FAMILY LEARNING TOOEKIT FOR HEARING FAMILIES OF DEAF CHILDREN CHALLENGES AND SOLUTIONS

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INTRODUCTION

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Everyone knows the saying that it takes a village to raise a child. This toolkit focuses on the specific roles and responsibilities of parents and guardians, siblings, extended family members, peers and friends, nannies and caregivers in the life of a deaf child. Understanding and embracing these roles can significantly impact the child's development and the well-being of all family members.

PARENTS AND GUARDIANS

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Advocacy and Legal Rights

Parents and guardians must advocate for their deaf child to ensure they receive appropriate services and accommodations. You can learn more about advocacy in Module 4 of the SILENT online training.

This involves:

- Understanding legal rights: Familiarize yourself with international and European-level treaties such as the <u>United</u> <u>Nations Convention on the Rights of Persons with Disabilities</u> (CRPD), the <u>United Nations Convention on the Rights of the</u> <u>Child</u>, The <u>European Accessibility Act</u> and the <u>European Charter</u> <u>of Fundamental Rights</u> as well as your national regulations.
- Navigating healthcare: Advocate for timely and appropriate medical care, including audiology services and speech therapy.

Practical tips:

- Research: Find the local member of the <u>European Federation</u> of <u>Parents of Hearing Impaired Children</u> in your country and sign up for their newsletter to hear about relevant updates in research, policies or ways to connect with families in a similar situation as yours.
- Documentation: Keep detailed records of all meetings, evaluations, and correspondences with healthcare providers and educators.

Join support groups: For support and advice, engage with local or online parent advocacy groups. The local FEPEDA member is a good place to start, but many groups and communities are on social media. Advocating for the rights of children together can amplify your voice and increase your impact on local decision-making. Keep in mind that while these connections are invaluable, always discuss medical interventions with a healthcare professional as well.

Communication Strategies

Learning sign language: Parents should consider learning sign language if this is the chosen mode of communication for their child. The benefits of learning sign language include promoting effective communication for better understanding and bonding, as well as helping children connect with the deaf community and its culture.

Using technology: To support communication, consider the utilization of hearing aids, cochlear implants, and assistive listening devices. Ensure proper maintenance and regular updates.

Visual and written aids: Use visual aids, written notes, and gestures to enhance communication. Visual schedules and cue cards can help in daily routines.

Explore the different options for communication explained in Module 2 of the SILENT online training.

The following websites can give you some insight on how to choose an approach best for your particular situation.

https://www.ndcs.org.uk/information-and-support/language-andcommunication/choosing-an-approach/

https://en.hesperian.org/hhg/Helping_Children_Who_Are_ Deaf:Using_spoken_language

https://www.aussiedeafkids.org.au/making-choices-aboutcommunication.html

Practical tips:

- Online courses: Enroll in online sign language courses or attend local classes, these can also help connect with the local and the national deaf community.
- Apps and tools: Explore apps that allow you and your child to learn sign language in an easy way. Keep in mind that sign language changes from country to country, so it is best to ask the local community or FEPEDA members for recommendations on where to get the best sign language education. Look up the <u>Spread the Sign</u> project which is a collection of signs from all around the world. You can also consider the usefulness of international sign language. Find here the alphabet in international sign language. https://www.youtube.com/ watch?v=Nphu-FC07KQ
- Regular maintenance: Schedule regular check-ups for hearing aids and cochlear implants to ensure they function correctly.

Emotional Support

Creating a supportive environment: Provide a loving and supportive home where the child feels safe and valued and where their personality, hopes and dreams, talents and difficulties get appropriate attention. Allow them to make mistakes and experience a childhood that isn't centred around their disability.

Building self-esteem: Encourage and celebrate the child's achievements. Focus on their strengths and interests.

Counselling and support groups: Consider counselling for emotional support. Joining support groups for parents of deaf children can provide valuable resources and community connections.

Practical tips:

- Celebrate milestones: Regularly celebrate your child's achievements, no matter how small.
- Positive reinforcement: Use positive reinforcement to encourage desired behaviours.
- Family counselling: Consider family counselling to address any emotional or communication challenges. Raising a child with a disability can have a serious impact on the family dynamics, it is best to ask for help as early as possible.

Education and Learning

Early intervention: Engage in early intervention services to support language and cognitive development from a young age. Watch this video about the importance of early intervention and family routines.

Educational choices: Explore different educational settings, such as mainstream schools, schools for the deaf, or bilingual-bicultural programs, to find the best fit for your child. You, as the parent, and your child can together make the best decisions for the appropriate education institute for them. Consider the opinions of healthcare and education professionals or other families in the same situation, but the final choice should be made by you and your child. Fight for your right to have the best education for your child, without financial limitations as per the UNCRC.

Continuous learning: Stay informed about new research and resources related to deafness and education. Attend workshops and conferences to enhance your knowledge and skills; your peers, education, and healthcare professionals can provide you with reliable sources of information.

Learn more about inclusive education in this video

and this infographic

Practical tips:

- Try to get opportunities to make the professionals working with your children to share information with each other and collaborate in finding the best tools and strategies for your child's success. If they cannot find the opportunity or time to do so, you can be the one to share information received from other professionals.
- Keep in mind that if you choose to have your child in an integrated school, it is possible that the school staff will have no or very little information on how to provide schooling for your child in an appropriate way. Communicate closely and clearly with the school professionals to ensure your child's best possible educational opportunities. Non-formal or informal education institutes, NGOs, or even other families with deaf children can help you to create a comprehensive learning programme for your child, filling in the gaps left by formal schooling.

SIBLINGS

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Introduction

Siblings play a crucial role in the development and well-being of a deaf child. Their understanding, empathy, and support can significantly impact the child's social, emotional, and communicative growth. This chapter delves into the various aspects of how siblings can support their deaf brother or sister, including understanding deafness, effective communication, inclusion, and emotional support.

Understanding Deafness

Education: It's essential for siblings to understand deafness clearly. This knowledge can foster empathy and reduce misunderstandings. For detailed information on hearing and hearing loss, as well as the available assistive technologies, rely on module 1 of the SILENT project's online training.

Types of hearing loss: Explain the different types of hearing loss (conductive, sensorineural, and mixed) how they affect hearing, and the causes of deafness. Explain this to your children at an age-appropriate level. You can find many books or online resources aimed at various age groups of children. Other families with a deaf child can share inspiring practices.

Communication methods: Introduce and explain the various communication methods deaf people use, like sign language, lipreading, and the use of hearing aids or cochlear implants.

Practical tips:

Books with deaf characters: <u>This list</u> by the National Deaf Children's Society in the UK has many books for different age groups that have a deaf character in them, recommended by parents of deaf children. <u>This list</u> is compiled by Deaf Unity. These books are all available in English, but reach out to local libraries and deaf communities for recommendations in your language. You can encourage the local library, or the school library to stock up on books accurately representing deaf characters.

Interactive Learning: Use interactive tools like the "Signed Stories" app, which offers stories in sign language and spoken words.

Open discussions: Regularly discuss and answer siblings' questions about deafness to foster a deeper understanding, make sure there are no taboo questions, and don't be afraid to admit if you don't know the answer to something. Research the answer together!

Communication

Learning sign language: Encourage siblings to learn sign language to improve communication and strengthen their bond with the deaf child.

- Sign language classes: Enroll in local or online sign language courses.
- Daily Practice: Integrate sign language practice into daily routines.
- Using technology: Familiarize siblings with the technology their deaf sibling uses.
- Assistive devices: Teach siblings how hearing aids and cochlear implants work.
- Communication apps: Introduce apps like "Ava" and "Google Live Transcribe" to facilitate communication.

Inclusion and support

Involving in activities: Ensure the deaf sibling is included in all family activities and social events.

- Adapted games: Choose games and activities that are accessible for the deaf child. Encourage the children or have the whole family play games together where deafness isn't a disadvantage, but it is equally enjoyable and challenging for all participants. Such games can be drawing games, hangman, charades, and board games.
- Inclusive communication: Ensure all family members use inclusive communication methods during activities.

Emotional support: Siblings can provide invaluable emotional support by being understanding, patient, and encouraging.

- Listening and empathy: Encourage siblings to listen actively and empathize with their deaf sibling's experiences, without minimizing the importance of the experiences of the hearing sibling.
- Celebrating euccesses: Celebrate the achievements of the deaf child together as a family.
- Role models: Siblings often serve as role models. Encourage them to exhibit positive behaviour and inclusive attitudes at home and outside of home. Building a good relationship between siblings can be an invaluable training ground for social interactions for a deaf child, preparing them to build friendships and peer relationships with other children. Encourage hearing siblings to help educate other children on how they can involve

their deaf sibling in their play and other activities. At the same time, siblings of deaf children mustn't be stuck in the role of the elucidator, as it can result in irritation, resentment, and the feeling of being overburdened.

- Family meetings: Hold regular family meetings to discuss making family activities inclusive. Allow all family members to make suggestions and bring up issues or barriers they face. Ensure that no blaming language is used when certain family activities cannot be realized due to the inability to accommodate the needs of the deaf child to prevent resentment from the hearing sibling(s).
- Peer support: Encourage older siblings to mentor their deaf siblings in social and academic settings.
- Recognition: Recognize and praise siblings for their support and inclusive behaviour, and acknowledge and name the concrete positive actions to reinforce desired behaviour.
- Role-playing: Use role-playing to teach siblings how to handle different social situations involving their deaf sibling.

Resources and good practises

- Sibling Support Project: Provides support and resources specifically for siblings of children with disabilities. Although it is an American initiative, the resources and stories shared on their website can be interesting and useful for families all over the world.
- <u>This page</u> by the National Deaf Children's Society has some inspiring input from siblings of deaf children, as well as an activity sheet just for hearing siblings to help them understand deafness and explore and express their emotions.
- https://ariellaknight.com/clubsoda/ This is a free activity book for hearing siblings of deaf children or adults

Monitoring and Support

- Regular check-Ins: Schedule regular check-ins with siblings to discuss their feelings and experiences. Make sure that the siblings' successes are celebrated with equal enthusiasm, and they receive appropriate time and care as well. It is easy for the siblings of children with disabilities to feel that they do not get enough attention, or that their problems and struggles aren't important enough.
- Professional support: Consider professional counselling or sibling support groups if needed.

EXTENDED FAMILY MEMBERS

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Introduction

Extended family members, including grandparents, aunts, uncles, and cousins, can play an essential role in the life of a deaf child. Their involvement can provide additional support, enhance the child's social network, and promote a broader understanding and acceptance of deafness within the family. This chapter will explore how extended family members can effectively support a deaf child through learning communication methods, providing practical and emotional support, and actively involving themselves in the child's life.

Learning Communication

Basic sign language: Extended family members should learn basic sign language to communicate effectively with the deaf child. This effort shows support and fosters closer relationships.

- Sign language courses: Enroll in local or online sign language classes.
- Learning together: Encourage the whole family to learn together to create a cohesive communication environment and initiate regular practice of sign language during family gatherings.
- Using visual aids: Visual aids can help bridge communication gaps when sign language is not feasible.

Practical tips:

- Online resources: The family should share with each other a pool of apps or tools that make communication easier and allow everyone to contribute with their ideas.
- Family sign language games: Play games such as "Sign Language Memory" or "Sign Language Charades" during family gatherings to make learning fun.

Providing Support

Child care assistance: Extended family can offer practical support by helping with childcare and transportation to appointments and activities.

- Regular babysitting: Schedule regular times for babysitting to give parents a break and build a bond with the deaf child.
- Transportation help: Assist with transportation to and from therapy sessions, school, and extracurricular activities.

Emotional support for parents: Extended family members can provide invaluable emotional support to the parents, helping them navigate challenges and celebrate milestones.

- Active listening: Family members should be available to listen to parents' concerns and offer encouragement.
- Sharing experiences: Share any similar experiences or insights that might be helpful. It is important that while bad experiences can provide learning points, it is best not to share horror stories with the already stressed parents, especially if they are only based on hearsay.
- Celebrate together: Celebrate milestones and achievements of the deaf child together as a family.

Active Involvement

Participating in events: Involve extended family members in significant events and milestones in the deaf child's life, such as school activities, therapy sessions, and family gatherings.

- School events: Attend school plays, sports and other events to show support.
- Creating Inclusive Environments: Ensure family gatherings and activities are inclusive and accessible for the deaf child.
- Deaf-friendly activities: Plan activities that are accessible and enjoyable for the deaf child.
- Inclusive communication: Make sure all family members use inclusive communication methods during family events.

Books and Educational Materials:

- "The Silent Garden: Raising Your Deaf Child" by Paul W. Ogden: A comprehensive guide for families of deaf children.
- "Deaf Child Crossing" by Marlee Matlin: A book that helps family members understand the experiences of a deaf child through storytelling.

Support Groups and Workshops:

- National Family Association for Deaf-Blind (NFADB): Offers resources and support for families with deaf or deaf-blind members.
- Hands & Voices: Provides workshops and resources for families with deaf children, including extended family members.

Online resources and communities:

- Hearing Like Me: An online community with articles, forums, and resources for families with deaf members.
- "Grandparents Joining the Journey." is an article about the testimony from a deaf child's grandmother, sharing her experiences and journey. https://handsandvoices.org/articles/ fam_perspectives/V15-1_grandparents.htm
- "You and Your Grandchild. Aussie Deaf Kids " is a page dedicated to the grandparents of deaf children.https://www. aussiedeafkids.org.au/you-and-your-grandchild.html

Good practices:

- Regular communication: Maintain regular communication with the parents to stay updated on the child's needs and progress.
 - Inclusive gatherings: Make family gatherings inclusive by planning deaf-friendly activities and ensuring everyone uses inclusive communication methods. Choose activities that are naturally inclusive, such as visual arts and crafts, board games, and outdoor activities that do not rely heavily on hearing.
 - Positive reinforcement: Use positive reinforcement to encourage and acknowledge the deaf child's efforts and achievements.

Creating a supportive environment:

 Family gatherings: Use family gatherings as opportunities to practice sign language and include the deaf child in all activities. Empathy exercises: Conduct empathy exercises with the extended family to help them understand the experiences of the deaf child, such as trying to communicate without sound.

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 Accessible communication: Ensure that all forms of communication within the family are accessible, including written notes, visual aids, and sign language.

PEERS AND FRIENDS

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Introduction

Friends and peers play a vital role in the social and emotional development of a deaf child. They can provide a sense of belonging, boost self-esteem, and enhance communication skills. This chapter explores how friends and peers can support a deaf child through understanding, effective communication, inclusivity, and social support. The chapter is divided into sections based on age groups to address the specific needs and interactions at different stages of development: early childhood, elementary school-age, and adolescence.

If possible, deaf children should interact with both children who are deaf or hard of hearing and children who do not have a hearing disability. This chapter focuses on interaction with peers and friends who do not have a hearing disability.

Early Childhood (Age 2-5)

Understanding Deafness

Basic education: It's crucial to teach young children about deafness in simple and understandable terms at this age. Parents of the deaf child should offer explanations and resources to the hearing friends' parents.

- Simple explanations: Use straightforward language to explain that their friend hears differently and may use sign language or devices to help them hear.
- Visual aids: Use pictures and videos to illustrate how hearing aids or cochlear implants work.

Practical tips:

- Storybooks: Read books like "El Deafo" by Cece Bell and "My Friend Isabelle" by Eliza Woloson that explain deafness in a child-friendly way.
- Educational Videos: Watch videos designed for young children, such as "Sesame Street" episodes featuring deaf characters.
 - Sesame Street Episode 2288 (1987, Bob's deaf friend / Singing out of tune
 - Linda Moves to Sesame Street

Effective Communication

Learning basic sign language: Encourage children to learn basic signs to communicate with their deaf friends.

- Simple signs: Start with simple signs for common words like "friend," "play," and "share."
- Interactive games: Use games to teach and practice sign language.

Using visual and tactile cues: Young children can use visual cues and gestures to aid communication.

- Gestures: Encourage the use of natural gestures to complement spoken language.
- Visual tools: Use visual tools like picture cards to support understanding. Create visual communication boards with pictures and signs to facilitate interaction.

Inclusivity

Inclusive play: Ensure play activities are inclusive and accessible for the deaf child.

- Adapted games: Choose games that do not rely heavily on hearing, such as puzzles, building blocks, and arts and crafts.
- Group activities: Plan group activities that encourage interaction and teamwork.

• Encouraging interaction: Promote interaction between the deaf child and their peers through structured and unstructured play.

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- Playdate planning: Organize playdates with inclusive and enjoyable activities for all children.
- Inclusive toys: Use toys that facilitate inclusive play, such as those with visual and tactile elements.

Preadolescence (6-12)

Understanding Deafness

Educational programmes: Schools should provide programmes to educate students about deafness and promote inclusivity. If the child attends school with children who are not deaf or hard of hearing, the school can reach out to the family for guidance or to a local NGO or representative organisation of deaf people. At this age, the child should be allowed and provided with an opportunity to present and lead the discussion on their own condition.

- Classroom presentations: Arrange presentations about deafness and how to communicate with deaf peers.
- Interactive learning: Use interactive activities to teach children about deaf culture and sign language.

Practical tips:

Deaf awareness days: Organise Deaf Awareness Days at school to educate students and celebrate deaf culture.

Peer education programmes: Implement peer education programmes where students learn about deafness and inclusivity. This could be extended to other disabilities as well, focusing on the concept of Universal Design. (Universal design is the process of creating products that are accessible to people with a wide range of abilities, disabilities, and other

characteristics. Universally designed products accommodate individual preferences and abilities; communicate necessary information effectively (regardless of ambient conditions or the user's sensory abilities); and can be approached, reached, manipulated, and used regardless of the individual's body size, posture, or mobility. Application of universal design principles minimises the need for assistive technology, results in products compatible with assistive technology, and makes products more usable by everyone, not just people with <u>disabilities</u>.

Effective Communication

Learning sign language: advocate for students to learn sign language to communicate effectively with their deaf peers.

- Sign language classes: Offer sign language classes as part of the school curriculum or as an extracurricular activity.
- Buddy system: Pair students with a "sign buddy" to practise sign language together.

Using technology: Introduce students to technology that supports communication with their deaf peers.

- Assistive devices: Educate students about the assistive devices their deaf peers use.
- Communication apps: Use apps that facilitate communication, such as "Google Live Transcribe."

Practical tips:

- Sign language clubs: Start sign language clubs where students can learn and practise together.
- Tech workshops: Conduct workshops on how to use communication technology effectively.

Inclusivity

Inclusive classroom activities: Ensure classroom activities are designed to be inclusive for deaf students.

- Visual aids: Use visual aids, subtitles, and written instructions to support learning.
- Group work: Encourage group work that allows deaf students to participate fully.

Extracurricular involvement: Promote the involvement of deaf students in extracurricular activities.

- Accessible activities: Ensure sports, clubs, and other activities are accessible to deaf students.
- Peer support: Encourage peers to support their deaf classmates in extracurricular settings.

Adolescence (Age 13-18)

Understanding Deafness

In-depth education: Provide more detailed education about deafness, including its impact on communication and social interaction.

- Deaf culture: Educate students about deaf culture, including its history, values, and norms.
- Guest speakers: Invite deaf individuals and professionals to speak at school about their experiences.

Effective Communication

Advanced sign language: Encourage students to continue learning and improving their sign language skills.

- Sign language llectives: Offer advanced sign language courses as electives.
- Peer tutoring: Implement peer tutoring programs where students can learn from each other.

Using advanced technology: Introduce students to advanced communication technology and encourage its use.

• Video relay services: Educate students about video relay services that facilitate communication between deaf and

Practical tips:

- Sign language certification: Encourage students to pursue certification in sign language proficiency.
- Tech integration: Integrate communication technology into daily activities, such as using captioned videos for assignments.

Inclusivity

Inclusive social activities: Ensure social activities and events are inclusive and accessible for deaf students.

- School events: Make sure school events like dances, assemblies, and sports are accessible to deaf students.
- Leadership roles: Encourage deaf students to take on leadership roles in school clubs and organisations.

Bullying prevention: Implement programmes to prevent bullying and promote student kindness and understanding.

- Anti-bullying campaigns: Conduct anti-bullying campaigns that emphasise the importance of inclusivity and respect.
- Support groups: Create support groups for deaf students and their peers to discuss challenges and solutions.

Practical tips:

- Inclusive event planning: Work with event planners to ensure all school events are accessible and inclusive.
- Leadership opportunities: Provide opportunities for deaf students to lead and participate in school governance and activities.

Resources and good practices

Books and educational materials:

- "Wonderstruck" by Brian Selznick: A novel that includes a deaf protagonist and explores themes of deafness and communication.
- "Real Friends" by Shannon Hale: A graphic novel that addresses friendship and inclusion among school-age children.

Support groups and workshops:

- Hands & Voices: Offers workshops and resources for peers and friends of deaf children.
- National Deaf Children's Society (NDCS): Provides resources and programs for educating peers about deafness.

Online resources and communities:

Hearing like me: An online community with stories, forums, and resources for friends and peers of deaf individuals.

Good practices:

- Peer mentorship programmes: Establish peer mentorship programmes to foster supportive relationships between deaf students and their peers.
- Inclusive policies: Advocate for school policies that promote inclusivity and accessibility for deaf students.
- Regular training: Provide regular training for students and staff on deaf awareness and communication strategies.

Creating a supportive environment:

- Empathy exercises: Conduct exercises to help students understand the experiences of their deaf peers, such as using earplugs to simulate hearing loss.
- Inclusive communication: Ensure that all forms of communication within the school are accessible, including using interpreters, captions, and written materials.
- Developing social skills:
- Role-playing: Use role-playing exercises to teach students how to handle social situations involving deaf peers.
- Social stories: Create social stories to help students understand and navigate interactions with their deaf classmates.

Monitoring and support:

- Regular check-ins: Schedule regular check-ins with peers to discuss their experiences and any challenges they might be facing in supporting their deaf friendsProfessional support: Consider professional guidance or workshops for students to understand better and support their deaf peers.
- Friends and peers can significantly contribute to the development and well-being of a deaf child by understanding and implementing these strategies. These efforts not only benefit the deaf child but also foster a more inclusive, empathetic, and supportive community.

NANNIES AND CAREGIVERS

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Introduction

Nannies and caregivers play a pivotal role in the daily life of a deaf child, providing both care and support that can significantly impact the child's development and well-being. Their responsibilities extend beyond basic caregiving to include effective communication, creating a supportive environment, and ensuring inclusivity in daily activities. This chapter explores the various roles and responsibilities of nannies and caregivers in supporting a deaf child, with practical tips and resources to enhance their ability to provide the best possible care.

Understanding Deafness

Comprehensive education: It is crucial for nannies and caregivers to have a thorough understanding of deafness, including its causes, types, and implications for communication and learning.

- Types of hearing loss: Familiarise yourself with the different types of hearing loss (conductive, sensorineural, mixed) and how they affect hearing.
- Causes of deafness: Understand the various causes of deafness, such as genetics, illness, or injury.
- Communication methods: Learn about the different communication methods used by deaf individuals, including sign language, lip-reading, and the use of hearing aids or cochlear implants.

- Educational courses: Take courses on deafness and deaf education offered by organisations like the National Deaf Children's Society (NDCS) or the American Society for Deaf Children (ASDC).
- Reading material: Read books and articles on deafness, such as "The Silent Garden" by Paul W. Ogden.

Learning sign language

Basic and advanced Sign language: Learning sign language is essential for effective communication with a deaf child. Start with basic signs and gradually advance to more complex language skills.

- Sign language classes: Enrol in sign language classes, either inperson or online, to gain proficiency.
- Daily practice: Incorporate sign language practice into daily routines to reinforce learning.

Interactive learning: Use interactive tools and resources to learn and practise sign language.

- Sign language apps: Use apps like "SignSchool" and "ASL Kids" to learn and practise sign language.
- Online videos: Watch online videos and tutorials on platforms like YouTube and "ASL Nook" to enhance your skills.ASL, BSL, LSL

- Flashcards: Create flashcards with common signs to practise regularly, like this for American Sign Language
- Sign language games: Engage the child in sign language games like "Sign Language Bingo" to make learning fun.
- Regular interaction: Practice sign language during all interactions with the child to build fluency.

Effective Communication

Using technology: Familiarise yourself with the technology used by the deaf child, such as hearing aids, cochlear implants, and communication apps.

- Assistive devices: Learn how to operate and maintain the child's hearing aids or cochlear implants.
- Communication apps: Use apps like "Proloquo2Go" and "Google Live Transcribe" to facilitate communication.

Visual and tactile communication: Use visual and tactile methods to support communication.

- Gestures and facial expressions: Utilise gestures and facial expressions to complement spoken language and sign language.
- Visual aids: Use visual aids such as picture cards and written instructions to support understanding.

- Tech training: Attend training sessions on how to use and troubleshoot assistive devices and communication apps.
- Visual reminders: Place visual reminders and cues around the home to support communication and routines.
- Regular updates: Keep updated on new communication technologies and methods.

Inclusive activities

Adapted activities: Ensure all activities are inclusive and accessible for the deaf child.

- Inclusive games: Choose games and activities that do not rely heavily on hearing, such as puzzles, building blocks, and arts and crafts.
- Group Activities: Plan group activities that encourage interaction and teamwork, ensuring all children can participate fully.

Encouraging Social Interaction: Facilitate social interactions with peers and other children, organising playdates and social activities.

- Playdates: Organise regular playdates with peers to encourage social interaction and friendship building.
- Social Skills Development: Support the development of social skills through role-playing and social stories.

- Activity Kits: Prepare activity kits with inclusive games and materials.
- Social Stories: Use social stories to help the child understand and navigate social interactions.
- Buddy System: Implement a buddy system where the child is paired with a peer for activities.

Continuing Education and Professional Development

Ongoing Training: Continuously seek opportunities for professional development to stay informed about best practices in caring for deaf children.

- Workshops and Seminars: Attend workshops and seminars on deaf education and caregiving.
- Certification Programmes: Consider certification programmes in deaf education and sign language proficiency.

Collaboration with Parents and Professionals: Work closely with the child's parents, teachers, and other professionals to ensure a coordinated approach to care and education.

- Regular Meetings: Hold regular meetings with parents to discuss the child's progress, needs, and any concerns.
- Professional Guidance: Seek guidance from audiologists, speech therapists, and educators to enhance your caregiving skills.

- Professional Associations: Join professional associations such as the National Association of the Deaf (NAD) or the Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) for resources and networking.
- Online Courses: Take online courses on platforms like Coursera or Udemy to improve your knowledge and skills.

Resources and Good Practices

Books and Educational Materials:

"Raising a Deaf Child" by Linda L. Daniel: A comprehensive guide for caregivers and parents.

"The Silent Garden" by Paul W. Ogden: Offers insights into the challenges and rewards of raising a deaf child.

Support Groups and Workshops:

- Hands & Voices: Provides workshops and resources for caregivers of deaf children.
- National Family Association for Deaf-Blind (NFADB): Offers support and resources for families and caregivers.

Online Resources and Communities:

- Deaf Education Web: Offers articles and resources on supporting deaf children in educational settings.
- Hearing Like Me: An online community that shares stories and resources for families and caregivers of deaf children.

Good Practices:

- Consistent Communication: Maintain consistent communication methods and reinforce the use of sign language or other preferred communication methods.
- Inclusive Planning: Plan activities and routines that are inclusive and cater to the child's needs.
- Positive Reinforcement: Use positive reinforcement to encourage and support the child's efforts and achievements.

Creating a Supportive Environment

- Daily schedules: Develop and follow a daily schedule to provide consistency.
- Visual Timetables: Use visual timetables to outline daily activities and routines.
- Regular feedback: Hold regular meetings with parents to discuss and align on routines and strategies.

Communication training: As a nanny or caregiver, ensure you receive training in the child's communication methods and the use of hearing technology. Arrange the details of the necessary training to perform your job with the child's parents, or the social services.

Regular updates: Keep caregivers informed about any changes in the child's needs or technology.

- Training programs: Enrol in training programs for sign language and assistive technology.
- Communication journals: Maintain a communication journal to document daily interactions and updates.
- Resource kits: Ask the parents or social services for resource kits that include sign language materials and information on assistive devices.

Providing emotional and social support: Create a warm and nurturing environment that fosters the child's emotional wellbeing.

Social interaction: Facilitate social interactions with peers and other children, organising playdates and social activities.

Observing and reporting: Caregivers should be observant and report any concerns regarding the child's development or wellbeing to the parents.

Practical tips:

- Playdates: Schedule regular playdates to encourage social interaction.
- Emotional check-Ins: Conduct regular emotional check-ins with the child to gauge their well-being.
- Reporting systems: Develop a system for caregivers to report observations and concerns to parents promptly.

By implementing these strategies and utilising the recommended resources, nannies and caregivers can provide comprehensive and effective support to a deaf child, ensuring their development and well-being in a nurturing and inclusive environment.

ADVANTAGES AND DISADVANTAGES OF COCHLEAR IMPLANTS

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Parents of deaf children are often advised to agree on a cochlear implant at a very early age of the child, when the child is still too young to make a decision about it. It is important for parents to understand the advantages and disadvantages of cochlear implants to be able to make an informed choice. Children and their families have the right to access unbiased information about the benefits and risks of cochlear implants. They also should have access to resources and support whether they choose implantation or opt for other communication methods like sign language.

In this chapter, you can read about cochlear implants and also have a list of questions to ask a physician recommending the implantation.

What is a cochlear implant?

A cochlear implant is a sophisticated medical device designed to provide a sense of sound to individuals who are profoundly deaf or severely hard of hearing. Unlike traditional hearing aids, which amplify sound, cochlear implants bypass damaged parts of the inner ear and directly stimulate the auditory nerve. This allows the brain to receive sound signals, potentially enabling the user to hear.

Components of a cochlear implant

- 1. External components:
- Microphone: captures sound from the environment.
- Sound processor: converts the captured sounds into digital signals. It is usually worn behind the ear.
- Transmitter: sends the processed signals to the internal implant. This is often a small disc that attaches magnetically to the scalp.
- 2. Internal components:
- Receiver/stimulator: implanted under the skin behind the ear, it receives signals from the external transmitter and converts them into electrical impulses.
- Electrode array: a set of electrodes surgically inserted into the cochlea (the spiral-shaped organ in the inner ear). These electrodes directly stimulate the auditory nerve fibres within the cochlea.

How cochlear implants work

1. Sound collection: the microphone on the external sound processor picks up sounds from the environment.

2. Sound processing: the sound processor converts these sounds into digital signals.

3. Signal transmission: the transmitter sends these digital signals through the skin to the implanted receiver/stimulator.

4. Electrical stimulation: the receiver/stimulator converts the digital signals into electrical impulses.

5. Auditory nerve stimulation: The electrode array in the cochlea delivers these electrical impulses to the auditory nerve fibres.

6. Sound perception: The auditory nerve carries the electrical signals to the brain, which interprets them as sound.

Cochlear implants represent a significant advancement in medical technology, offering the potential for profound hearing improvement and enhanced communication abilities for individuals with severe hearing loss. They can offer significant benefits to small children with severe hearing loss, particularly in terms of hearing, speech development, and social integration. However, they come with surgical risks, long-term maintenance needs, and ethical considerations regarding the child's rights and identity. Parents and caregivers must carefully weigh these factors and make informed decisions that prioritise the child's overall well-being and future potential.

Advantages

1. Improved hearing and speech development: cochlear implants can significantly enhance a child's ability to hear, which is crucial for the development of speech and language skills. Early implantation often leads to better outcomes in terms of language acquisition and educational achievement.

2. Social integration: improved hearing can facilitate better communication, leading to more successful social interactions and integration with hearing peers. This can reduce feelings of isolation and improve overall quality of life.

3. Educational opportunities: with improved hearing, children may have access to a broader range of educational opportunities and resources. This can enhance their academic performance and future prospects.

 Neuroplasticity: young children have high neuroplasticity, meaning their brains are more adaptable.
 Early implantation can take advantage of this, leading to more effective auditory processing and language skills development.

Disadvantages

1. Device limitations: cochlear implants do not restore normal hearing and may provide limited benefit in noisy environments. The quality of sound is different from natural hearing, which can require significant adaptation.

2. Maintenance and upgrades: the device requires ongoing maintenance, including external parts that can be damaged or lost. Upgrades may be needed as technology advances, which can be costly and logistically challenging.

3. Long-term commitment: The success of cochlear implants depends on long-term, intensive follow-up, including speech therapy and regular programming of the device. This requires a significant commitment from families and caregivers.

4. Limitations for the child to participate in activities: parents will need to consider the ability of the child to maintain and safekeep the cochlear implant, especially its external parts alone. This aspect may limit the child's ability to join peers in certain activities.

Health risks

1. Surgical complications: besides general surgical risks, specific complications can include meningitis, particularly in children with certain anatomical issues or cochlear malformations. Vaccination and prophylactic antibiotics are crucial to mitigate this risk.

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2. Hearing loss in the implanted Ear: cochlear implantation usually destroys any residual hearing in the implanted ear, making the individual completely dependent on the device.

3. Device failure: the internal device can fail, necessitating additional surgeries for repair or replacement. This poses further health risks and psychological stress.

Health risks

1. Informed consent: Small children cannot provide informed consent. From a child rights perspective, parents or guardians should only give consent to surgery if it is absolutely necessary, and it must be based on comprehensive information and understanding of the potential outcomes, risks, and lifelong implications.

2. Right to identity: deafness is not seen as a disability by the deaf community but as a unique cultural identity. The decision to implant a cochlear device can be controversial, as it might be perceived as an attempt to "normalise" the child rather than embracing their Deaf identity.

3. Psychosocial impact: the child's social and psychological wellbeing must be considered. This includes understanding the potential impact of living between the hearing and Deaf worlds and ensuring the child has support systems in place in both communities.

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What to consider about early cochlear implantation?

While early cochlear implantation has its benefits, there are compelling reasons to consider waiting until a child can give informed consent. These reasons often revolve around ethical considerations, the child's right to autonomy, and potential impacts on identity and social integration.

Waiting until a child can provide informed consent for a cochlear implant respects their autonomy and allows them to make a deeply personal decision with full understanding of the implications. This approach considers the child's right to self-determination, cultural identity, and the potential for technological and medical advancements.

Ethical considerations and autonomy

- Respect for autonomy: Allowing the child to reach an age where they can understand the implications of the procedure respects their right to make informed decisions about their own body and medical treatment. This is a fundamental ethical principle in medical practice.
- Informed consent: True informed consent requires the individual to understand the risks, benefits, and alternatives of the procedure. Small children lack the cognitive and emotional maturity to fully grasp these concepts. Waiting allows the child to participate meaningfully in the decision-making process.

Identity and cultural considerations

- Deaf identity: For some individuals and communities, deafness is not viewed as a disability but as a unique cultural and linguistic identity. Children should have the opportunity to grow up within this culture and make an informed choice about whether they want to pursue a cochlear implant.
- Community integration: Waiting can allow the child to become more integrated into the Deaf community, potentially developing a strong sense of identity and belonging before deciding if they want to explore the hearing world with the aid of a cochlear implant.

Technological and medical advancements

- Advancements in technology: cochlear implant technology is continually advancing. Delaying the procedure could mean that the child will have access to more advanced and effective technology in the future, potentially resulting in better outcomes.
- Medical risks: Surgery at a very young age carries inherent risks.
 Waiting until the child is older and physically more robust could mitigate some of these risks.

Technological and medical advancements

Psychological impact: Undergoing surgery and adapting to a cochlear implant can be psychologically demanding. Older children can cope with these challenges better as they have a more developed support system to help them through the process.

Social and educational considerations

- Educational resources: Waiting does not preclude the child from developing language and communication skills. Many resources, including sign language and specialized educational programs, can support the child's development while they grow older and more capable of making an informed decision.
- Balanced perspective: As the child grows, they can experience both the hearing and Deaf worlds, allowing them to make a more informed decision about which path they wish to pursue with full awareness of the implications.

Potential counterarguments and mitigating factors

- Family Support: A strong family support system can help mitigate some of the developmental delays associated with later implantation. Families can provide a nurturing environment that promotes language and cognitive development through alternative means.
- Holistic Development: Emphasizing holistic development through early childhood education and social integration in both the hearing and Deaf communities can help balance the potential disadvantages of waiting.

Questions to ask if a physician recommends cochlear implant(s) for a young child

When a doctor recommends a cochlear implant for a small child, parents should ask a comprehensive set of questions to fully understand the implications, benefits, and risks involved. Here are key questions to consider:

1. Eligibility and suitability

- Why do you recommend a cochlear implant for my child specifically?
- Is my child a suitable candidate for the implant? Are there any medical conditions that could complicate the procedure?

2. Surgical details

- Can you explain the surgical procedure in detail?
- What are the risks and potential complications of the surgery?
- How long will the surgery take, and what is the expected recovery time?

3. Post-surgical care

- What post-operative care will be needed?
- How often will follow-up appointments be required after the surgery?
- What are the signs of complications we should watch for postsurgery?

4. Device information

- What brand and model of cochlear implant do you recommend, and why?
- How does the device work, and what kind of hearing can we expect for our child?

5. Performance expectations

- What level of hearing improvement should we realistically expect?
- How will the implant affect my child's ability to hear in different environments, such as noisy places?

6. Device maintenance

- What maintenance and care will the device require?
- How often will the external parts need to be replaced or upgraded?

7. Rehabilitation process

- What kind of rehabilitation will be necessary after the implant?
- How long will my child need speech and language therapy?
- Can you recommend local resources or therapists specializing in cochlear implant rehabilitation?

8. Long-term outcomes

- What are the long-term outcomes for children with cochlear implants?
- How will the implant affect my child's development and education?

9. Health risks

- What are the potential health risks associated with the implant, both short-term and long-term?
- How often do complications occur, and how are they managed?

10. Alternative options

- What are the alternatives to cochlear implants?
- Can you explain the pros and cons of each alternative, including hearing aids and non-surgical options?

11. Informed consent and decision making

- How do you ensure that we, as parents, are making a fully informed decision?
- What should we consider regarding our child's future autonomy and decision-making about their own hearing?

12. Cultural and social limpact

- How will the implant impact my child's identity and relationship with the Deaf community?
- What are the social and psychological considerations we should be aware of?

13. Cost and insurance

- What is the total cost of the cochlear implant procedure, including surgery, device, and post-operative care?
- Does insurance cover the procedure and subsequent therapy?
 What out-of-pocket expenses should we expect?

14. Support and resources

• Are there support groups or networks for families with children who have cochlear implants?

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• Can you provide resources or references for further information?

15. Monitoring and follow-up

- How will my child's progress be monitored over time?
- What benchmarks or milestones should we expect, and how will they be assessed?

HELPFUL WEBSITES AND RESOURCES

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https://www.silent-project.online/

https://fepeda.eu/

https://www.ndcs.org.uk/

https://www.avuk.org

https://hearinghealthfoundation.org/

https://www.aidthesilent.com/resources/

https://www.babyhearing.org/

https://www.agbell.org/

https://ncbegin.org/

https://www.infanthearing.org/

https://www.mydeafchild.org/