

Family engagement for effective intervention for children who are deaf or hard of hearing in resource-constrained settings

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Context

Researchers in many developed countries have shown that parental engagement improves the speech and language outcomes for children who are deaf or hard of hearing. However, in resource-constrained settings, family engagement is likely to be a very complex process

Variety of Family Structures!

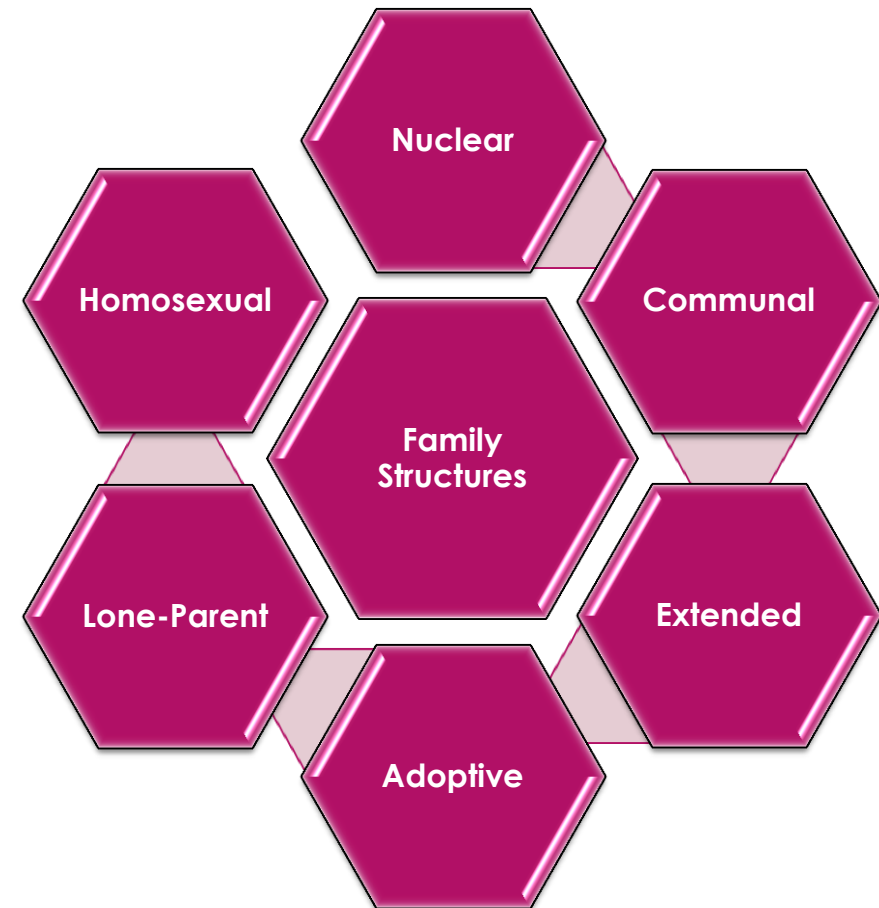
Paternalistic Family Arrangements

Women and Girls have little or no say

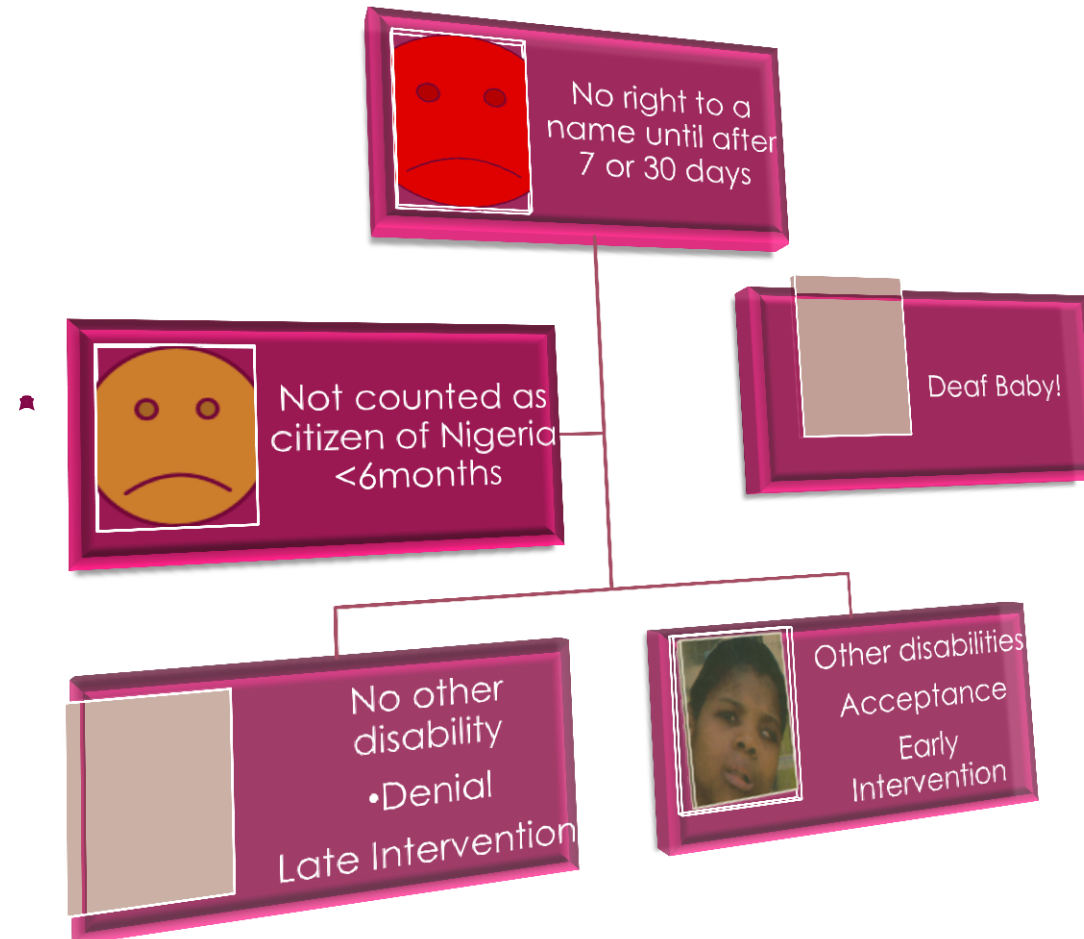
- Women on the paternal side have more say than maternal side
- Modern economically independent women now able to assert their rights over their child

Mothers almost always receive the blame for the disabilities in their children

- May be sent away with the disabled child
- May be forced to abandon her child to family members who live in villages far away from them.



Hearing Loss & Other Disabilities



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**JUSTIFICATION FOR ENGAGING
FAMILIES
IN RESOURCE-CONSTRAINED
SETTINGS**

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Societal Picture of Deafness & Hearing Loss



Societal Perception of Deafness

Societal stigmatisation of the family

Social exclusion of the affected family members

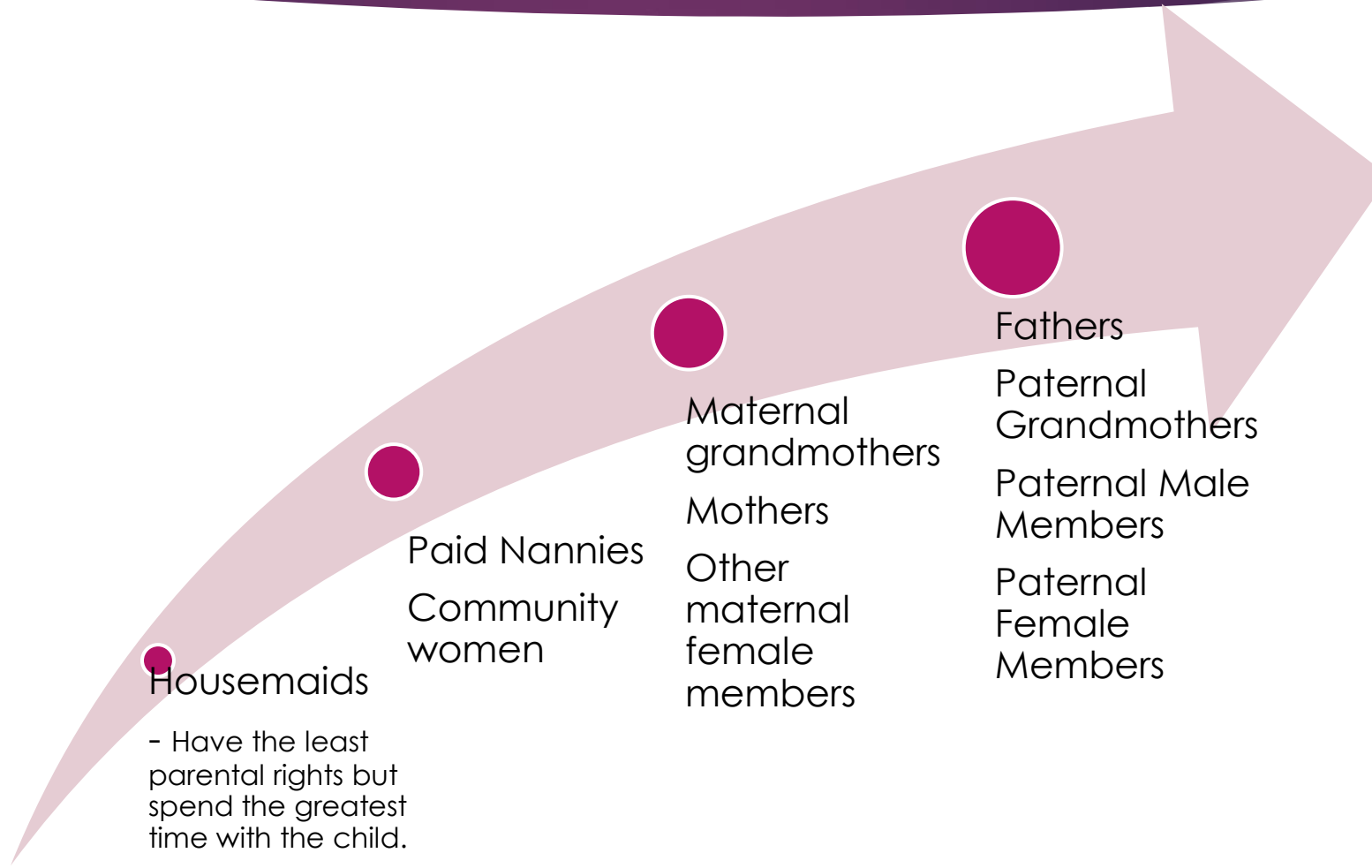
Isolation or abandonment of a child who is disabled

Infanticide is not new or considered a crime

Benefits of Engaging Family Members

- ▶ Strengthens family relationships by helping them to cope
- ▶ Ensures early Intervention
- ▶ Ensures attendance with seamless intervention sessions
- ▶ Continuity of ongoing intervention with home support
- ▶ Early detection of obstacles and drawbacks with opportunities for quick resolution
- ▶ Better intervention outcome

Parental Rights Hierarchy!



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CHALLENGES OF ENGAGING FAMILIES IN DEVELOPING COUNTRIES

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Individual barriers



Nationality or racial inequalities

Sexual inequalities (Female gender is deprived of basic rights)

Presence of additional or multiple disabilities

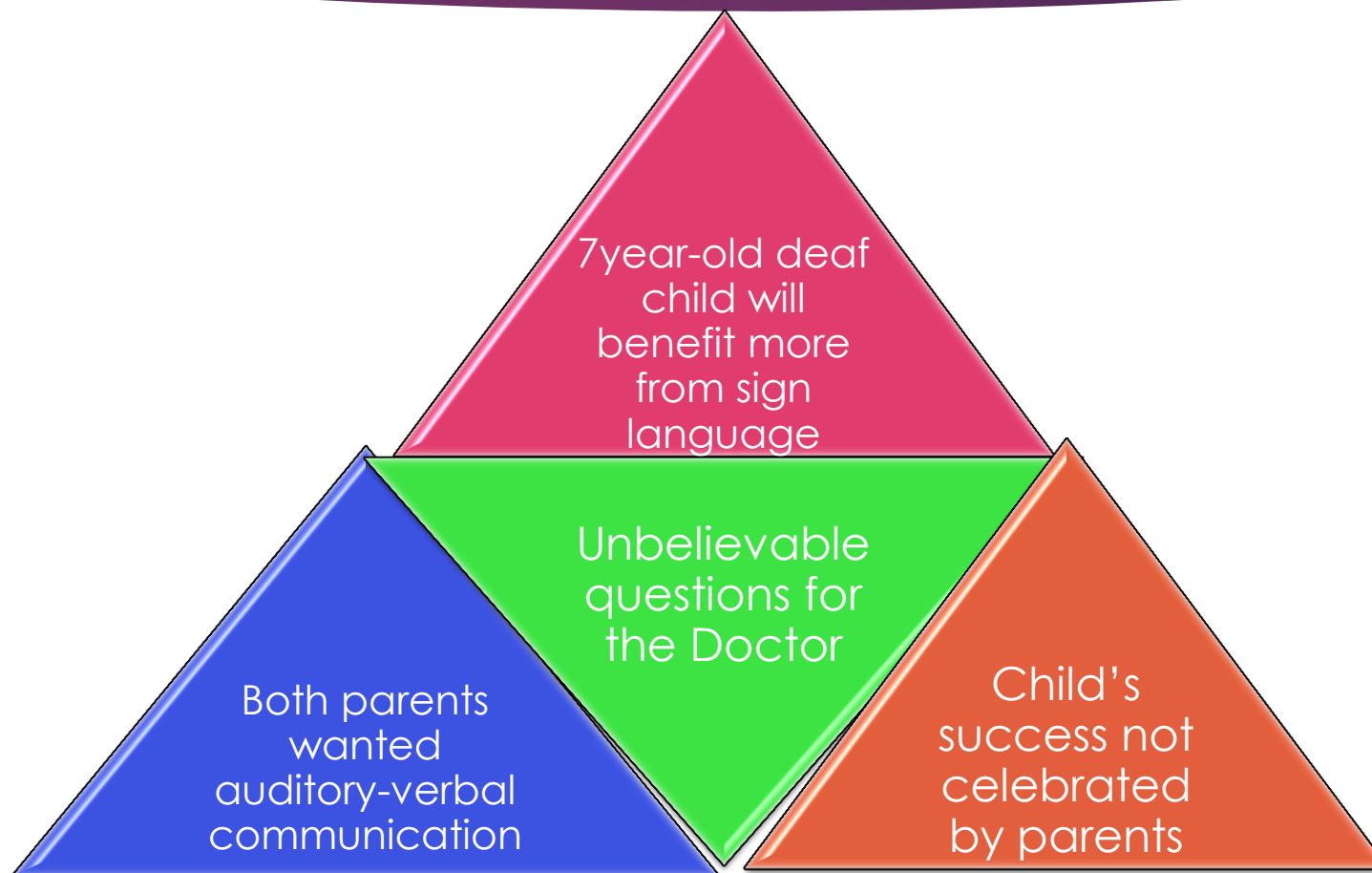
Family Structure

Fathers are culturally seldom involved with child care issues

Recognise other women with greater rights

Recognise distrust for non-family members

Challenges To Family Engagement: Parental Autonomy: Case 1



Culturally Judgemental Attitudes & Parental Grief

The fear of stigmatisation and societal alienation.

The deaf child is believed to be evil, retribution from Deity and a source of misfortune for the family

The child should therefore be excluded from others

- Infanticide,

- - Child abuse & Isolation

What's in the News!

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THE PUNCH

Girl, 15, locked up for 10 years

Akin Oyedele, Ibadan

A source confided in our correspondent that the girl had been kept incommunicado for an unspecified number of years, making it impossible for her to communicate in any language.

One neighbour said she had been held for 10 years. It was gathered that a middle-aged woman who rented a wing on the first floor of the building, was responsible for keeping the hapless girl.

She was said to be living in the building until about two years ago when she relocated to Akure, Ondo State, where

During the period she stayed in the house, it was learnt that a sister-in-law to her pastor-husband, who stayed in an apartment in the same building, was responsible for feeding the girl.

The sister-in-law, identified simply as Victoria, who used to teach in a private school located in Sango area and owned by the woman, padded out of the building late last year.

When Victoria was still around, the source said she used to take three days' food supply to the girl.

Victoria, it was gathered that a woman who comes from outside once a week now brings food to the girl. The only time the girl was said to see brightness was once in two weeks when she was made to wash her only apparel in the nearby bathroom, even in her condition.

Due to the poor feeding, the girl was said to always moan at night thereby keeping residents awake.

On one occasion, Victoria was alleged to have travelled for two weeks without making any arrangement for the girl's

The source said, "On such occasions, neighbours will buy a long loaf of bread and pass it to the girl after finding a means to open the padlock without giving any room for detection.

"Sometimes, the girl will be singing at night, but in an unintelligible language. She cannot speak any language since she has been disallowed from mixing with the outside world.

"I don't know why people should be that wicked, if they don't need the girl, the Cheshire Home is close to the

Other News
'Why AIG Ekpodom is still Oyo police boss'


POLICE authorities have justified the continued stay of Mr. Udom Ekpodom, an assistant inspector-general of police, in the office as police commissioner in Oyo State.

Force spokesman, Mr. Aghorebi Akpoebi, who spoke with our correspondent on the telephone, said it was not unusual for an AIG to be in charge of a state command.

According to him, all the necessary steps had been taken and that at the appropriate time, Ekpodom would be

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How police rescued girl incarcerated for 10 years



Akin Oyedele

Although she is now free, rehabilitation of a girl incarcerated for 10 years in Ibadan, Oyo State, may be an uphill task

Poverty

Screening

Intervention

Out-of-pocket
expenses

Cost, maintenance and
replacement of equipment
(HAs or CI)

Educational/ school support
services

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**ADDRESSING THE BARRIERS TO
FAMILY ENGAGEMENT IN
RESOURCE-LIMITED COUNTRIES.**

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The dearth of skilled professionals in resource-limited countries.

- ▶ Resource-limited communities often lack facilities for including individuals with deafness or hearing impairment in the larger society.
- ▶ The concept of humanitarian support for individuals with disabilities and their families is rare
- ▶ Resource-limited societies
 - ▶ Stigmatise individuals with disabilities and their families and lack legal, educational or economic support for individuals with disabilities
 - ▶ Largely exclude individuals with disabilities

The Challenges of Raising a Child with Hearing Loss in Resource-poor Countries

- ▶ Pervasive culture of not accepting hearing loss
 - ▶ Traditional – somebody must be blamed for the deafness
 - ▶ Religious – to accept deafness is complete lack of faith for healing
- ▶ Educational possibilities restricted to normal hearing individuals
- ▶ Limited vocational opportunities

Case Studies: Maternal Attitude to HL

Questions	Mum OAT (BOY)	Mum TAL (GIRL)
Marital Status & No of Children	M (3)	M (3)
Birth Order	2 nd (1 st of Twins)	2 nd (Singleton)
Using HAs? (How Long?)	Yes (1.5yrs)	Yes (5.5yrs)
Language Development	Fair	Poor
Time mum spends playing with child	Half an hour	All day
Frequency of Misbehaviour (Compared to other Siblings)	Often (Less)	Often (More)
Response from Mum (Compared to other Siblings)	Rebuke (Less)	Spank (More)
Maternal feelings towards the child	Optimistic	To learn better

Case Studies: Maternal Attitude to HL

3 mths F/U

Mum now spends about 2 hours with OAT daily with good progress

3 mths F/U

Mums remark in the clinic during a follow-up appointment:
'See the child they want us to play with'

Parental Empowerment

Motivate and empower families to:

- ▶ Realise that the child is not to blame for the deafness
- ▶ Recognise the difficulties that the child has to confront and the enormous needs required to succeed
- ▶ Parents need to
 - ▶ Acknowledge their own strengths and limitations
 - ▶ Identify resources they require to help their child
 - ▶ Be active advocate for the rights of children who are deaf or hard of hearing

Empowering Children with Hearing Loss

Motivate and empower children with hearing loss to:

- ▶ Understand that they are on equal terms with their siblings
- ▶ Realise that they have equal rights with other children
- ▶ Recognise that they have the freedom to make friends with other children and play with them
- ▶ Understand why they are different from other children
- ▶ Advocate for their listening or special educational needs

Professionals' Attitude to Outcomes

Low Lying Fruits

- ▶ Embrace and celebrate
 - ▶ Family enthusiasm & regular attendance
 - ▶ Regular enquiries and updates on progress
 - ▶ Any support from the father
 - ▶ granting permission for session attendance
 - ▶ Involvement of multiple enthusiastic family members

Promoting Inclusive Societies

- ▶ Promoting parent support groups
- ▶ Showcasing and celebrating accomplished individuals who are deaf or hard of hearing
- ▶ Advocating for basic human rights for individuals who are deaf or hard of hearing
- ▶ Advocating for special educational facilities and support beyond sign language which is currently the sole medium of education in resource-limited countries like Nigeria

Any Questions?



Many thanks indeed for your attention!