great need to improve communication between parents and children. As highlighted in this study, Deaf students struggle to communicate their thoughts and needs with their parents and other family members. Life for these students mainly consists of the time they spend at the schools for the D/deaf.

According to the literature, the needs of this population are distinct, and they present with many challenges different to D/deaf and hard-of-hearing children without an additional disability. A more family-centred approach to aural rehabilitation is necessary (Palmieri, Forli & Berrettini, 2014; Nelson & Bruce, 2019; Luft, 2022).

According to the data gathered from the interviews and the literature, there is limited research and practice of communication intervention for this population, as well as limited aural rehabilitation tools. AAC systems, which has been highlighted as a vital part to improving receptive and expressive language for this population (Nelson & Bruce, 2019), are rarely used. More tools, such as scales, checklists, and questionnaires should be developed and standardized for a South African population. Most tools are not available in the various South African languages, for children with typical intellectual abilities and those with an intellectual disability. This might be challenging considering SA is a resource-constrained middle-income country, unable to provide the first world facilities and services accessible in high-income countries.

Children with hearing loss are primarily placed in the country's small number of schools for the D/deaf. There aren't enough of these schools to meet the needs of D/deaf South African children. Like other schools in the public schooling system the schools included in this study are under-resourced, with overcrowded classrooms and high teacher-child ratios (Human Sciences Research Council, 2018). There is a clear need to not just increase the budget for audiology services, but also to increase funding to allow for the smaller classrooms where the needs of these children will most likely be met by teachers and audiologists.

It is also clear from the data collected from the interviews that there is a need for more advocacy for aural rehabilitation for D/deaf and hard-of-hearing children and adolescents with intellectual disability and their caregivers or parents. Especially since it was stressed in the literature that whether the D/deaf and hard-of-hearing children and adolescents had a mild, moderate, or severe intellectual disability, they showed improved speech, language, or auditory skills, as well as an overall improved quality of life. However, improvement is dependent on the severity of the intellectual disability (Palmieri, Forli & Berrettini, 2014; Luft, 2022).

5.3 Limitations of this study

a) Since the interviews did not include any D/deaf or hard-of-hearing young adults with a severe to profound intellectual disability and the scoping review did not cover this population with a profound intellectual disability, the findings of this study are only applicable this population with a mild to severe intellectual disability.
b) The study results focused on aural rehabilitation practices and tools used on D/deaf and hard-of-hearing students with a coexisting intellectual disability in special schools and will therefore not necessarily reflect services provided to children and adolescents in mainstream schools or hospitals. The study results may not be generalizable outside of the Western Cape Province. Aural rehabilitation practices and tools utilized in schools for the D/deaf in the Western Cape Province might not be the same aural rehabilitation practices and tools utilized in the rest of country. Since this was a qualitative research project, the sample size was quite small.
c) While interviews were conducted until data saturation was reached, insights from other D/deaf and hard-of-hearing young adults with an intellectual disability and their caregivers in other settings may have provided new insights.
d) Language differences may have repercussions because concepts in one language may be understood differently in another language. This is especially true for qualitative research, which involves the use of words. Data are crucial at every stage of the process, from data collection through data analysis and reporting of the data. For qualitative research to be valid, the data obtained by the researcher must be comparable and representative. The employment of a trained SASL interpreter helped reduce the loss of rigour in languages (van Nes, Abma, Jonsson & Deeg, 2010).
e) The results of this study might not be applicable for children with severe and profound intellectual disability since they were not included as participants in this study.
f) Back translation of these interviews, and of the SASL to English interviews was not done due to resource constraints for the study.

5.4 Future research recommendations

a) Future research should focus on deaf and hard-of-hearing participants to evaluate if speech and language outcomes, as well as quality of life, have improved post-aural rehabilitation.
b) Studies should also be conducted on participants from other South African provinces to determine how aural rehabilitation practices and tools used on this population compare to those provided in the Western Cape Province.

c) Future research studies should include older D/deaf and hard-of-hearing participants with an intellectual disability, aged 25 to 35, to see how their quality of life and speech and language outcomes have changed since receiving aural rehabilitation services at the special schools.
d) Future research studies should be conducted in other settings, such as hospitals, to determine how aural rehabilitation practices used with D/deaf and hard-of-hearing children and adults with an intellectual disability differ from services provided in special schools.
e) Given that most diagnostic audiological assessments and sensory management are performed at the hospital, future research studies may be able to overcome the study's limitations in this setting.
f) Community based studies through organisations offering services to D/deaf individuals may also provide greater input from families regarding the delivery of audiological services.

6. Conclusion

Aural rehabilitation practices and tools that are utilized on D/deaf and hard-of-hearing children and adolescents without an additional disability, are also utilized on D/deaf and hard-of-hearing children and adolescents with an intellectual disability. This is even though their speech and language outcomes are generally poorer. The severity of intellectual disability is a major factor influencing this population's speech, language, and auditory outcomes. The findings of this study clearly indicate that aural rehabilitation practices and tools should be selected based on the needs of the child or adolescent, and a family-centred approach to aural rehabilitation is encouraged. The findings of this research study indicate that there is a significant need for additional research focusing on aural rehabilitation practices and tools utilized on this population in other settings in a South African context.

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Appendix A: recruitment flyer

D/deaf and hard-of-hearing young adults with a coexisting intellectual disability and their guardians' experiences of aural rehabilitation practices and tools utilized in public schools for the D/deaf in the Western Cape, South Africa

Who am I?

My name is Sandiswa Mashologu, and I am an audiologist as well as a masters student at the University of Cape Town. My supervisors are Mr Siyabulela Mkabile and Professor Sharon Kleintjes. This study will be done for my studies at the university. The study has been approved by the Faculty of Health Sciences' Human Research Ethics Committee (HREC) and the HREC reference number is 781/2021.

For more information, please contact me at 0647929561/ sandiswamashologu65@gmail.com or supervisors: Mr. Siyabulela Mkabile (s.mkabile@uct.ac.za) and Professor Sharon Kleintjes (sr.kleintjes@uct.ac.za, 0216502147) at the University of Cape Town, Faculty of Health Sciences, Department of Psychiatry and Mental Health (Division: intellectual disability), Neuroscience Institute, Groote Schuur Hospital, Anzio Rd, Observatory, 7925.

Why will this study be done?

An audiologist is a person who works in health, tests people's hearing, helps people cope with their hearing loss, and is a person who helps people with hearing loss communicate better with other people. Aural rehabilitation includes giving hearing aids to people with hearing loss so that they can hear better. It also includes giving information or treatment that can help people with hearing loss communicate better with other people. Intellectual disability limits a person's ability to learn information and function in their daily life.

This study will aim to find out audiologists' thoughts and experiences of aural rehabilitation practices and tools used on children and teenagers with intellectual disability and hearing loss. This study will also aim to find out your experience of aural rehabilitation which you received from an audiologist when you were a child/teenager. This study will also aim to find out your parent/ guardian's thoughts and experiences on aural rehabilitation which was provided to you by an audiologist.

How and what information will I collect?

I will ask you questions about your experiences of aural rehabilitation which was provided to you. I will also interview your guardian to find out their experiences and thoughts on aural rehabilitation which was provided to you.

When will this be done?

I will set a date and time to interview you and your parent/ guardian at the school.

What will happen when if agree to take part in this interview?

I will take a video recording of the interview and use this recording to go over the information you have shared in the interview at a later stage. Your personal details will not be included in the write-up of the study. You may choose not to take part in this study at any time during the interview. There are no risks in taking part in this study. Refusing to take part in the study will not affect your schooling or the services you are receiving at the school or in healthcare.

Appendix B: questionnaire for audiologist

1. How long have you been providing aural rehabilitation for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability?

2. Let's talk about what you provide in terms of aural rehabilitation for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability at schools for the D/deaf.

    a. Do you encounter any challenges when treating patients with a hearing and intellectual disability?
    b. What are those challenges you encounter?
    c. Have you been able to overcome these challenges?
    d. What has assisted you to do so?

3. Let's discuss the sensory management that you provide to this population.

    a. Do you provide hearing aids or other forms of amplification devices?

    b. What impact do the amplification devices have on their communication and their quality of life?

    c. Do you see children who have received cochlear implants? If yes, please explain what impact the cochlear implants have on their communication and their quality of life?

4. Let's discuss the types of counselling provided to the children/ adolescents and their guardians.

    a. Do you provide informational and psychosocial adjustment counselling?
    b. What impact do you feel informational and psychosocial adjustment counselling has on the lives of D/deaf and hard-of-hearing children/ adolescents and their guardians?

5. Let's discuss the communication intervention you provided to this population.

    a. Please elaborate on the types of communication interventions you provide.
    b. Do the guardians of the D/deaf and hard-of-hearing children and adolescents actively participate or assist in communication intervention? If not, can you provide reasons why they do not actively participate or assist?
    c. How do the guardians assist or participate in communication intervention?
    d. What impact do you feel communication intervention has on the children and adolescents' participation in school and their overall quality of life?

6. Let's discuss the aural rehabilitation tools and resources that you have for patients with hearing and intellectual disability.
    a. Do you feel that the aural rehabilitation tools and resources are suitable for D/deaf and hard-of-hearing children and adolescents with an intellectual disability? Please elaborate.
    b. What impact do you feel do these aural rehabilitation tools and resources have on their communication skills, social interactions with other children in the school, and their participation in the classroom?
    c. What are the strengths and limitations of the aural rehabilitation tools and resources available to you?
    d. Do you know any other aural rehabilitation tools and resources you would recommend that are suitable for D/deaf and hard-of-hearing children and adolescents with an intellectual disability?
    e. Why would you recommend these aural rehabilitation tools and resources?
7. Are you familiar with the use of the terms Deaf with a capital D and deaf with a small d? What impact does this have on your work with deaf and hard-of-hearing learners and their families, if any?
8. How does aural rehabilitation provided at this school fit in with the South African Sign Language (SASL) use policy?
9. How open are Deaf school-going children and adolescents and their families to aural rehabilitation?
10. What do you think can be done to improve aural rehabilitation practices and tools for individuals with hearing and intellectual disability in our context?
11. Has your approach to aural rehabilitation changed since the COVID-19 pandemic? Please elaborate
12. Is there anything from your experience that you would like to share that you feel is important to consider, that I might not have addressed.

Appendix C: questionnaire for young adults with an intellectual disability and a hearing loss

- Please tell me a little about yourself,
- What grade or studies are you doing this year, or the work you do if you already have a job?
- Who do you live with?

1. Can you tell me a little bit about what you know about your deafness/ hearing loss?

2. Can you tell me what your main way of communicating with others is?

    a. Do you use Sign Language, spoken language and lip-reading, or both?
    b. How do you prefer to communicate with others?

    c. What is the main way in which your family communicates with you?

3. Are you a member of your local deaf community or do you spend most of your time with the hearing community?
    a. Where do you feel most comfortable, and can you tell me why?
    b. What do you think would help you be more comfortable?
4. What do you understand by intellectual disability? What term is/was used at school?
5. Can you please tell me what an audiologist is? (Pictures will be used to show what each element entails)
6. Can you tell me what you know about hearing aids and cochlear implants?
    a. Have you ever been fitted with a hearing aid, or did you receive a cochlear implant?
    b. When were fitted with a hearing aid or when did you receive a cochlear implant?

    c. Did you receive any information about the hearing aid/cochlear implant before you were fitted with the hearing aid/cochlear implant?

    d. Can you please tell me how the hearing aid or cochlear implant has helped or not helped you to communicate with other people when you were a child or teenager?

7. What impact did having an intellectual disability have on services you have received?

8. Has your intellectual disability had any effect on how you have been able to communicate/use your hearing aids/use your cochlear implant?

9. Were you given information on how you can communicate better with other people?

10. How did this information help you communicate better with other people?

11. How did you find communicating in noisy and quiet places after receiving sessions with the audiologist? – this question will be asked if the participant uses oral communication.

12. How have the sessions with the audiologist changed or not changed your learning at school?

13. How have the sessions with the audiologist helped or not helped you to take part in activities at school and home when you were a child or teenager?

14. Did you have any problems when communicating with the audiologist when you were a child or teenager? If yes, please tell me what these problems were.

15. What do you think can be done to make the sessions you received from the audiologist better for children and teenagers with hearing loss and intellectual disability?

16. What changed in the sessions you received from the audiologist since COVID-19 started? Ask this question if the young adult is still attending school.

Appendix D: questionnaire the guardians and caregivers of the young adults

- Please tell me a little about yourself,
- How are you related to the young adult (young adult's name)?
- Who, besides the young adult, do you live with?

1. Can you tell me a little bit about what you know about the young adult's deafness/ hearing loss?
2. Can you please tell me what an audiologist is?
3. What do you understand by intellectual disability? What term is/was used at the young adult's school?
   a. Can you tell me what you know about hearing aids and cochlear implants?
   b. Were you told how you can help the young adult use and look after their hearing aid/cochlear implant at that time?

   c. Did she/he and you receive any information about the hearing aid/cochlear implant before the young adult was fitted with the hearing aid or received a cochlear implant?

   d. Was the information enough?

   e. What other information would have helped you and the young adult when they were a child or teenager?

   f. Were you given information on how you can communicate better with young adult now and when they were a child or teenager?

4. How did you find communicating with him/her in noisy and quiet places now? – this question will be asked if the participant uses oral communication.

5. Let's discuss how did he/she cope at school after receiving sessions with the audiologist.
   a. Did the sessions with the audiologist change or not change his/her learning at school?

   b. Did the sessions with the audiologist help or not help him/her take part in activities at school?

6. Did you encounter any problems when communicating with the audiologist at that time? If yes, please explain what these problems were.

7. What do you think can be done to make the sessions you and the young adult received from the audiologist better for children and teenagers with a hearing loss and intellectual disability?

8. Has the young adult's intellectual disability had any effect on your work with the audiologist?

Appendix E: consent forms for the audiologists

D/deaf and hard-of-hearing young adults with a coexisting intellectual disability and their guardians' experiences of aural rehabilitation practices and tools utilized in public schools for the D/deaf in the Western Cape, South Africa

Who am I?

My name is Sandiswa Mashologu I am an audiologist , and I am also a masters student at the University of Cape Town. My supervisors are Mr Siyabulela Mkabile and Professor Sharon Kleintjes.

Why is the research done?

I am doing a research project on D/deaf and hard-of-hearing young adults with a coexisting intellectual disability and their guardians' experiences of aural rehabilitation practices and tools utilized in public schools for the D/deaf in the Western Cape, South Africa. This research project will be done for degree purposes. The study has been approved by the Faculty of Health Sciences' Human Research Ethics Committee (HREC) and the HREC reference number is 781/2021.

The purpose of the study will be to investigate your perceptions and experiences of aural rehabilitation practices and tools for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in schools in the Western Cape, South Africa. This study will also investigate D/deaf and hard-of-hearing young adults with intellectual disability experiences of aural rehabilitation tools and practices that were utilized on them when they were children and adolescents. This study will also investigate of guardians these young adults' experiences and perceptions of aural rehabilitation practices and tools that were utilized on young adults when they were children and adolescents.

How will you be involved if you agree to participate in the research?

I would like to interview you and gather information on your perceptions and experiences of aural rehabilitation practices and tools for D/deaf and hard-of-hearing children and adolescents with a coexisting intellectual disability in schools for the D/deaf. You will receive the interview schedule before the interview. This interview will take approximately 1 hour to complete. Notes will be taken on everything discussed and audio recordings will be taken during the interview. Audio recordings will be taken so that the researcher can analyse the data from the interviews at a later stage. You may choose not to participate in the interview at any time , with no risks or associated consequences. Please remember there are no right or wrong answers. I will describe the information you and other participants provide in a report called a dissertation and a shorter report called an article.

What are the benefits of participating in the research?

There are no direct benefits to taking part in this study. This study will allow you to reflect and discuss all your experiences and perceptions of aural rehabilitation resources and tools currently or historically utilized on D/deaf and hard-of-hearing school-going children and adolescents with a coexisting intellectual disability. The information that you and other participants provide will be used to make recommendations for future practice and research on aural rehabilitation for intellectually disabled and D/deaf or hard-of-hearing children and adolescents in Western Cape, South Africa.

What are the disadvantages of participating in the research?

They are no disadvantages associated with participating in this study.

What are the risks of participating in the research?

There are no potential risks associated with participating in this study.

How will your personal details remain confidential?

Your name and your personal details shared will not be mentioned in the write-up of this study. Your details will be kept private. The researcher and the supervisors will be the only people who have access to your personal details. When we use the recordings, all hints that lead us to know that you participated in the study will be hidden, so no one else will be aware that I interviewed you. The information you provide will be kept in a secure place.

What will happen if I decide to not take part in the research?

Participation in this research study is entirely voluntary. You may decide to withdraw consent to participate in this study at any point of the interview. There are no risks associated with this. Refusing

to take part in the study will not affect your position with me, at the school/s for the D/deaf or at your workplace.

If you have any concerns or questions feel free to raise them before, during, or after this interview or you can contact me using the contact details provided below.

- Researcher: Sandiswa Thozama Mashologu (0647929561, mshsan007@myuct.ac.za)
- Supervisors: Mr Siyabulela Mkabile (s.mkabile@uct.ac.za) and Professor Sharon Kleintjes (sr.kleintjes@uct.ac.za, 0216502147)
- Institution address: University of Cape Town, Faculty of Health Sciences, Department of Psychiatry and Mental Health (Division: intellectual disability), Neuroscience Institute, Groote Schuur Hospital, Anzio Rd, Observatory, 7925
- If you have any concerns about how this interview and study is conducted as well as your rights as a participant, please contact Prof. Marc Blockman, Chair: Faculty of Health Sciences' Human Research Ethics Committee, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town, (021) 406 6626, Email: ethics@uct.ac.za.

If you agree to take part in this study, please sign below

I, ~~(Name and Surname) give in full i~~nformed consent to participate in this interview on (date)

_____

Signature _____

If you agree to recording of this interview, please sign below

, _____ (Name and Surname) give full informed consent for this interview to be recorded on_(date)

Signature _____

_____ Researcher

_____ Signature

_____

Date

Appendix F: consent forms for the young adults with an intellectual disability and a hearing loss

D/deaf and hard-of-hearing young adults with a coexisting intellectual disability and their guardians' experiences of aural rehabilitation practices and tools utilized in public schools for the D/deaf in the Western Cape, South Africa

Who am I?

My name is Sandiswa Mashologu, and I am an audiologist as well as a Masters student at the University of Cape Town. My supervisors are Mr Siyabulela Mkabile and Professor Sharon Kleintjes. This study will be done for my studies at the university. The study has been approved by the Faculty of Health Sciences' Human Research Ethics Committee (HREC) and the HREC reference number is 781/2021. An audiologist is a person who works in health, tests people's hearing, helps people cope with their hearing loss, and is a person who helps people with hearing loss communicate better with other people.

Aural rehabilitation includes giving hearing aids These help people with hearing loss so that they can hear better. It also includes giving information or treatment that can help people with hearing loss communicate better with other people. Intellectual disability limits a person's ability to learn information and function in daily life.

Why is the study done?

This study will aim to find out audiologists' thoughts and experiences of aural rehabilitation provided to children and teenagers with intellectual disability and hearing loss. This study will also aim to find out your experiences of aural rehabilitation you received from an audiologist when you were a child

or teenager. This study will also aim to find out your guardian's thoughts and experiences of aural rehabilitation which was provided to you and your guardian by an audiologist.

How will you be involved if you agree to take part in the study?

If you agree to take part in this study, I will interview you and your guardian/ parent. I will need your permission to interview your parent or guardian. You will receive a page that has a list of the questions I will ask during the interview. This interview will be 1 hour long. A video recording will be taken of this interview. I will take notes of the information you share during the interview. I will record the interviews so that I can go through the information you have given during the interview at a later stage. You may choose not to take part in the interview at any time that will be fine. Please remember there are no right or wrong answers. I will describe the information you and other people provide in a report called a dissertation and a shorter report called an article.

What are the benefits of taking part in the study?

There are no direct benefits from taking part in this study. By taking part in this study, you will get to share your experiences on aural rehabilitation which you received from the audiologist. The information you and other people have shared with me will help me find out if the work audiologists do is helpful for children and teenagers with hearing loss and intellectual disability.

What are the disadvantages of taking part in the study?

They are no disadvantages to taking part in this study.

What are the risks of taking part in the study?

There are no risks in taking part in this study.

How will your personal details remain private?

Your name, and any personal details shared, will not be added to the write-up of this study. Your details will be kept private. Only the researcher and the supervisors will know your personal details**.** When we use the recordings, all hints showing that you took part in the study will be hidden, so no one else will know that you took part in the interviews. The information you provide will be kept in a secure place. **What will happen if I decide to not take part in the study?**

You may choose not to take part in this study at any time during the interview. There are no risks to doing this. Refusing to take part in the study will not affect your schooling or the services you are receiving at the school or in healthcare.

If you have any questions feel free to let me know before, during, or after this interview. You can contact me using the contact details provided below.

- Researcher: Sandiswa Thozama Mashologu (0647929561, mshsan007@myuct.ac.za)

- Supervisors: Mr Siyabulela Mkabile (s.mkabile@uct.ac.za) and Professor Sharon Kleintjes (sr.kleintjes@uct.ac.za, 0216502147)
- Institution address: University of Cape Town, Faculty of Health Sciences, Department of Psychiatry and Mental Health (Division: intellectual disability), Neuroscience Institute, Groote Schuur Hospital, Anzio Rd, Observatory, 7925
- If you have any concerns about how this interview and study is conducted as well as your rights as a participant, please contact Prof. Marc Blockman, Chair: Faculty of Health Sciences' Human Research Ethics Committee, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town, (021) 406 6626, Email: ethics@uct.ac.za.

If you agree to take part in this study, please sign below

I, _____(Name and Surname) agree to take part in this study and this interview (date) _____

Signature _____

If you agree to recording of this interview, please sign below

I, _____(Name and Surname) agree to recording of this interview on (date) _____

Signature _____

If you agree to your guardian to be interviewed, please sign below

I, _____(Name and Surname) agree to my guardian to be interviewed on (date) _____

Signature _____

Researcher _____

Signature _____

Date _____

Appendix G: consent forms for the guardians and caregivers of the young adults

D/deaf and hard-of-hearing young adults with a coexisting intellectual disability and their guardians' experiences of aural rehabilitation practices and tools utilized in public schools for the D/deaf in the Western Cape, South Africa

Who am I?

My name is Sandiswa Mashologu, and I am an audiologist as well as a masters student at the University of Cape Town. My supervisors are Mr Siyabulela Mkabile and Professor Sharon Kleintjes. This study will be done for my studies at the university. The study has been approved by the Faculty of Health Sciences' Human Research Ethics Committee (HREC) and the HREC reference number is 781/2021. An audiologist is a person who works in health, tests people's hearing, helps people cope with their hearing loss, and is a person who helps people with hearing loss communicate better with other people. Aural rehabilitation includes giving hearing aids to people with hearing loss so that they can hear better. It also includes giving information or treatment that can help people with hearing loss communicate better with other people. Intellectual disability limits a person's ability to learn information and function in their daily life.

Why is the study done?

This study will aim to find out audiologists' thoughts and experiences of aural rehabilitation provided to children and teenagers with intellectual disability and hearing loss. This study will also aim to find out the young adult's experiences of aural rehabilitation which he/she received from an audiologist when they were a child or a teenager. This study will also aim to find out your thoughts and experiences on aural rehabilitation which was provided to you and the young adult by an audiologist.

How will you be involved if you agree to take part in the study?

I would like to interview you to gather information on your thoughts and experiences on aural rehabilitation which was provided to you and the young adult. You will receive a page that has a list of the questions I will ask during the interview. This interview will be 1 hour long. I will take notes of the information you share during the interview**.** A video recording will be taken of this interview. I will record the interviews so that can go through the information you have given during the interview at a later stage. You may choose not to take part in the interview at any time that will be fine. Please remember there are no right or wrong answers. I will describe the information you and other people provide in a report called a dissertation and a shorter report called an article**.**

What are the benefits of taking part in the study?

There are no direct benefits from taking part in this study. By taking part in this study, you will get to think about your experiences and share thoughts on the aural rehabilitation which you and the young adult received from the audiologist. The information you and other people have shared with me will help me find out if the work audiologists do is helpful for children and teenagers with hearing loss and intellectual disability.

What are the disadvantages of taking part in the study?

They are no disadvantages to taking part in this study.

What are the risks of taking part in the study?

There are no risks in taking part in this study.

How will your personal details remain private?

Your name and your personal details shared will not be added to the write-up of this study. Your details will be kept private. The researcher and the supervisors will know your personal details. When we use the recordings, all hints that lead us to know that you took part in the study will be hidden, so no one else will know that you took part in the interviews. The information you provide will be kept in a secure place.

What will happen if I decide to not take part in the study?

You may choose not to take part in this study at any time during the interview. There are no risks to doing this. Refusing to take part in the study will not services you or the young adult are receiving at the school or in healthcare.

If you have any questions feel free to let me know before, during, or after this interview. You can contact me using the contact details provided below.

- Researcher: Sandiswa Thozama Mashologu (0647929561, mshsan007@myuct.ac.za)
- Supervisors: Mr Siyabulela Mkabile (s.mkabile@uct.ac.za) and Professor Sharon Kleintjes (sr.kleintjes@uct.ac.za, 0216502147)
- Institution address: University of Cape Town, Faculty of Health Sciences, Department of Psychiatry and Mental Health (Division: intellectual disability), Neuroscience Institute, Groote Schuur Hospital, Anzio Rd, Observatory, 7925
- If you have any concerns about how this interview and study is conducted as well as your rights as a participant**,** please contact Prof. Marc Blockman, Chair: Faculty of Health Sciences' Human Research Ethics Committee, Room G50 Old Main Building, Groote Schuur Hospital, Observatory 7925 University of Cape Town, (021) 406 6626, Email: ethics@uct.ac.za.

If you agree to take part in this study, please sign below

I, _____(Name and Surname) agree to take part in this study and this interview ___(date)___

Signature _____

If you agree to recording of this interview, please sign below

I, _____(Name and Surname) agree for this interview to be recorded on (date) _____

Signature _____

_____ Researcher

_____ Signature

_____

Date

Appendix H: confidentiality agreement for the South African Sign Language (SASL) translator

Translator Confidentiality Agreement

I was contracted to translate or interpret interviews as part of a study being conducted by Sandiswa Thozama Mashologu of the University of Cape Town's Department of Mental Health and Psychiatry, Division: intellectual disability.

During the interviews, I shall refrain from expressing any personal ideas or engaging in any activity other than translating.

Confidentiality

I pledge to keep any conversations I translate private. I will not disclose, publish, or share any information shared in the interviews with anybody other than the researcher.

Accuracy and Completeness

I will provide a thorough and accurate translation to the best of my abilities, not omitting or changing anything stated during the interview.

Impartiality

My personal opinions will never be permitted to interfere with any communication.

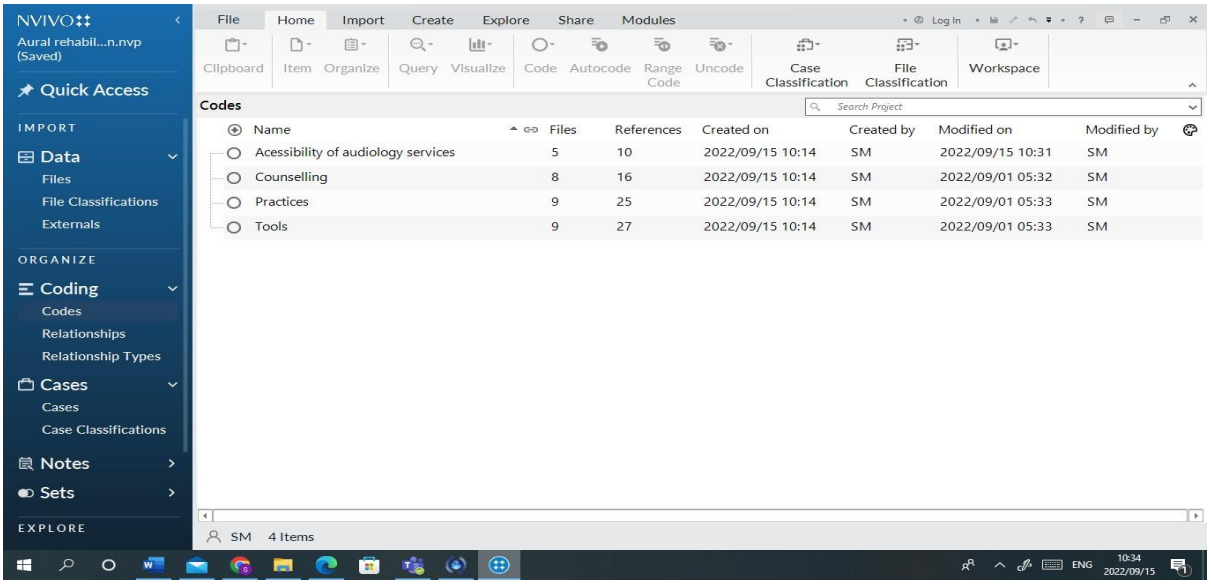
_____ _____

Translator/Interpreter's Name Date

_____

Translator/Interpreter's Signature

Appendix I: Coding frame for Nvivo



Appendix J: Letter to the Department of Education

4 Luvuyo Road

Malunga Park

Gugulethu

Cape Town

7750

27 January 2022

Dr Andile Siyengo

Research director

Western Cape Education Department

Private Bag X9114

Cape Town

8000

Permission to conduct research study at the schools for the D/deaf in Western Cape

Dear Dr Andile Siyengo

I am writing this letter to ask for permission to conduct my research project at schools for D/deaf in Western Cape. I am currently a second year masters student in the Department of Psychiatry and Mental Health in the division of intellectual disability at the University of Cape Town. My research project focuses on aural rehabilitation practices and tools utilized with D/deaf and hard-of-hearing children and adolescents with coexisting an intellectual disability in public schools for the D/deaf in the Western Cape, South Africa. My Faculty of Health Sciences' Human Research Ethics Committee (HREC) reference number is 781/2021.

I would like to conduct this research project at De La Bat School for the Deaf, Noluthando School for the Deaf, Dominican School for the Deaf, and Mary Kihn School for Deaf and partially hearing children. These are schools for the D/deaf who will most likely have D/deaf and hard-of-hearing participants with an intellectual disability and they also have an audiologist currently working there who utilizes aural rehabilitation.

This research project will be done for degree purposes. This project aims to gather information on aural rehabilitation practices and tools for D/deaf and hard-of-hearing school-going children and adolescents with a coexisting intellectual disability in schools in the Western Cape, South Africa. This project will also investigate the experiences of young adults as well as the experiences and perceptions of guardians on the appropriateness of aural rehabilitation practices and tools been provided. Aural rehabilitation is a broad term that refers to a variety of services aimed at minimizing the negative impact of hearing loss can have on a person's ability to function, as well as their activities, participation, and quality of life. These services include counselling, sensory management in the form of hearing aids, and communication intervention. The information that will be provided by participants will be used to make recommendations for future practice and research on aural rehabilitation for intellectually disabled and D/deaf or hard-of-hearing children and adolescents in Western Cape, South Africa.

Thank you for taking the time to read this letter. Hope to hear from you soon.

Yours sincerely

Sandiswa Mashologu

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Appendix K: Letter to the Department of Education

Western Cape Government
Education

Directorate: Research

meshack.kanzi@westerncape.gov.za
Tel: +27 021 467 2350
Fax: 086 590 2282
Private Bag x9114, Cape Town, 8000
wced.wcape.gov.za

REFERENCE: 20220504-1841
ENQUIRIES: Mr M Kanzi

Ms Sandiswa Mashologu
26 Lower Rochester Road
Observatory
Cape Town
7925

Dear Sandiswa Mashologu,

RESEARCH PROPOSAL: D/DEAF AND HARD-OF-HEARING YOUNG ADULTS WITH A COEXISTING INTELLECTUAL DISABILITY AND THEIR GUARDIANS' EXPERIENCES OF AURAL REHABILITATION PRACTICES AND TOOLS UTILIZED IN PUBLIC SCHOOLS FOR THE D/DEAF IN THE WESTERN CAPE, SOUTH AFRICA.

Your application to conduct the above-mentioned research in schools in the Western Cape has been approved subject to the following conditions:

1. Principals, educators and learners are under no obligation to assist you in your investigation.
2. Principals, educators, learners and schools should not be identifiable in any way from the results of the investigation.
3. You make all the arrangements concerning your investigation.
4. Educators' programmes are not to be interrupted.
5. The Study is to be conducted from **4 May 2022 till 31 July 2022.**
6. No research can be conducted during the fourth term as schools are preparing and finalizing syllabi for examinations (October to December).
7. Should you wish to extend the period of your survey, please contact Mr M Kanzi at the contact numbers above quoting the reference number.
8. A photocopy of this letter is submitted to the principal where the intended research is to be conducted.
9. Your research will be limited to the list of schools as forwarded to the Western Cape Education Department.
10. A brief summary of the content, findings and recommendations is provided to the Director: Research Services.
11. The Department receives a copy of the completed report/dissertation/thesis addressed to:

The Director: Research Services
Western Cape Education Department
Private Bag X9114
CAPE TOWN
8000

We wish you success in your research.

Kind regards,
Meshack Kanzi
Directorate: Research
DATE: 4 May 2022

Appendix L: Ethics approval letter

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room 45 E-52-E-Floor- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

24 March 2022

HREC REF: 781/2021

Prof S Kleintjes
Department of Psychiatry & Mental Health
Division of Intellectual Disability
GSH
Email: Sr.kleintjes@uct.ac.za
Student: Sandiswamashologu65@gmail.com

Dear Prof Kleintjes

PROJECT TITLE: D/DEAF AND HARD-OF-HEARING YOUNG ADULTS WITH A COEXISTING INTELLECTUAL DISABILITY AND THEIR GUARDIANS' EXPERIENCES OF AURAL REHABILITATION PRACTICES AND TOOLS UTILIZED IN PUBLIC SCHOOLS FOR THE D/DEAF IN THE WESTERN CAPE, SOUTH AFRICA-
(MASTERS CNADIDATE-MISS SANDISWA MASHOLOGU

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study, subject to the following: -

1. The following sentence in Appendices E,F,G -requires editing: *When we use the recordings, all hints that lead us to believe know it is you will be hidden, so no one else will be know that you took part in the interviews.*
2. Please include the supervisors' contact details on the letter to the WCED.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, our letter dated 02 February 2022 provides guidance found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

Approval is granted for one year until the 30 March 2023.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: - Miss Sandiswa Mashologu will also be involved in this study.

Please quote the HREC REF 781/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE
Federal Wide Assurance Number: FWA00001637. Institutional Review Board (IRB) number: IRB00001938 NHREC-registration number: REC-210208-007
This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2020), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.