Section One

Early Detection of Hearing Impairment
Early hearing detection and intervention (EHDI) has been extensively researched internationally, with a significant focus on the efficacy of implementing early identification through universal newborn hearing screening (UNHS) programmes (Kanji, 2016). However, most of this research has been conducted in high-income countries, and is not easily generalisable to low and middle-income (LAMI) contexts such as Africa, which differ in terms of populations, resources (human, equipment), health priorities, the burden of disease, as well as the neonatal protocols adopted. These differences require African countries to carefully consider context in EHDI programme implementation in order to ensure best practice that is contextually relevant and responsive. We thus call for a paradigm shift in EHDI initiatives within the African context. This chapter offers an introduction to such initiatives in South Africa, detailing the rationale for their value and relevance in this context. We outline approaches to EHDI, factors that influence its implementation, the positioning of these factors in the various levels of service delivery in the South African health care context, as well as continuity of care of the hearing impaired within the educational setting. Also addressed are the complexities surrounding EHDI implementation in South Africa, including EHDI in the context of other sensory impairments, in the context of the family, in the context of HIV/AIDS and in the context of tele-audiology. The goal is to recommend a paradigm shift for best/next practice for children at risk of, or with confirmed hearing impairment.

EHDI encompasses the earliest possible identification, diagnosis and provision of intervention for newborns and infants with hearing impairment in order to enable them to develop to their maximum potential and communicate effectively. This approach supports their individual needs as well as their later involvement in society and the country’s economy (Health Professions Council of South Africa [HPCSA], 2007). The implementation of EHDI has been clearly associated with positive developmental outcomes, including communication (Fulcher, Purcell, Baker, & Munro, 2012; Kennedy et al., 2006; Sininger, Grimes, & Christensen, 2010). These outcomes have been specifically
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recorded in high-income countries where EHDI programmes, particularly early identification programmes, are well established.

EHDI arguably falls within the broader focus area of early childhood intervention (ECI), particularly as ECI programmes encompass a range of specialised services extending from service planning, rehabilitation and family-centred support to special education. Previous definitions of early intervention (EI) define ECI as the early identification and management of children from birth to three years of age (Rossetti, 2001). However, this definition has evolved, with the Consultative Group on Early Childhood Care and Development (2012) specifying early childhood as the period from prenatal development to eight years of age. The South African National Integrated Early Childhood Development Policy refers to the provision of early childhood development (ECD) services, and defines this period from conception until the year before children enter formal schooling. In the case of children with developmental difficulties and disabilities, this period is defined as the year before the calendar year they turn seven, as this is the age of enrolment in compulsory schooling or special education (Republic of South Africa, 2015). To position this book within the African context, the definition we adopt falls within the ECI programmatic outlook, and stretches to the elementary, basic education age.

EHDI remains a significant need for Africa, given the global prevalence and incidence of childhood hearing impairment. Recent estimates indicate that globally, 34 million (7 percent) of the 466 million individuals with disabling hearing impairment are children, of whom 7.5 million are below five years of age (Neumann, Chadha, Tavartkiladze, Bu, & White, 2019). Within these global estimates, prevalence rates have been reported to be higher in LAMI countries, specifically in South Asia, sub-Saharan Africa and the Asia Pacific regions. LAMI countries comprise 80 percent of the world’s population, and are home to two-thirds of individuals with hearing impairment (Tucci, Merson, & Wilson, 2010). These prevalence and incidence rates are further exacerbated by the health care realities in LAMI countries, such as the burden of disease and poor social determinants of health, which place individuals at greater risk for hearing impairment.

The health care systems, as well as linguistic, cultural and socio-economic diversity in the sub-Saharan African context, present a unique setting for knowledge generation in terms of research, as well as academic and clinical teaching and practice in this field. Published evidence has acknowledged the impracticalities of attempting to implement developed world models for EHDI in LAMI countries such as South Africa (Moodley & Störbeck, 2015; Swanepoel, Delport, & Swart, 2004; Swanepoel, Hugo, & Louw, 2005). While research findings from high-income countries may be of value, it is vital to acknowledge that outcome-based recommendations
from these studies may be costly and more difficult to implement in practice in LAMI countries. This is due to a number of reasons, including contextual differences, disease definition and response, as well as a different focus on disease prevalence. The sole reliance on evidence from international contexts may result in the specific, local needs of LAMI countries being neglected (Chetwood, Ladep, & Taylor-Robinson, 2015), leading to inappropriate and inefficient interventions and impacting negatively on the health outcomes of these populations. This highlights the need for a paradigm shift in EHDI in (South) Africa to a more contextually relevant and responsive approach driven by research that is sensitive to context while being internationally comparable.

Various initiatives are in place to address the gap in transferring theory into practice in the area of EHDI. The South African government’s heightened focus on increasing access to health care through the re-engineered primary health care (PHC) model, and the efforts to achieve universal health coverage through National Health Insurance (NHI) as well as ECD programmes, make this an opportune time for establishing and documenting evidence-based research for clinicians, researchers and students. The existing body of literature in the field is almost entirely from the global North. This book therefore aims to provide evidence-based and contextually responsive information on EHDI from the global South, covering both detection and intervention aspects of hearing impairment. The information provided extends beyond the strictly defined age period of seven years. EHDI implications and possibilities are explored in the educational setting as part of the continuity of care for hearing-impaired children.

The book has deliberately adopted an African rather than a South African perspective, for several reasons. Firstly, the contextual realities under which health care delivery occurs are similar across the African continent. These include:

- resource constraints
- reliance on international aid and guidelines for some health care initiatives
- inadequate human resources across sub-Saharan African health systems, resulting in the use of task shifting in attempts to increase access (Maphumulo & Bhengu, 2019)
- negative impact on health care systems of the high burden of diseases such as HIV/AIDS and tuberculosis (Naidoo, 2012)
- challenges in terms of the social determinants of health.

Secondly, borders across Africa are porous. Migration due to socio-political and economic reasons is common and impacts health care planning, implementation and monitoring. Thirdly, the influences of linguistic and cultural diversity on seeking and delivering health care are arguably similar across the
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African continent in terms of cultural beliefs and how illness is understood, as well as linguistic differences between patients, nurses and doctors.

This book is divided into three sections. The first two sections focus on the early detection of hearing impairment and EI, respectively. The third section considers factors that are significant to the South African context and how they influence EHDI, including family influences, the burden of disease, co-morbid conditions and ethical considerations.

EHDI is the gold standard for practising audiologists and the families of infants and children with hearing impairment. According to international guidelines, EHDI programmes aim to identify hearing impairment within one month of birth, diagnose by three months, and provide intervention to children with hearing impairment (as well as those at risk of hearing impairment) by six months of age to ensure that they develop and achieve in line with their hearing peers (Joint Committee on Infant Hearing [JCIH], 2007). Context-specific adjustments to these timelines have been made for South Africa: completion of hearing screening by six weeks of age, diagnosis by four months of age and commencement of intervention by eight months of age (HPCSA, 2018). These adjustments have taken the various South African screening platforms into account as well as other contextual factors such as home births, discharge timeframes and scheduled immunisation visits at the PHC level. The health care system in South Africa consists of both public and private health care. The public system is multi-tiered with primary, secondary and tertiary contexts offering different levels of care and service delivery. The feasibility of implementing EHDI programmes requires further deliberation in South Africa due to the country’s unique health care context, as well as future plans for NHI and the re-engineering of PHC. The practicability and efficiency of newborn hearing screening (NHS) is discussed in chapter 4 of this book to ascertain feasibility within each level of service delivery. The chapter illustrates factors that may positively contribute to or impede early identification services, with clear recommendations for the South African context.

While international guidelines have been successfully achieved in studies from high-income countries (Ching, Dillon, Leigh, & Cupples, 2018; Fulcher et al., 2012; Fulcher, Purcell, Baker, & Munro, 2015), this is not so in sub-Saharan Africa. A retrospective review of the audiological management of children with hearing impairment, conducted at three public sector hospitals in South Africa’s Gauteng province, found that the average age of diagnosis of hearing impairment is 23.65 months. Enrolment into an EI programme occurs at an average age of two years and five months (Khoza-Shangase & Michal, 2014). Similar findings were reported in the Western Cape and Free State provinces by Van der Spuy and Pottas (2008) and Butler et al. (2013). Delays in meeting the stipulated EHDI timeframes have been attributed to administrative challenges (such as procurement delays), lack of human resources, the busy schedules of speech-language therapists and audiologists
in the public health care sector, and a lack of NHS services (Khoza-Shangase, Barratt, & Jonosky, 2010; Khoza-Shangase & Michal, 2014).

Early detection of hearing impairment

With regard to NHS services, significant focus has been placed on UNHS as the screening approach for early identification. While this approach is commonly practised in high-income countries, with well-established, standardised programmes and dedicated screeners outside of the profession of speech-language pathology and audiology, this is not the case for sub-Saharan Africa. Chapter 2 of this book explores the status of early identification services in sub-Saharan Africa, and highlights the status of these services in South Africa against the backdrop of the broader health care challenges and priorities in the country. The establishment of NHS services in higher-income countries has allowed for a shift in focus from hearing screening to diagnostic follow-up and intervention. However, South Africa and other countries in sub-Saharan Africa still appear to be at the infancy stages of implementing NHS programmes for early identification of hearing impairment. While the HPCSA guidelines are aimed at implementing UNHS, the benchmark for early identification, they are not necessarily currently applicable in all health care sectors in South Africa (HPCSA, 2018). Furthermore, they might not be adopted by other countries in the broader sub-Saharan African context. In fact, research from these contexts consistently indicates their state of unpreparedness to implement UNHS.

Early detection of hearing impairment continues to be a challenge throughout sub-Saharan Africa, for various reasons: the health care context; the focus on other, life-threatening health care priorities that are aimed at saving lives; and the challenges with social determinants of health. It is vital to understand the current status of early identification services, and the factors influencing their implementation in order to monitor progress and suggest realistic ways forward. Chapter 2 explores early detection services in sub-Saharan Africa with reference to health and health care and the availability of audiology and otolaryngology services, which are vital for implementing NHS programmes.

Despite UNHS being the gold standard that audiologists should strive to achieve, this approach to screening may not be feasible for some LAMI countries, where contextual challenges to implementation exist. These include a shortage of personnel and equipment, as well as associated costs. Chapter 5 explores the implementation of EHDI in South Africa. The author offers suggestions for EHDI service provision in this context, including the implementation of targeted NHS (TNHS) as an intermediate national approach.
Kanji (2018) asserts that all programmes need to have a starting point and go through their infancy stages and that doing something is better than doing nothing at all, particularly in contexts plagued by a lack of sufficient resources. NHS of high-risk neonates or infants through TNHS or risk-based programmes is a possible interim approach in such contexts. Chapter 3 discusses the feasibility of UNHS and TNHS as early identification methods in South Africa.

Should TNHS be the choice of approach, careful deliberation of the risk registry is required to assist in identifying children who need audiological screening and assessment. This is important in order to identify those requiring audiological or medical surveillance and to address the preventable risks associated with hearing impairment (JCIH, 2000; Kanji & Khoza-Shangase, 2018; Núñez-Batalla, Trinidad-Ramos, Sequí-Canet, De Aguilar, & Jáudenes-Casaubón, 2012; Olusanya, 2009). While risk registries in high-income countries are mainly used to identify children at risk for postnatal hearing loss and those in need of audiological monitoring and surveillance, they are useful tools in countries such as South Africa where a universal platform for NHS has not been established. The current high-risk registries have been compiled and revised by the Joint Committee on Infant Hearing (JCIH), based on evidence from developed world contexts (JCIH, 1982, 2000, 2007). The HPCSA has adapted these for the South African context (HPCSA, 2018). However, findings from international studies as well as some South African studies have indicated the need to continuously re-evaluate both the JCIH and the HPCSA risk registries and tailor them to the context (Beswick, Driscoll, & Kei, 2012; Beswick, Driscoll, Kei, Khan, & Glennon, 2013; Kanji & Khoza-Shangase, 2012). Chapter 6 reviews the key risk factors for hearing impairment used globally and evaluates their relevance to the South African context.

‘Considering the realities of the South African healthcare context, and given that EHDI is vital for newborns and infants with hearing loss, we need to seriously consider how NHS services may be adapted to better meet these realities’ (Kanji, 2018, p. 2). Following identification and diagnosis of hearing impairment, EI services need to be similarly evaluated and adapted to the realities of access to and availability of such services, as well as to the unique challenges that present within each of the relevant service delivery contexts.

**Early intervention for hearing impairment**

Diagnosed hearing impairment without adequate intervention may have long-term consequences for the affected individual. Besides affecting communication abilities, it can influence vocational performance and result in
isolation and stigmatisation (Yoshinaga-Itano, 2004). Specific international principles and goals for EI for hearing impairment guide service provision. These principles and goals are discussed in chapters 7 and 11, which deal with approaches to EI and family-centred EHDI, respectively.

EI services are particularly important in children who are considered at risk for developmental delay. It is well documented that a lack of intervention may have negative consequences for development, school readiness, educational outcomes and vocational opportunities (World Health Organization [WHO], 2012; Yoshinaga-Itano, 2004). EI services may be provided at different sites or levels of service delivery, including health care clinics, hospitals, EI centres, rehabilitation centres, community centres, homes and schools (WHO, 2012). Exploring models of care in the various levels of service delivery in South Africa is important to ensure efficacious intervention that is contextually responsive and responsible.

Chapter 8 looks at how specific communicative therapy approaches can be delivered to children with hearing impairment and their families. It considers contextual factors such as patient-to-professional ratios, as well as cultural and linguistic diversity issues that may influence these options and patient outcomes.

EI for hearing impairment is a multi-staged process that commences with the provision, fitting and adjustment of amplification devices followed by early communication intervention (McPherson, 2014; Peer, 2015). Most high-income countries have been able to access hearing health care through private and publicly funded aural (re)habilitation systems. However, many LAMI countries have not had these same opportunities for access despite the higher prevalence of childhood hearing impairment (McPherson, 2014; Stevens et al., 2011). The challenges to implementation are further influenced by the availability of and access to EI services. Chapter 7 highlights these challenges and discusses contextual considerations in terms of the cultural and linguistic diversity in South Africa. The chapter also explores various modes of communication and communicative therapy approaches to EI, and addresses the value and implementation of auditory verbal therapy in the South African context.

Ensuring continuity of care is important in the multifaceted process of EHDI, and requires the involvement of various stakeholders from different government sectors such as health, social development and education. Access to education is a key priority of the South African government. However, this access does not always practically translate into inclusivity in the educational sector for children with hearing impairment. Access has therefore not necessarily transformed into success in the educational setting for these learners. Addressing hearing impairment as a barrier to learning is vital to facilitate success, and to ensure maximal benefits from EHDI implementation. While chapter 7 highlights educational access for children
with hearing impairment in sub-Saharan Africa, chapter 9 discusses EI in the South African basic education setting. It offers recommendations for inclusive education and explores telehealth in the form of tele-audiology as well as task shifting to facilitate this process.

Complexities of early hearing detection and intervention

To ensure contextually responsive practice in South Africa, clinicians and other stakeholders working in the EHDI field need to consider various complexities, including: EHDI in the context of other sensory impairments; EHDI in the context of family; EHDI in the context of HIV/AIDS; and ethical considerations for EHDI in the context of tele-audiology.

While the focus on hearing impairment and its influence on developmental outcomes, education and vocational attainment is vital, it is also important to recognise the possibility of additional sensory impairments in children with hearing deficits to ensure effective holistic assessment and management. Current studies have focused on the EHDI outcomes of children with hearing impairment only, with little to no consideration of any co-morbid conditions. This is a disservice to this cohort within a minority grouping of children. Chapter 10 explores this complexity, with a specific focus on deafblindness, and highlights the need for consideration of other co-morbid sensory impairments in the EHDI framework.

The primary member in an EI team is the family. Hence, EI programmes need to be responsive to the needs of the families of children with hearing impairment (HPCSA, 2018). The HPCSA guidelines specify that EI services following diagnosis of hearing impairment must be family-centred and tailored to cultural differences. The definitions, dynamics and compositions of families in an African context need to be considered, including their impact on health-seeking and intervention-adherence behaviours. Chapter 11 discusses family-centred EHDI in South Africa, with recognition of the cultural and linguistic aspects of a family. The chapter notes the complexities in defining family structures and functions in an African context, highlighting the influence of culture, migration and the burden of HIV/AIDS on families and thus on intervention outcomes.

Various reasons have been offered for the failure to successfully implement EHDI in South Africa. One of the most common reasons is linked to the burden of disease, specifically the HIV/AIDS pandemic. Besides the budgetary and resource burden linked to HIV/AIDS, this pandemic also results in auditory and otologic manifestations in those affected. Chapter 12 explores EHDI in the context of HIV/AIDS and highlights the implications for EHDI in this segment of the population.
Other common barriers to successful EHDI implementation include access to services and human resource shortages. These barriers have resulted in consideration of alternative models of service delivery, such as tele-audiology, to increase reach and access in resource-constrained environments. However, the core ethical aspects related to tele-audiology need to be taken into account, particularly given the lack of national regulations and guidelines. Chapter 13 looks at ethical and legal aspects and strategies to implement risk management and programme validation in the South African context.

Conclusion

International guidelines and research findings related to EHDI may not be easily transferable to clinical practice in Africa due to significant differences in context. This book is a research-driven intervention into the EHDI space and is aimed at providing current, contextually relevant and responsive evidence related to EHDI in LAMI countries, with a specific focus on the African context and South Africa in particular. The book covers all aspects of EHDI, with careful consideration of the complexities and challenges to implementation in South Africa. However, the findings may be applicable to other LAMI country contexts. After carefully engaging with local evidence, local context and local policies, the book offers possible solutions and recommendations for the challenges identified.

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