

Inclusive practices of upbringing children and what parents need to know about adverse childhood experiences

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Birth of child with disability: The most adverse experience for a family

- For a mother in particular and for the whole family in general the birth of child with disabilities is a painful experience.
- Much of this pain is because of ignorance and uncertainties
- Basic knowledge of disabilities or full range of human diversity among mothers and family is seriously lacking
- Unfortunately our health system with its rural set-up is not properly ready to deal with new born babies with disabilities
- In such vacuum of information the hearsays and superstitions become the only choice for the family.
- So much stigma and blaming is attached with the birth of a baby with disabilities

Early identification and the system of delays

- Mother is the first person to notice abnormalities in the child
- She keeps this information secret from her husband because of fear and a tendency to deny difference
- Since mother is always inclusive by thought and actions she is afraid to notify a difference which can isolate/ exclude her child from others
- It can take up to 3 months in sharing the odds of child with her husband
- Then they both scared and tried to hide abnormalities in the family
- Grandparents perhaps the second immediate circle where they went for elderly advice.
- Their dependence on grandparent again indicates the lack of relevant information for making a right decision independently.

The role of belief system of the early care givers

- The roots of a belief systems are multiple. They may include traditions, religious teaching with all distortion, myths and superstitions.
- The mainstream remedy of any possible disability is to go to peer sb or a shrine for dua and Taweez/ medicine to avert disability.
- The trust on this remedy consumes 9 months to a year before the parents come to realise the shallowness of this pseudo treatment.
- Remember the condition of the child is still a secret which restricts the wider sharing and consultation.
- Serious disappointment then compels the parents to seek help from medical doctor.
- Then it is their luck to whom they contact; a quack, commercially available doctors or a genuine medical specialist. It is almost too late to intervene effectively

Gradually fadding accessibilty

- Depending upon of the handicaping conditions, the mother in particular and father along with other family members in particular starts feeling ever increasing distance from the child because of their inability to communicate with the child.
- The increasing distance or inaccessibility creates fear and uncertainty which in the long run has devastating impact on child growth and development.
- Mother. in spite of being a symbol of inclusivity and sustained care, starts feeling helpless for her own child.
- What could be the feelings of small baby on this dreadful increasing exclusion are not known but are quite imaginable.
- Immediate support is needed by the mother to remain effective in mothering.

An isolated world to live in

- The family of a child with disability is desperate in finding meaningful and sustained support but finds no way to go.
- The mapping of services in a locality is poor. The services available at the door step are sometime difficult to access because of poor networking.
- I remember, once the Sightsavers conducted mapping activity among top notch professionals in the area of visual impairment gathered in Islamabad. Surprisingly, all professionals were found ignorant what allied services were locally available and where. What to talk about how to access and obtain help from them.
- This barren space mapping creates an isolated world to live in.

Recommendations

In order to establish an inclusive support for the families of children with disabilities particularly in early childhood a three-prong strategy is needed.

Prong one: The lady health visistors and maternity staff must be trained for screening tests and any abnormality should be a part of birth cerficate. Then the disaabilty spport center established at Tehsil level should take on to conduct a close follow up till the early intervention is successfully administered.

Prong two: An online familiy support system must be established to provide immediate and sustained technical and financial support to the family so the family is capable to access all avilable support easily.

Prong three: Early childhood inclusive educational services should be established for long run development of the child with disabilities.