Chapter 14

Interdisciplinary Approach to Management of Childhood Hearing Loss

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'Alone we can do so little; together we can do so much'.

~Helen Keller

Introduction

Children with hearing loss (HL) have a myriad of needs that must be met in a timely manner by the interdisciplinary team. The critical period of neuroplasticity in the first years of life is where the foundation of cognitive, linguistic, social, emotional and motor development is laid (Çelik et al. 2021). While HL may directly lead to delays in language and listening development without appropriate intervention, approximately 40% of children with HL have additional disabilities beyond the HL (Núñez-Batalla et al. 2023). The impact of additional disabilities also affects children with mild or unilateral HL. The presence of additional needs may delay the diagnosis of HL and/or intervention, and impact communication and educational decisions. These additional needs may include: visual impairment (4-57%), autism spectrum disorder (ASD) (2-4.2%), speech language disorder (61-88%), cerebral palsy (CP) (2-13%), intellectual or developmental disabilities, specific learning disabilities, vestibular and balance disorders, multisensory processing and auditory processing difficulties, as well as additional health concerns (Núñez-Batalla et al. 2022; Alkhamra and Abu-Dahab 2020).

Decreased vestibular function is also common in children with HL (see chapter 7), with teachers reporting poor co-ordination, balance issues and clumsiness (Wiener-Vacher, Quarez and Le Priol 2018). Vestibular dysfunction may impact gaze stability, which is essential for reading, standing and walking. Children with HL are also more likely to have difficulty with praxis, visual processing, spatial integration, sustained attention and executive functioning, with an increased incidence of Sensory Processing Disorders in children with HL (Alkhamra and Abu-Dahab 2020). Fifty percent of congenital or early childhood HL is genetic in origin. For many children, HL is one of many sequelae of a genetic syndrome. Many of these syndromes result in additional learning impairment, progressive visual impairment and other medical challenges. Other aetiologies include illnesses such as meningitis, congenital Cytomegalovirus (CMV) and congenital rubella (see Chapter 2), which may also result in visual impairment, vestibular dysfunction, cognitive impairment and other medical challenges. All of these have a significant impact on the child's development as well as on the burden to the family and their ability to attend and implement intervention plans.

According to Çelik et al. (2021), the presence of an additional disability is the strongest variable impacting on developmental outcomes in children with HL. Another critical predictor of outcomes is parent-child interaction, which emphasises the need for family-focused intervention (Holzinger, Fellinger and Hofer 2022). For those children with additional needs, a fluid interdisciplinary collaboration including multiple professionals and the family is essential (Núñez-Batalla et al. 2022). Case study 1 highlights the additional needs of a child with HL and suggests the type of interdisciplinary team that can be formed to meet the needs of the child and family.

Interdisciplinary Collaboration

Interdisciplinary collaboration is a partnership in which a diverse group of professionals develop a collective identity and shared responsibility, with the aim of providing comprehensive patient and family-centred services (Golom and Schrek 2018). An interdisciplinary approach which results in enhanced person-centred care (PCC) and leads to improved outcomes is recommended when addressing the multifaceted needs of children with HL (WHO 2010). This approach boosts productivity by using time and human skills optimally (Dinh et al. 2020) which is critical in a resource-constrained context like South Africa (see Chapter 15). Professionals working within this model of care engage in joint problem solving, which relies on the expert opinion of each member (Bendowska and Baum 2023). A collaborative, synergistic system is created in which professionals work together to establish goals and priorities with the families of children with HL.

Effective communication

Interdisciplinary collaboration is dependent on effective communication within the team. To achieve this, professionals need to establish open communication, understand and respect each member's contribution, develop a shared language and coordinate their approach as a team (Newhouse and Spring 2010). Failure to communicate effectively can directly impact the outcomes of intervention programmes for children with HL. Diaz et al. (2023) state that effective interdisciplinary communication must be clear, brief and include all the required information to make treatment decisions. Formal communication systems, for example, team meetings, should be set up to ensure that recommendations are followed through. Having these formal communication systems ensures that patient privacy and confidentiality are protected (HPCSA 2019). Informal communication, such as a meeting during lunchtime, also increases trust among team members (O' Reilly et al 2017), which is imperative for achieving successful patient outcomes. Trust can be built by taking time to establish and build relationships, especially if the team members have not worked together previously. A team-building programme that is integrated into already-existing spaces and programmes is more likely to succeed.

Role definition

Diaz et al. (2023) identify clear role definitions and the standardisation of formal processes to be key factors in achieving effective interdisciplinary communication. Hudson et al. (2017) emphasise that understanding team roles is essential for fostering trust and mutual respect. Improved awareness of team members' roles enhances role clarity, enabling the optimal utilisation of professional expertise and leading to better patient outcomes and more cost-effective healthcare systems (Ganann 2019). The varied organisational and reporting structures related to interprofessional teams highlight the need for clear policies and procedures to guide collaboration and communication. The use of technology can furthermore support continuity of care and decision making in interprofessional teams. Social media applications like WhatsApp are being used successfully in many settings as they allow for instant communication between several team members. Interprofessional teams need to be aware of policies and ethical guidelines that govern the use of these platforms, especially due to the risk they pose to patient confidentiality (HPCSA 2019).

Care co-ordination

Due to the involvement of multiple providers and services within a complex healthcare system, coupled with frequent transitions across the care continuum, families are at risk of care being uncoordinated, inconsistent and challenging to navigate (Leach, Stack and Jones

2021). In addition, communicating with multiple professionals within varied hierarchical structures can be daunting for parents of children with HL. The lack of co-ordination can result in increased costs to families, fragmented care from multiple service providers, and duplication of services for children with complex needs (Geese and Schmitt 2023; WHO 2018). Identifying a key person who coordinates appointments and information with families could increase the continuity of care and improve child and family outcomes. Adopting the use of a primary carer or a primary care practitioner (WHO 2018) is recommended to assist with improved communication and co ordination between families and professionals (Geese and Schmitt 2023). This will ensure a consistent and continuous flow of information through a constant point of contact. Care co ordination could also address the gap between diagnosis and timely management (Flindlen 2019) which is critical in the South African context where the burden of HL is disproportionate to the services available (Kuschke et al. 2021). Co-ordinated care is integral to interprofessional collaboration as well as to increased access to services for children with multiple disabilities. Co-ordinated care works best within a family-centred model of care (Dunst 2016), which incorporates family perspectives and goals. A study by Adugna et al. (2020) found that when interprofessional care was provided, families were more motivated to attend health care services.

Caring for a child with multiple disabilities within a low-to-middle income country (LMIC) is very challenging for families who cannot afford the transport costs to access services, and who sometimes put their employment at risk to attend multiple appointments (Adugna et al. 2020). Coordinated care is critical for transitioning children between different levels of health to ensure continuity of care (Kuschke et al. 2021). The National Referral Policy for South African Health Services and Referral Implementation Guideline (NDOH 2020) maintains that for the referral system to work optimally, each facility must clarify its roles and responsibilities, and establish protocols and effective communication systems between health care providers. This remains a longstanding challenge in LMICs like South Africa, where different levels of healthcare are involved in the care of children with complex needs (Amri, Chatur and O'Campo 2022). Brooks, Winship and Kuzel (2020) recommend collaborative visits so that families of children can be connected to appropriate services at a single location.

Interdisciplinary Team

Due to the complex needs of children with HL and the relatively high rate of related medical, social and developmental challenges, it is essential to build a supportive team around the child and family (Findlen, Malhotra and Adunka. 2018). As described in Table 4.1, the team includes (but is not limited to) audiologists, speech-language therapists, otolaryngologists, psychologists, social workers, occupational therapists, physiotherapists, neurodevelopmental paediatricians, geneticists, community health workers, educators and community-based organisations.

Table 14.1: The interdisciplinary team

Team Member	Role
Audiologists	• Audiologists manage early identification programmes (screening), ensure accurate diagnosis of HL, co-ordinate timely audiological services and deliver effective family support and counselling. • They ensure that amplification devices recommended are delivering the intended benefits by verifying and validating their performance. • They regularly monitor the child's hearing status, manage hearing technologies to ensure proper use, care and functionality, and provide training, troubleshooting and guidance as needed for adjustments. • They play a key role in establishing the referral system for early intervention services and possibly serve as the care co-ordinator within the interdisciplinary team. • Some audiologists are AVT trained and can provide these services to children.

Team Member	Role
Speech-language therapists	• Speech-language therapists play a vital role in screening, assessing and providing speech, language, literacy and cognitive-communication services for children with HL. • They provide families and caregivers with information about various language modalities (such as signed, spoken and other forms, including AAC), communication tools, strategies and programmes to help them make informed decisions that align with their child's and family's goals (Chapter 13). • For those families who choose to work towards spoken language outcomes, AVT provided by a speech-language therapist helps children with HL thrive in a mainstream learning environment, becoming independent, active and contributing members of society. • AVT promotes natural conversations and the use of spoken language for communication, emphasising a parent-centred approach. For those families where Sign Language (SL) or Total Communication (TC) is selected (Chapter 13), it is essential that the speech language therapist assists the family in accessing services to support this decision.

Team Member	Role
Deaf Mentor/Deaf Role Model	• A deaf mentor provides families with lived experience perspectives on deafness and hearing loss, supporting informed decision making and realistic expectations regarding communication, identity and participation. • The mentor offers role modelling for children who are deaf or hard of hearing by promoting positive Deaf identity, self-advocacy and social-emotional development. • The mentor supports families in understanding and accessing Deaf culture, sign language and community resources, where appropriate, and complements clinical input provided by healthcare professionals.
Otolaryngologists (ENTs)	• ENTs play a key role in the diagnosis and management of HL in children. • They identify the underlying causes of hearing loss, and assess and manage conditions that contribute to HL. • ENTs perform various surgical interventions such as placement of ventilation tubes, tympanoplasty, cochlear implantation, ossicular reconstruction and implantable hearing aids (Chapter 9 and 11). • They work closely with audiologists in monitoring the progression of HL.

Team Member	Role
Neuro-developmental Paediatrician	• The neuro-developmental paediatrician plays a vital role in diagnosing neurological causes of HL, managing associated conditions and ensuring the child receives appropriate therapies for optimal development. • They identify underlying causes: HL in children may have neurological causes, such as congenital infections (for example, CMV), genetic syndromes or brain abnormalities (JCIH 2019). • They assess and monitor neurological function: Since HL can be part of broader neurological disorders (for example, auditory neuropathy and neurodegenerative diseases), a neurologist evaluates brain function. • Imaging and tests: They can orderi MRI or CT scans to check for structural brain abnormalities, auditory pathway issues or inner ear malformations.

Team Member	Role
Paediatrician or Primary Care Provider (PCP)	• The paediatrician or other primary care provider is responsible for monitoring the overall health and development of the child. • The PCP plays a critical role in ensuring that newborn hearing screening has taken place, following up on the EHDI process, and in monitoring middle ear status and developmental milestones (Chapter 4). • The PCP's role includes partnering with other specialists to facilitate co-ordinated and comprehensive care for children who are deaf or hard of hearing (JCIH 2019).
Geneticist	• At least two thirds of childhood HL have a genetic cause. • An aetiologic diagnosis forms the foundation for accurate genetic counselling and precise assessment of the likelihood of HL recurrence within families.

Team Member	Role
Psychologist	• Parents of children who are deaf or have a hearing loss have rated psychosocial development as one of their main concerns (Wong et al. 2018). • Children with HL are at risk for behavioural problems, increased stress and depression (Dougherty and Day 2022) and therefore a psychologist is required on the team. • Parents of children with deafness and HL require additional support and counselling to cope with the complex needs of their children as well as their own emotional needs.

Team Member	Role
Social Worker	• Children who are deaf or have a hearing loss have complex disabilities, with socio-demographic challenges which may require support from social services. • This support can include informational and emotional counselling to help families better understand their child's disability (JCIH 2019). • Social work services may also include a parent support group to help parents navigate the challenges of raising a child with HL. • These groups foster a supportive environment where parents can share experiences and access valuable information. • Social workers also provide guidance on suitable educational placements and access to social grants.
Physiotherapist	• HL in children is closely linked to challenges in maintaining balance. • Physiotherapy is necessary for children with HL that have underlying vestibular challenges.

Team Member	Role
Occupational Therapist (OT)	• Occupational therapists can assist children with HL who present with various co-morbidities, such as fine and gross motor delays, visuo-motor integration disorders, sensory processing disorders and difficulties within the vestibular system (Alkhamra and Abu-Dahab 2020). • They also assist with preparedness for school.
Community based Organisations and community Health Workers	• Community based organisations and community health workers assist with providing support to families of children with HL. • Organisations like HI HOPES offer home-based support and information to families with an infant or toddler with HL (Chapter 13). • Community Health Workers are a key component of the ward-based community intervention (Khuzwayo and Moshabela 2017). They are in a prime position to help families identify early HL by referring them to their closest health facilities.

Team Member	Role
Educators	• Educators play a crucial role in supporting children with HL, fostering their academic, social and emotional development. • They support the child's mode of communication, for example Sign Language, and support the optimal use of assistive devices within the learning environment. This may include tasks like battery checks (Chapter 10). • It is critical for educators to collaborate with the child's family and intervention team to ensure carry over into the classroom (Chapter 13).

Working Within a Systems Approach

Holistic intervention for children with HL, particularly those with multiple disabilities, needs to account for the complex needs of the child within a Bioecological Systems Approach (Bronfenbrenner 1986). The child's microsystem should be described by identifying everyone who is involved in their care and interaction. This could be achieved by completing an ecomap with the family. An ecomap allows insight into the mesosystem, which encompasses the interactions between the child's microsystems (Sadownik 2023). This process will help the family and the primary care practitioner to identify methods of increasing the support available to the child and family and strengthening the collaboration between the interdisciplinary team and the community involved with the child. The ecomap in Figure 14.1. shows the strong relationship between the speech therapist, who is the care coordinator, with the family and the team based at the hospital. The relationship is moderate for team members outside of the hospital. This could be due to time constraints or large caseloads, which could contribute negatively to collaboration. This ecomap could also be used to motivate more regular communication and consultation between team members. A systems approach also accounts for the ecosystem which refers to the broader formal and informal social structures that are not directly linked to the child's intervention, but impact on the child's well-being and development (Sadownik 2023).

A community resource map could build on the team's understanding of resources available to the family, thereby strengthening their informal support systems and facilitating transitions between different microsystems. Engaging in developing a community resource map could assist the family in increasing their opportunities for learning outside the home and increase the family's informal support system.

Case study 1: Nsuku's story

Nsuku is a 16-month-old child who presents with syndromic features, including a bilateral profound sensorineural hearing loss (SNHL) diagnosed at four months old, as well as cortical visual impairment, severe learning difficulties, low muscle tone and abnormal appearance of the hands and feet. He has abnormally formed cochleae and auditory nerves. He has difficulty with sensory registration and regulation. Nsuku received binaural hearing aids (HA) at the age of five months. After extensive engagement between the ENT surgeon, paediatric neurologist, psychologist, audiologist, speech therapist and the family, it was determined that he was a candidate for cochlear implants (CI), which he received at one year of age. He has attended weekly speech therapy with a Listening and Spoken Language (LSL) Therapist (certified in Auditory Verbal Therapy) since the age of eight months, alternating between face-to-face and telehealth sessions from his home. In the past months, he has shown increased engagement with his environment, an understanding of cause and effect and anticipation of preferred activities. He turns inconsistently to loud sounds, is vocalising an increased range of sounds, and occasionally imitates the suprasegmentals/rhythm of another person's voice or singing.

Nsuku has been on the waiting list for physiotherapy at his local clinic for over a year, and his family has recently managed to find a private physiotherapist to assist twice a month. He can now sit independently, pull to stand and is starting to cruise. He attends occupational therapy once a month at his local clinic. He has limited hand function but has started to grasp and release objects. A paediatric neurologist facilitated appointments for scans and referred the child to a geneticist for diagnosis of a possible syndrome. He was assessed at the Genetics Clinic, but the required tests to confirm his diagnosis are currently not available in the country. His vision has been assessed by an ophthalmologist and an occupational therapist, who report that he can see light and dark and can occasionally focus on a nearby object. His mother disagrees with the results of the visual assessment and feels that his vision is an area of strength for him.

His parents are divorced, and he alternates weeks between the two homes, travelling with a full-time caregiver between houses. The parents consider each other to be a significant source of practical support to one another, and they communicate and co-parent effectively. His mother was recently retrenched from her employment. She is attending psychology services for the anxiety she is experiencing. Nsuku's father understands that his child may not develop language but wants to give him access to hearing through a CI and multimodal communication to offer him the best possible quality of life. His mother believes that a cure may be found but would like to explore South African Sign Language (SASL) to help facilitate his academic journey until then. His family have elected to follow a Total Communication Approach, communicating with him in a combination of gestures, tactile cues, SASL and SeSotho.

His family attends a monthly caregiver support group for families of children with HL and reports that this has been extremely helpful in reminding them that they are not alone on this journey. They report that his speech-language therapist has provided them with a space to process Nsuku's challenges and to experience hope and joy as his parents. His maternal grandmother, who was his mother's primary support, has passed away. His mother reports that she avoids taking him to church and public spaces because she feels he becomes overwhelmed and is happier when home with family.

Application of interdisciplinary principles to Case Study 1

a) Identifying the team

There are many professionals involved in Nsuku's management team, including the team at the hospital that made his initial diagnosis, his occupational therapist at the local clinic, his physiotherapist in private practice and his CI interdisciplinary team, which includes ENT, radiology, speech therapy, audiology, occupational therapy and child and adult psychology. This places him at risk of duplication and fragmentation of services. Unfortunately, hospital catchment areas (in healthcare, a catchment area refers to the geographical region that encompasses the population served by a particular health facility), as well as the fact that his father lives three hours from the hospital, make it impossible to bring all his management under one medical roof. His CI programme has been established as his medical home.

b) Coordination and communication

The CI multi-disciplinary team (MDT) meets monthly to discuss challenging cases and develop care plans for patients. Factors that facilitate successful case management include regular communication between team members, an annual plan with meeting dates, a meeting agenda and minutes that are circulated monthly, with feedback shared with the families involved. Family meetings take place between the relevant professionals and the family to ensure that there is shared understanding of progress and joint goal setting with the family. The team has policies and protocols that guide processes and clarify roles for each member of the team and case management responsibilities in preparation for team meetings. This ensures that case management is done effectively and that the family is involved in all aspects of decision making for their child.

c) Case management within the MDT

Interdisciplinary management within the CI unit is facilitated by clear roles and responsibilities for each member and a shared online booking system with access to online notes from some of the professionals. The team works from one institution and facilitates regular meetings as well as impromptu discussions and joint sessions as the need arises. It is important to have a structured programme for strategic planning, including increased collaboration in service planning and teambuilding to strengthen interpersonal relationships between professionals. Nsuku's speech therapist takes the role of case manager in flagging concerns to the team and in helping the family to advocate for Nsuku with the service providers at other institutions.

d) Communication platforms

A WhatsApp group was created that includes Nsuku's parents, nanny, audiologist and speech therapist. To facilitate the success of the WhatsApp group, all members of the group agreed to clear boundaries regarding the content, times and expected turnaround times for communication on the group. His speech therapist shares take-home messages from their sessions, the family shares videos of his progress in other therapies and their implementation of

strategies (See Chapter 16). The WhatsApp group is also used for telehealth troubleshooting of his device, co-ordination of appointments and sharing of family triumphs and concerns.

e) Facilitating access

Attendance at multiple appointments has proven challenging for the family, and this has resulted in role release, with the occupational therapist and physiotherapist providing programmes and strategies to the family and speech therapist for sensory regulation, visual therapy and motor development. The team has worked to develop open and robust relationships between professionals at different sites and within both public and private healthcare sectors. Telehealth has allowed the speech therapist to observe Nsuku in his natural environment and to work around his nap times to facilitate more successful sessions.

f) The family and informed choice

The team has supported Nsuku's family in making decisions regarding the type of amplification they select for their child, the language they choose and the modality in which he learns language. It is important that the team working with the child collaborates so that the family can make decisions based on their child's profile of strengths and abilities, their values and beliefs, social circumstances, cultural influences and personal choice (Harris, Hemer and Chur-Hansen 2021; Findlen, Malhotra and Adunka 2018). Nsuku was referred to services that support SASL and provided with therapy that utilised Makaton, spoken language, gestures and the introduction of Alternative and Augmentative Communication (AAC). The caregiver support group has facilitated contact between Nsuku's parents and other families of children with additional needs. This has helped them to further develop their own views and goals for his future.

g) Educational placement

A functional communication method is imperative in the deaf-blind learner's establishment of relationships, facilitation of social participation and independence, access to social activities and, most importantly, in their progress across their education trajectory. Finding the right educational environment for Nsuku will be critical in ensuring that he reaches his academic and communicative potential (see Chapter 13). This will require intersectoral interdisciplinary teamwork and communication throughout his educational journey.

e) Ecomap

Figure 14.1 shows Nsuku's interdisciplinary ecomap, providing which provides a visual display of the members of his interdisciplinary team and the strength of their relationships with one another as well as with Nsuku and his family. This tool will guide the team in terms of improving the communication and collaboration between members in Nsuku's ecosystem.

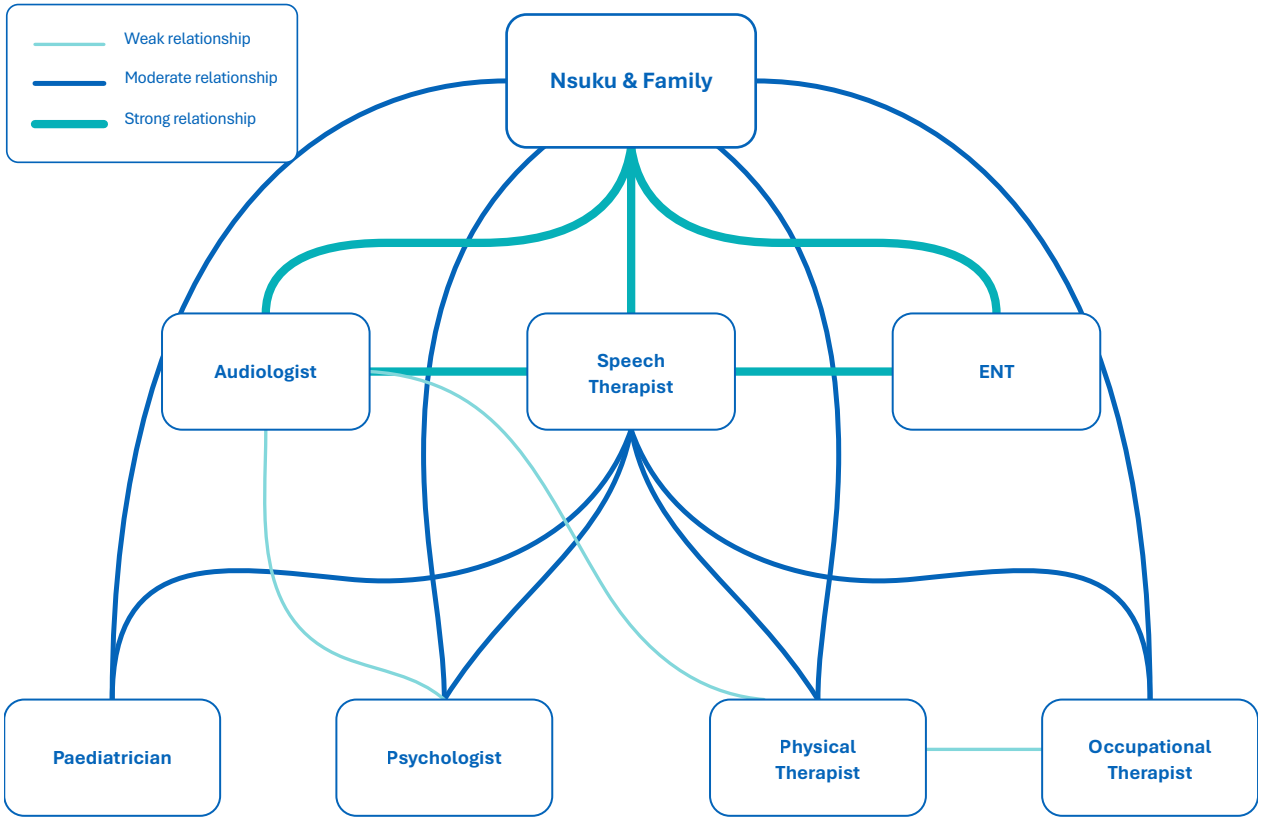


Figure 14.1: Nsuku's interdisciplinary teams ecomap

Conclusion

The importance of interdisciplinary teamwork in the intervention approach with children with HL and their families has been identified as key to achieving positive outcomes. Various practical tools can be utilised to improve communication, such as establishing regular meeting dates, developing protocols and guidelines, setting up communication systems such as WhatsApp groups, and keeping the patient and their families at the centre of all decision making. A systems approach allows for solution-based thinking to improve child and family outcomes by strengthening the relationships between all involved in the child's wellbeing.

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