

Dr. S. R. Chandrasekhar Institute of Speech and Hearing A Unit of Bangalore Speech and Hearing Trust



(A Project of Lions Club of Bangalore East) (Affiliated to Bengaluru North University, Recognized by Rehabilitation Council of India, New Delhi and NAAC Accredited) Lingarajapuram, Hennur Main Road, Bangalore- 560084 Tel: 080-25460405/25470037/25468470 e-mail: <u>dr.srcish@gmail.com</u> Web: <u>www.speechear.org</u>

Key Indicator: 7.2 Best Practices (30) 7.2.1 Describe two Institutional Best Practices as per the NAAC format provided in the manual

Topic 1:

Title: Parent Support Network (PSN)

Objectives:

- To connect with and empower other parents facing similar challenges
- To share their experiences and concerns regarding their child in order to reduce stress
- To learn about the processes, professionals, school options and therapeutic services that can help, and advocacy
- To help and support parents to plan activities for their children

3. The Context

Parents who have a child with special needs feel alone and isolated. They need support in finding the best services for their child and guidance for making well informed decisions. Several parents do not receive the necessary information required for helping their child, which may lead to delay in identification and intervention. This compounds their child's difficulties and increases the gap between the child and his/her peer group. When parents meet others who have been in the same situation, they feel connected and are able to share their deepest fears and concerns. This can be a cathartic experience that is necessary for every parent that struggles with feelings of guilt, helplessness and agony.

Parents require a support group that provides strong relationships, strategies for dealing with stress, resources, knowledge and an understanding of child development. The type of support needed by families may vary based on individual needs. One family may require advice on educational support, while another may need guidance in terms of feeding and self-help skills. Parents who receive timely support and guidance are able to provide safe homes for their children, who thrive in a healthy environment.

4. The Practice

PSN functions as a network that provides opportunities for parents to meet on a regular basis to discuss the progress of their child, the challenges they face in their daily lives and also to share their experiences in raising a child with special needs.

With reduction in Covid restrictions, the PSN meeting for the month of August was held face-to-face in the auditorium of the Institute. All the parents, who are members of PSN are also part of a WhatsApp group that is used for planning the meetings and helping parents with their queries.



Dr. S. R. Chandrasekhar Institute of Speech and Hearing A Unit of Bangalore Speech and Hearing Trust (A Project of Lions Club of Bangalore East) (Affiliated to Bengaluru North University, Recognized by Rehabilitation Council of India, New Delhi and NAAC Accredited) Lingarajapuram, Hennur Main Road, Bangalore- 560084 Tel: 080-25460405/25470037/25468470 e-mail: <u>dr.srcish@gmail.com</u> Web: <u>www.speechear.org</u>

In India, the concept of Parent Support Groups is relatively new. A lot of clients come from lower socio-economic backgrounds so they expect support in terms of monetary benefit, free resources, or discounts in therapy sessions. It needs a lot of counselling on the part of the staff to help parents understand that PSN is not about tangible benefits. It is a platform that helps parents create a Network that helps them connect with other parents who are in the same boat. The aim of PSN is to create a network that supports parents medically, emotionally, and socially. It also provides easier access to information, resources, and services.

5. **Evidence of Success**

Till date, 44 parents have joined PSN. They are happy to be part of the parent support group and have provided feedback on how these meetings have helped them manage their children better. Parents mention that interacting with others in similar circumstances gives them hope and strengthened their faith in the process of rehabilitation. PSN meetings have provided parents with deeper insights about their child and have helped them learn new strategies to manage their child's communication, behaviour, and social skills.

The Deputy Director Clinical of Dr.SRCISH, Dr. Sarika Khurana personally interacts with parents during these meetings. She counsels them regarding the need for parent involvement in the intervention process and guides them to support their child's communication and learning at home. Dr Khurana motivates parents to participate wholeheartedly and participate in PSN by sharing their experiences with other parents.

6. **Problems Encountered and Resources Required**

Some challenges faced by PSN include:

• Difficulty convincing parents to join the network since the majority of parents expect tangible gains such as discounts and free resources/sessions.

• Several parents are in denial. They feel that their child does not have any disability so they do not sign up for PSN meetings and fail to avail the necessary services.

• Majority of parents are working so they are unable to find the time to attend PSN meetings.

• Due to the pandemic, many parents discontinued services and returned to their hometown.

• Poor internet connectivity for some parents made it difficult for them to join online PSN meetings.



Dr. S. R. Chandrasekhar Institute of Speech and Hearing A Unit of Bangalore Speech and Hearing Trust



(A Project of Lions Club of Bangalore East) (Affiliated to Bengaluru North University, Recognized by Rehabilitation Council of India, New Delhi and NAAC Accredited) Lingarajapuram, Hennur Main Road, Bangalore- 560084 Tel: 080-25460405/25470037/25468470 e-mail: <u>dr.srcish@gmail.com</u> Web: <u>www.speechear.org</u>

Topic 2:

1. **Title of the Practice:** Neonatal hearing screening at government hospitals provided free of charge

2. Objective of the practice:

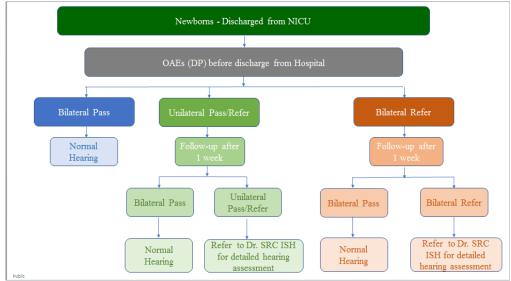
- To provide early access to ear and hearing care from the time of birth.
- To intervene at the earliest in regards to hearing in turn facilitating age-appropriate language and speech development.
- To achieve best practice recommendations stipulated by JCIH 2019 (In case of meeting 1-3-6-month benchmark i.e., screening completed by 1-month, Audiological Diagnosis by 3 months and enrolment in early intervention by 6 months should strive to meet 1-2-3month benchmark timeline)

3. The Context:

Congenital Hearing impairment in children continues to be one of the debilitating conditions with high incidences. As it is a hidden disability mostly it is identified late which in turn delays the child's ability to listen and learn through hearing as well as their speech and language development. This can have a profound impact on their social, economic and academic development as well.

The screening for hearing can be carried out from the 2nd day of birth through a test called as Otoacoustic emissions. This requires a Handheld equipment known as the OAE screener. As this screener contains sensitive microphones, they are costlier than certain other equipments. Also, this program is not that widely spread and available in all the states and parts of India.

4. The Practice:





Dr. S. R. Chandrasekhar Institute of Speech and Hearing



A Unit of Bangalore Speech and Hearing Trust (A Project of Lions Club of Bangalore East) (Affiliated to Bengaluru North University, Recognized by Rehabilitation Council of India, New Delhi and NAAC Accredited) Lingarajapuram, Hennur Main Road, Bangalore- 560084 Tel: 080-25460405/25470037/25468470 e-mail: <u>dr.srcish@gmail.com</u> Web: www.speechear.org

The institute provides free New-born hearing screening to 2 eminent government hospitals in Bengaluru (KC General, Vani Villas). On an average 250-300 New-borns are screened for Hearing loss for these two centres every month. The clientele belong to low socioeconomic background and many a times are from rural areas who otherwise does not have access to undergo this important procedure because of cost and availability.

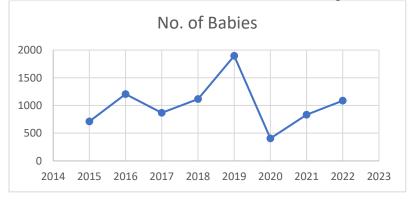
The screening procedure illustrated above follows an elaborate protocol formed based on JCIH guidelines and Indian Paediatric Association.

New-borns who fail the screening are evaluated in detail at the Institute at a subsidised cost. Post which they are provided early intervention options (Amplification devices, Implantable Hearing devices and subsequent therapy) which best suit them. We also provide quotations for Hearing Aids or other accessories as needed by clients. Additionally we provide documentation to help apply for CM Relief fund to procure amplification devices. In some cases donors or the management of the Institute provides Amplification devices free of cost or at a subzisied cost. The institute is empanalled in the Central government program of ADIPS and the state government scheme of RBSK-SAST for providing government sponsored amplification device along with therapy for a period of time free of cost.

5. Evidence of Success:

The institute takes every opportunity in increasing awareness related to early intervention especially at government aided centres to implement and provide NHS. There has been an increase in hospitals approaching us to carry out NHS at their centres. And in places we have been carrying out NHS we have an increase in the number of babies being screened as years go by.

From the start of the program till date we have screened approximately 13,500 babies. The increase seen in one centre where NHS is being carried out is portrayed below.



6. Challenges Encountered and Resources Required: <u>ADMINISTRATIVE HURDLES</u>:

1. There is no uniform program throughout the State.

2. Multiple levels of clearance and red tapes to be crossed to initiate NHS at government setups which are time consuming.

IMPLEMENTATION OF NHS AND LACK OF RESOURCES:



Dr. S. R. Chandrasekhar Institute of Speech and Hearing A Unit of Bangalore Speech and Hearing Trust



(A Project of Lions Club of Bangalore East) (Affiliated to Bengaluru North University, Recognized by Rehabilitation Council of India, New Delhi and NAAC Accredited) Lingarajapuram, Hennur Main Road, Bangalore- 560084 Tel: 080-25460405/25470037/25468470 e-mail: <u>dr.srcish@gmail.com</u> Web: <u>www.speechear.org</u>

1. Inadequate infrastructure: This includes non-availability of sound treated rooms for testing. Due to this, tests like OAEs which are highly sensitive to noise needs to be monitored constantly and noise levels to be reduced through different mechanisms.

2. The screening program needs to be conducted in a uniform and organized manner which requires a dedicated team which should contain trained personnel who provide dedicated service to NHS.

3. Digital database that can be shared or accessed by different medical personal for the overall wellbeing of the child is not available

4. Birth rate in India per day as reported by UNICEF is 67,365 which require several personnel to be employed and deputed at all hospitals. Non-availability of resource persons and equipment create lack of penetration of NHS program.

PATIENT RELATED CHALLENGES:

1. Travel related issues.

2. Lack of awareness and need for Hearing screening and evaluation.

3. Many come from low-socioeconomic status which makes the follow ups a financial burden for them.