Parent’s engagement in a cochlear implant orientation program

CI 2019 Pediatric– Miami

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São Paulo, Brazil
9.7 millions of brasilian have a disability

Every 10 babies born, 3 have hearing loss and 1 is severe

2000 – 2016: 7,409 cochlear implant surgeries in Brazil

4,432 in children between 0 to 12 years.

Fonte: Ministério da Saúde do Brasil e Publicação Implante Coclear Fmusp Bento Ricardo
Presentation goal: Show how the families’ engagement was and to explore reasons for attendance or the lack of it.

Weekly multidisciplinary program (Time: 2h30 for children AND family)

Language and speech therapists, psychologist and social worker

Activities designed specifically for parents and children, both together and separate
Introduction - Process

1. Evaluation (3/4 visits) speech and language therapist, psychologist and social worker

2. Social worker: Contract of attendance and families/organization responsibilities; amount of money the family can invest

3. After the evaluation, the family is ready to attend the weekly group with other families
Introduction - Groups

All families were visited in their homes by the social worker during July, which is winter break in Brazil.

The groups are closed and annual, with approximate 30 weeks through the year.
Method

Our method was to collect and analyze information about families’ attendance and evasion from February through December/2018.
Results

27 families

- 16 completed the evaluation process
  - 12 stayed until the end of the year
- 11 did not complete the evaluation process
  - 2 of the families which did not complete the evaluation stayed
14 families divided in three group

1st group: average attendance 69.1%

2nd group: average attendance 75.8%

3rd group: average attendance 79.9%

Mean attendance rate during the year: 74.9%
Short term action

Completing the evaluation BEFORE beginning the weekly program
Long term actions

Bigger groups: considering we have a aprox. 25% absenteeism rate

Promoting families accession by engaging parents’ in the activities organization (workshop)
Unexpected result

Home visit: strong impact for low income families = the perception that we are interested in THEIR reality
Study Case

J

Uses sign language

6 years

unilateral CI
Mother has little support from biological father. She came to São Paulo and left the kid in the northeast with the grandmother for some time. Now they both live in São Paulo and she lives with a new partner.

Difficulty to engage in playing, tends to delegate the child’s development to “professionals”

Came to our service because “she was a good mother taking care of him, but not when it came to helping him learning how to talk” (as said by a professional at the CI center)
First semester: 50% of adherence

She was visited at her house in a social and physical vulnerability area

Second semester: 89.4% of adherence
Mother is closer to the service, shares her struggles, but is also more empowered about what SHE can do – when it comes to Js deafness, but also other familiar issues.

She stayed through the whole year and continued in 2019.
Conclusion

• Completing the evaluation process turned out to be a major factor when it comes to families’ accession.

• 50% of the families that reach us can’t actually keep up with the activities we offer, usually because of distance, money issues regarding transportation, and parents’ commitments of all kinds.

• For the 14 families that stayed through the year we considered we had a good engagement rate (74.9%), considering the weekly attendance for two and a half hours and the requirement for parents’ participation.

• For families with lower income, we found out that the social worker home visit had a noticeable impact on accession

• Individual strategies need to be thought to meet each families needs
THANK YOU!