

Role of Family, School and Community in Special Education

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Ideally speaking, education should cater to the development of cognition and emotional skills of students, ultimately equipping them with good life skills to face the challenges of the world. It should prepare a student to have a meaningful personal life and at the same time a productive work-life.

Unfortunately, the present concept of education is more academic progress through acquiring information instead of nurturing holistic development of students who need to be trained to face the challenges of life with confidence by making use of their potential as much as possible. Though this focus is side-lined in today's education system, most of the mainstream children manage to some extent to get equipped as they grow by seeing, hearing, analysing their experiences and observing the environment around them. Thus, they are self-trained for life skills.

Unfortunately, intellectually challenged children lack these skills and hence need to be trained with greater focus on life skills, starting with physical (motor) skills, cognition and emotional training at the right time, followed by functional academics and vocational skills training.

However, when it comes to educating children with disabilities it is a disappointing fact that family and community measure their educational progress by making comparisons with mainstream children, without considering whether the child is equipped for it and if that is what the child needs.

In this context, before exploring the best practices in early education, it is vital to understand what education means to children with disabilities. It should not be a mere watered-down version of the mainstream curriculum, which is just acquiring information.

An ideal education for children with disabilities should focus on a programme holistically, with independent living as the final goal. The training for this should be started as early as possible and be the foundation for their teenage and adult life skills, mainly focusing on imparting skills to maximise independent living followed by vocational training, based on individual strengths, so that students can

become employable and financially independent as having a disability of any kind should not be considered the reason for not being trained to become self-reliant. Children with disabilities should be given every opportunity to be educated in the right way, without any reservations and be trained in accordance to their requirements and abilities, so that, despite their challenges, they can develop independent living abilities along with suitable employability. Special education should be empowering (so that they are not considered 'liabilities' to the family or society, as is often the case).

In educating a child with disabilities there are three fundamental components, namely, the *school*, the *family* and the *community*, which undisputedly have significant roles to play by complementing each other. When all these three synchronise, then the greater objectives of acceptance, respect and accommodation are assured, it leads to empowerment and inclusion – the final goal of special education and the right of children with disabilities.

The role of the family

No one can dispute the fact that parents are the primary caregivers whose life's goal is to see that their children become independent and thrive on their own. Family awareness about the challenges of a child with disabilities, their unconditional acceptance and the involvement of siblings contributes a lot in educating/training a child with disabilities in the most productive way.

While school and other therapies facilitate the training process, the deep involvement of parents and the family is crucial in reaching the abilities that match the goals set for each child. We have evidence to show that children who have the support of their family are bound to succeed in any kind of training to become independent and productive.

The role of the community

The community in which a child grows up should realise that a child with disabilities is not just

one family's responsibility. Inclusion is a societal function and can happen in the real sense only when neighbours and the general public understand that children need to be understood as children first and given the acceptance and help they need in every walk of life. As we all know attitudes and assumptions influence our actions, hence, it is imperative that everyone aids children with disabilities in ensuring a smooth transition from their families to schools and, finally, in taking their place in society.

The role of the school

The primary objective of any school which wants to cater to children with disabilities, either as a special facility or as an inclusive set-up, should be providing and maintaining a learning environment conducive to the overall development of the children. They should also connect with and involve the families and community as much as possible. The curriculum should be designed focusing on all the five developmental domains, namely, *physical, linguistic, emotional, cognitive* and *social*. The criteria of assessments should be clearly set out in the Individual Education Plans (IEPs) with the starting level followed by expected level (goals) under each domain matching the challenges and the abilities of each student. Required therapeutic interventions must be included.

Holistic approach: Mandala

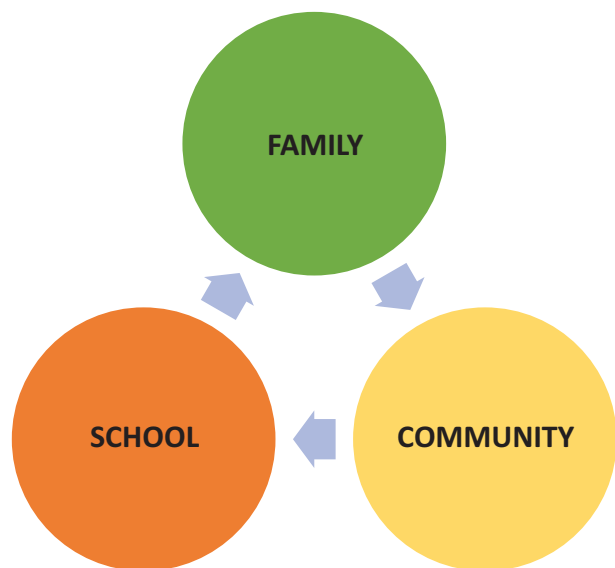
Deepika, a school for intellectually challenged children, envisages this holistic approach and our teaching objective is to train children with intellectual disabilities to lead as independent a life as possible.

We have a do-able, structured training programme called *Mandala*. We have been using this strategy in the development and implementation of educational innovations for children with intellectual disabilities for about fifteen years now and are happy to say that it has been quite successful in making our students independent. Based on our observation and experience with children with disabilities for all this time, we have understood that this kind of holistic education is the need of the hour and should encompass independent daily living skills, social skills, communication skills, motor skills and functional academics, followed by vocational skills training.

The purpose of this tool is to summarize evidence-based practices that identify and describe the three major components as discussed above, namely,

the *school, family* and *community* for the holistic training of children with disabilities. It has a set of practices for meeting the educational objectives of each group of students.

The picture below shows the terms and practice concepts of this structured intervention, which is trainer-directed and uses a planned set of resources. This occurs in both formal and informal learning environments. The technique used within these approaches is a behavioural model (for example, prompting and reinforcement) with gradual fading after skill acquisition. These objectives are student-centric and correspond with their potential with realistic expectations.



Strategies

School

Our core curriculum focuses on life skills, motor skills, communication skills and social skills along with functional academics, followed by vocational skills-set training. Here teachers, peers and therapists are involved.

Family

We conduct personal counselling sessions, especially for mothers for emotional management; parents' counselling for unconditional acceptance; quarterly sibling workshops; half-yearly extended family workshops for grandparents and other significant family members.

Community

The aim is to sensitise the public to the fact that children with disabilities are not just their family's responsibility, but a societal one. Awareness

programmes are conducted to educate corporate houses, public service departments and mainstream schools.

The Mandala process

In school

Our curricular objectives are inculcating life skills, social skills, communication skills and training for specific skill sets as well as and vocational training.

- *Life skills (independent daily living skills)*

This begins with assessing the level of daily living skills the children have acquired at the time of admission. The major focus is on toilet training, bathing, personal hygiene/care, independent eating habits.

It has been observed that many parents do not realise the significance of training children for basic life skills as early as possible because they either underestimate the potential of the children or are overprotective and find nothing wrong in doing these things for the children forever without realising the repercussions. The major challenge in such cases is that these students are not allowed to 'grow up'. For example, parents giving a bath to their growing children or letting them sleep in their beds makes these children fail to understand the *my body* concept, which in turn, exposes them to the risk of not being able to differentiate between good touch and bad touch. It also hampers training in the concept of personal space as it is very important to understand proper social boundaries for their own safety as they grow into adulthood.

Many parents fail to understand that children with intellectual disabilities will have normal physical and associated sexual growth at a certain stage in their lives and they need to be prepared well in advance to manage that. Otherwise, it not only becomes an unprepared challenge for many parents, it also leads to many teenage-associated behavioural issues. This can be quite challenging and frustrating to both, the parents and the children.

To address all these, three levels of inputs about the lifestyle of the children are taken once a child gets admission in our school: one from the parents, one from the in-charge teachers and the final, crucial, one from the *overnight stay programme* at the school after the first two months of schooling. This gives us a clear picture of their levels of toilet etiquette, personal hygiene, daily living skills abilities and associated dependency and parents' perspective on these important aspects of their special child. These observations help us to set

the goal for IEP in life skills and in educating and involving the parents to train their children at home. This is combined with structured motor skills training as physical fitness, muscle coordination, stamina are required to carry on daily chores and personal care.

- *Social skills*: Students with intellectual disabilities have problems in acquiring, understanding and applying social skills and they need lots of training to learn and internalise these. Training for this is provided by putting them in different social situations, starting from home visits to social functions, malls, public service departments, short (two nights) and long (seven nights), educational trips. Based on the observations of their styles of interaction and behaviour, notes are made about the level of social skills and personal skills development, social deficits/excess and social awkwardness and IEPs are then planned accordingly.
- *Communication skills*: The focus is on enhancing need-based expressive and situational conversation for better social connections by designing opportunity-related interventions to increase student engagement and participation throughout the day both in person and over the phone. Opportunities are created first within the school and the family and then extended to social situations.

For nonverbal children, teachers first assess and identify behaviour that conveys intent of communication. To understand the child better, information from the parents is also gathered about the common behaviours displayed to convey different emotions/needs. Also, a *functional analysis* of behaviour (antecedent-behaviour-consequence) is done to get an insight into behavioural intervention targets, for example, throwing a tantrum when hungry or running away to avoid a task. Students are then trained to replace these behaviours with a more understandable gesture/sign language which is also reinforced at home. We also have sign language workshops for parents so that there will be no difference in the way the school and family communicate with the child.

- *Functional academic*: Once these basic skills are acquired, then functional academics, like basic concepts of time and money, reading a calendar, identifying areas, landmarks etc, are taught. This is done in a very practical way by exposing them to real life situations. The training starts

with basics, such as making them understand the concepts of activities related to time periods of the day, concepts of *early* and *late*, less and more and slowly progressing to higher level concepts required in day-to-day life.

- **Skill sets training:** After all the above fundamental skills required for independent living are acquired, then skill sets training for home management followed by vocational training suitable for students are initiated. This again starts with training in personal grooming, home management skills, interpersonal relationships skills both inside and outside the family, getting familiar with the neighbourhood, independent travelling skills and, finally, specific on-site skill set training.

Family

The family is the most powerful and significant emotional support system in developing and moulding children with disabilities in becoming as well-equipped as possible for independence. Excellent results are seen when families are involved. The dreams, efforts and attitudes of parents with regard to their child underpins their performance, both in personal and vocational training, required for empowering them.

Nurturing children in a warm supportive environment and accepting and respecting them for what they are requires a lot of positive parenting and constant involvement of parents and other family members. This is quite a challenging and energy-intensive exercise for parents, especially mothers. Hence, regular one-on-one counselling sessions for mothers and both parents are conducted to create awareness about their child's potentials, limitations and to manage their personal emotions.

Parents' empowerment programmes through

spiritual healing workshops, introspection through art-based therapy, movement therapy, yoga therapy and family bonding day are offered. This is followed by sibling programs and extended family members workshops as they also contribute to making the child accepted and included the way he/she needs to be at the family level. This also reduces the stress on mothers to a large extent.

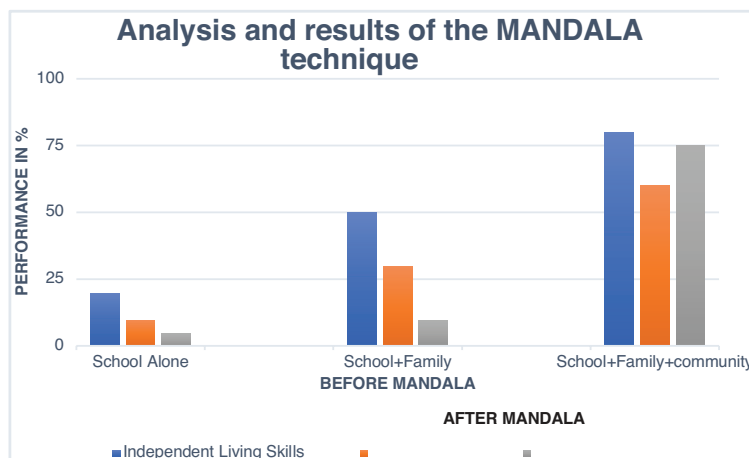
Community

The community undoubtedly plays a significant role in the overall preparation and quality of life of both, the students with intellectual disabilities and their families. Unfortunately, societal stigma, lack of awareness, negative attitudes and society's tendency to focus more on the disability and what a child cannot do, rather than focusing on the need to reach out to them and accommodating them as a community responsibility cannot be denied. This can only be addressed through appropriate public education and neighbourhood sensitisation programmes. So, regular interactions are designed and initiated with corporate houses, public service departments and mainstream schools, residents' welfare associations, transport staff, domestic help. This helps in making everyone understanding the need to be empathetic and supportive rather than sympathetic or judgmental.

Children are taken to vegetable markets, malls, milk booths, railway stations, post offices, pharmacies to interact and buy and these opportunities are used to educate service providers on the issues of children with disabilities, leading to the understanding of why and how we should accommodate them.

Analysis and results of the Mandala programme

The following chart clearly shows the contribution of the school, the family and the community in the education/training of children with disabilities



and their respective performance with respect to the three important ultimate goals of every child's (with disability) education, namely *independent living skills*, *employability* and *inclusion*.

Thus, an ideal education for students with intellectual disabilities should start with schools

teaming up with families and simultaneously, sensitising society. This approach will eventually facilitate a proper and smooth transition of these children from school and family environment to community living with dignity.



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