

Some additional points from Medico Social Worker's & Counsellors 'point of view:

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A] Reasons for non acceptance can be fear of the unknown, fear of genetic blame, fear of the stigma [Words like "Autism" "Speech Therapists" are stigmatized]

B] Readiness for accepting differences/disability will depend on whether it is the first born, precious pregnancy or not etc.

C] Parents and grandparents naturally want the best for the child. However the term 'neglect" places a certain amount of wilful wrongdoing on the part of the parents. This cannot be true, when there are so many systemic lacunae in monitoring child development and child health. Abuse/Neglect by parents is a mixed result of parental perceptions & systemic lapses.

- 1) Parental limitations as problem solvers or having a problem solving approach & hesitant seeking of information regarding alternative options, financial limitations to seeking already limited sources of information are important preludes to non compliance. So, we need to focus on information dissemination at various levels
 - A] At birth- by paediatricians –
 - B] By preschool teachers & by schools
 - C] By referral centres.
- 2) Presence of a subtle and nuanced power structure in every family, which is not necessarily resting on the senior most generation. However, our primarily patriarchal system does impose restrictions on seeking services, from specialists in the early years. Fear of genetic blame and guilt prevents parents from seeking or accepting advice.
- 3) There is a high cost on genetic testing and it is not easily available to all. It needs repeated visits to the genetic specialist. And the results are not specific and clear often.
- 4) No permission for preventive scanning for sex linked conditions, which are identifiable in the foetal stages.
- 5) No policy for neonatal thyroid screening being made mandatory
- 6) No policy for other neonatal screenings and their high cost.
- 7) No Protocol for adequate information on genetic conditions to prevent genetic blame which puts so much of stress on parents. Far too many women put the blame on themselves without knowing that male preponderance of many disabilities are because of different pathways of neurobiological injury in male &female foetuses. Many eligible couples are ignorant of the fact that it is the sperm which decides the sex of a foetus & not the egg.
- 8) Lack of adequate information on parenting techniques with a demographic change from joint or big families to small- One for you & one for me-nuclear families. Problems are multiplied in small but excessively mobile families moving frequently due to job placements. Lack of adequate social support systems in culturally different settings, add on to the stress of young parents.
- 9) Many parents decide not to have another child because of unknown fears- particularly in Autism- depriving children of the joys of sibling interactions & sacrificing their own old age emotional support.
- 10) Both siblings becoming invisible victims of caring for their challenged sibling or generational sandwich of parents having to look after their parents as well as their own challenged child

are realities & may make the senior citizens feel marginalised. With ambitious fathers or parents, siblings may be forced to compensate for the challenged child in terms of educational performance. These are some social attitudes that predispose families to neglect like situations particularly during adolescence of the challenged child when the denial turns to stark reality staring at them.

Recommendations

1] Systemic changes need to be implemented. Presence of systems in place would prevent non compliance with tailor made suggestions. This requires highly skilled and knowledge empowered manpower base, teamwork between medical and counselling professionals with systemic practices in place for cross -checking & call back systems to find out current status of the child and to cut dropout rates. Basically, this means implementing continuous developmental monitoring practices. Regular visits to Paediatricians for developmental monitoring should be made mandatory.

2] Parents also latch on to whatever suits their psychological state. They may remember that a nearby school teacher said "not to rush to a speech therapist" or some family member who may say "wait and see- child is not walking as he is fat" etc. This may obliterate from memory any warning or guiding words given earlier. This requires that sometimes the first communication to parents has to be clear and direct, sometimes to the point of being a little harsh. This has a risk of parents veering off from the warning consultant and going on a shopping trip, seeking multiple opinions. This requires that professionals use a common diagnostic protocol & common language of communication so that the consistency of information propels decision making & further action easier for parents. May be doctors themselves can recommend a second opinion from another expert without ego hassles. This approach will help in hastening the process for parents arriving at a functional response to the situation, rather than choosing dysfunctional but emotionally comforting action steps.

3] Can we have standardized self assessment questionnaires for parents so that they either choose to answer or get it administered, as this is a very effective tool to create a reflective approach in the parents? This reflection can work wonders for families for initiating adequate coping strategies.