Role Of Families In Inclusion

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What is Inclusion?

• Focussing on a child's strengths and abilities.
• Accepting difference as ordinary.
• Not being forced to lead separate lives away from their families and communities.
• Getting the full education they need to lead effective lives as adults.
• Their views and opinions being valued and acted on.
UN Convention on the Rights of Persons with Disabilities (UNCRPD)

The UNCRPD describes disability as an evolving concept of a ‘social’ nature. Families remain the first and most immediate environment where children with disabilities can develop their potential and enjoy a fulfilling life.
Preamble (“family is entitled to protection by the State ... to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”)

Article 5 (The state must respect the rights and responsibilities of parents)

Article 8 (awareness-raising at the family level)

Article 16 (“prevent all forms of exploitation, violence and abuse by ensuring, inter-alia, appropriate forms of gender- and age-sensitive assistance ”)

Article 18 (parental responsibilities)

Article 22 (respect for privacy)

Article 23 (respect for home and the family, intended as the right of children to family life)

Article 28 (access by persons living in situations of poverty to assistance from the State with disability related expenses, including adequate training, counselling, financial assistance and respite care)
Where do we start?

TALK

Is the first step
Benefits of ‘Talk’

• Finding solutions to common issues like dental problems and general medicine
• Gives confidence to bring their children outside the home (inclusion) and emotional support
• More effective and creative ways of coping with problems like discrimination
Where do we start?
An empowered parent:

1. knows the rights of her/his child with disability
2. knows about existing facilities and services for his/her child
3. knows what is good and wrong for the child and is confident enough to say “No” to what is wrong
4. can guide and gain the goodwill of other parents and the local community
5. explores national laws and policies to find out how they protect and serve her/his own child and others
6. knows the channels whereby to seek justice for her/his child
7. understands that their child needs assistance and support to benefit from the same environment as others
8. has the courage to promote inclusion in the family, community and seek to enforce this in the local and national government
9. understands that a child with disability deserves the same dignity as other children
10. understands the concept of human rights and social justice
How to empower parents?

Through Training - as trainees and trainers

- What is disability? The medical and social causes
- Activities of daily living (ADL) skills
- Counselling: about grief, trauma, blame & shame
- Rights: Relevant laws and documentation
- Approach to professionals
An example of Parent training

At MENTAID, with the support of SLF, we have trained three batches of parents. The training has included:

- **Medical aspects:**
  - Brain development and nervous system
  - Physical development
  - Psychological development
  - Immunisation

- **Disability**
  - What is disability
  - Types of disabilities
  - Epilepsy and management
  - Disability movements – Global, National and State scenario

- **Legal Provisions**
  - PWD Act
  - NT Act
  - New Draft Law

- **Special Education**
  - Assessment
  - Tools
  - Methodology
  - IEP
  - Teaching aids
Parents as Trainers

• The parents’ perspective – how attitudes towards disabled people effect parents and their relationship to their children
• Working well together with parents
• Supporting the workers – collaborative teaming, how we look after each other
• Sharing success – what does the future hold

• Examples:
  1. Parents for Inclusion in the U.K. run such courses such as Planning Positive Futures
  2. In India, parents or siblings applying for the B.Ed. in Special Education, get extra points in the admission process.
Inclusive education
(Article 24 of the UNCRPD)

Concerns of parents – Pros and cons

• Parents concerned about the degree to which their child’s individual education plan (IEP) actually addressed the needs of their child (Daniel and King, 1997)

• Parents viewed staff as lacking in knowledge about their child (Grove and Fisher 1999)
Concerns of parents – Pros and cons

• Parents who were positive towards inclusion had the following:
  – First, socialisation was an important educational goal.
  – Second, their child had relatively higher cognitive skills, had fewer behavioural problems and had fewer characteristics requiring special education.
  – Finally, their child had had more time in regular classrooms.

Palmer, Borthwick-Duffy, Widaman and Best (1998)
Concerns of parents – Pros and cons

Parents were negative towards inclusion because:

• The severity of the child’s disability meant that the regular classroom was not an option for their child.
• Concerned with class size, teaching conditions, and the demands of teaching to a diverse range of students.
• Regular classrooms focused on the academic curriculum, rather than on basic living or functional skills. (Palmer, Fuller, Arora and Nelson, 2001)
• Parents believed that students with severe disabilities who were included in regular classroom settings would be rejected socially. (Freeman and Alkin, 2000)
An Educational Model

Be it an inclusion or special setting model should include these components:

- a single language-based curriculum
- a curriculum that is activity based
- effective instructional techniques based upon research, including a strong focus on positive reinforcement
- frequent opportunities for the child to respond to instruction
- little time when the child is not engaged in instruction
- daily recording of academic work and behavior problems
- frequent review of progress and timely changes in procedures if progress is not occurring.
Parental Involvement in Schools

• An important role to play – visiting the school, observing during classroom therapy sessions, participating in meetings

• Often have to overcome some teacher perspectives eg. feeling parents are intrusive

• Physical presence of the parents in the school is important

• Improved communication with teachers will positively affect development of social, academic and developmental skills of the child.
Role of parents influenced by cultural factors

Study by Malika Mir, Aga Khan University, Karachi

Mothers and fathers of children play specific roles, which is mostly influenced by our cultural practices and perceptions.

Parents decision about inclusion is influenced by:

- Family support,
- Socio-economic background,
- Participation in trainings and workshops and
- By special educators in the school
Parents role in promoting social inclusion  
(Article 30 of UNCRPD)

Freiler identified intersecting dimensions of social inclusion / exclusion:

• Spatial
• Relational
• Functional
Social Context of Children’s lives

Families must ensure “visibility” of their children in all areas.

- Family and Home
  - Eg. Birthdays, weddings
- School
  - Eg. Extracurricular activities like dance and music.
- Community
  - Eg. Market, Mall, Religious celebrations at Church/Mandir/Masjid

Families must ensure “visibility” of their children in all areas.
Examples of Parent Organizations in India

• Parivaar-Bengal, part of Parivaar (National Confederation of Parents Organisations) has empowered parents in the districts of West Bengal

• Mentaid – Self advocacy for young adults with intellectual and developmental disability
• 1964 – First parents organization forms in Gujarat, Ahmedabad.
• 1995 – Parivaar was formed
• Today 222 parent organizations covering 28 states & 3 union territories have come together
• Recognized by Ministry of Social Justice and Empowerment, Govt. of India
• Various national and international partnerships
Key Principles and policy decisions

• Address basic needs of PwDs & families in poverty

• Families & caregivers to participate in decision making to ensure problems addressed
Parents play the most important role in inclusion of children with special needs in all aspects of life.