

Parental involvement as a strategy for cost reduction for an Early Intervention Centre: Case Study of Setu Developmental Intervention Centre, Ahmedabad

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1. Introduction:

According to the census data available, the infant Mortality Rate in India has fallen from 80/1000 in 1991 to 68/1000 in 2000 and is decreasing at a steady pace. It has been observed in the report (NSSO: 1991) that "experts are of the opinion that with greater pace of development and urbanization, disability prevalence rate is also likely to rise".

On the other hand, owing to better health care and advancement of medical sciences during the decade 1981-91, the incidence of some types of disabilities may show a decreasing trend. Although, as the survey also reveals, the overall impact of these factors is "a marginal rise in the prevalence rate of physical disability of all types, taken together, during the decade 1981-91".

According to the same survey, approximately 5.3% of the population suffers from some form of disability including Mental Retardation. At present, India's population stands at approximately 1,015,225,000 out of which 15.42% are children between 0- 6 years of age. 5.3%, or 8,297,028, children have a disability out of a total population of 156,547,695. If the population increases by 1.5% every year, the number of children in the age group 0- 6 years with a disability combined with lesser infant deaths will also necessarily increase.

When one combines these numbers with scientifically approved data that the first 5 years of a child are marked with the tremendous escalation in skills in all areas of development (**Eliot. L., 2000**), the need to intervene early becomes very important as the child runs the risk of missing an opportunity to learn during a state of maximum readiness.

1.1 Need for cost reduction measures for an upcoming early intervention centre:

1.1.1 All developmental areas are interconnected and hence delay in one may lead to delay in the other. Conversely, improvement in one may lead to improvement in the other. This is

the reason why complete development has to be addressed while working with a young child with a disability and not just one very visible problem.

As the professional and therapeutic services required by children with different disabilities are similar, an early intervention centre needs to provide for all-round developmental. For example, Speech therapy is a service all children, irrespective of having C. P., M. R., Autism or Multiple Disabilities, would need.

Thus, an early intervention centre, in order to be really effective, would need to plan for services addressing sensory integration, gross motor, fine motor, communication, cognitive, social, self-help and play skills (**Azad, F., 1986**). Due to the age factor, maintaining a better therapist: child ratio and parental counseling also become essential factors.

A centre catering to 30 children would require at least 9 professionals to provide interventions in all skill areas and to maintain 1: 1 therapist: child ratio. For a nascent organization, meeting personnel expenses is an uphill task, apart from the demands of other expenses. After initial expenses, it would require at least **\$ 21,253/-** p.a., which would be divided as follows:

Direct Expenses:	\$ 6130/-
Salaries and Other Indirect Expenses:	\$ 14705/-
Contingency @ ~ 2% of the Total:	\$ 418/-

This would mean each child approximately paying \$ 60/- per month, making the services financially unviable to a large section of the population.

1.1.2 Increasingly, funding towards capacity building and specific target oriented projects is replacing provisions for maintenance and recurring costs. These figures from 2 funding agencies, government and non-government speak for themselves.

Of a total of 18 projects financed for Disability Development by Sir Dorabji Tata Trust in FY 2002-03, only 5 were supported for recurring costs, that too, for a limited period. The total disbursement touched \$ 271,739/- of which only \$ 76,521/- was offered to the 5 projects mentioned **(28.16%)**.

National Trust disbursed \$ 844,564/- to registered organizations in FY 2002-03. \$ 664,771/- was directed towards establishment costs for the first 2 years with a clear instruction to encourage self-sustenance. Registration is not considered for the first 2 years.

Major funding agencies seek organizations, which show certain competence in adding value and offer a minimum promise to deserve funding. There is a tendency among large agencies to seek equally large organizations for partnerships. Hence, in a slowly growing market, already large organizations are likely to grow further to the detriment of smaller players. In this scenario, building resource mobilization capability is essential and indigenous resources, including indigenous practices, know-how and knowledge, and other domestic resources deserve more attention. **(Greensmith, J., 2002)**

1. Criteria for good cost reduction measures:

- The measures should not adversely impact the quality of program
- The measures should encourage financial independence
- The measures should be fair to all stakeholders
- The measures should be simple to implement and replicate

2. Different cost reduction strategies and their evaluation:

- Once a week/ fortnight schedules with home based plans

Early intervention services running on days when the special schools remain closed, easily takes care of personnel problems. But, due to inadequacy of available time, most out patient departments overflow, limiting opportunity for a professional to bond with the child and the parent and to look adequately into the progress and concerns of the child, leading to lack of understanding of the problem. They are likely to miss out important developments. Moreover, the expectation that sporadic interactions with caretakers would equip them to cater to the

child's needs is unrealistic. When told to do something as against made to understand, more harm than good is done.

- Provision for minimum/ apparent needs

A full-fledged rehabilitation centre, with the infrastructure already in place, can accommodate young children with minor adjustments, providing more structured and regular intervention. A lot of physiotherapy and speech therapy centres look into motor and communication needs. Unfortunately, this measure addresses only obvious needs and not complete development and ignores the fact that all developmental areas in early childhood are interconnected.

- Using consultants

Most consultants are professionals with flourishing private practice and are always looking for attachments to organizations to cater to non-affording population. Their cost to an organization is almost negligible, enabling it to provide high quality service for less expenditure. But having consultants creates a lacuna of core personnel for further development. Consultants require convenient schedules and hence, organizational work may not be a priority. Moreover, lack of clarity in the support staff about the plan and consecutive steps ultimately weighs heavily against such an arrangement.

- Using part timers/ trainees/ volunteers

Continuous student placements and committed volunteers can provide assistants and maintain adequate child: therapist ratio. Unfortunately, working with untrained personnel leads to a lot of stress and insecurity on part of the caretaker. Poor confidence in personnel translates into poor confidence in the organization, ultimately resulting in poor market value for the services.

3. Unintended consequences of such measures:

- Poor rehabilitation of the child

Provision of 'need based' intervention means missing out on the critical period where there is a "window of opportunity" for the child to develop skills. It allows the child to outgrow the stage of maximum readiness. **(Montessori, M. 1972)**

- Client dissatisfaction

An early intervention centre has to address parents as clients as they are the ones making decisions about their child's rehabilitation. Having infrequent visits by qualified personnel,

working with trainees or other untrained persons generates a lot of stress and dissatisfaction as their concerns and worries are not regularly addressed.

- Insecurity

Working under consultants and dealing with parental stress continuously puts the support staff under threat. With the margin for error being quite narrow for implementing someone else's decisions, there is a growing anxiety regarding their performance as well as job. Further, lack of appropriate knowledge and functional independence reduces self-confidence.

- Lack of ownership towards the organization

Client satisfaction and employees' anxiety are negatively correlated. With a decrease in the first, there is a marked increase in the second. Such a state leads to its own set of problems, the least being client and employee turnover rates. Thus, the last, but the most grievous consequence would be lack of ownership of the organization by all concerned groups.

4. Impact of these measures on Disability Management:

In absence of better strategies for cost reduction, an upcoming organization's ability to plan a long-term strategic role for itself suffers. A direct outcome of this would be 'identity crisis' leading to challenged integrity and blurred values and ways of working. This will make them less willing to take risks and run with new ideas.

One may argue that an organization can create tremendous local support and goodwill. But, the effort involved in such an exercise is a drain on whatever meager resources it may have. Moreover, local fundraising introduces another kind of dependency - on local opinion, which may threaten the survival of the most innovative and progressive projects carried out by smaller organizations. **(LVSRC, 1999)**

5. Evaluation of Parental Involvement as a strategy:

A budding early intervention centre may not have a large income pool, but it certainly enjoys a huge amount of voluntary labour in the form of its parent group. It can create a support base without really working towards it.

Parental involvement, when implemented in a regular and structured manner, reduces the fear on the parent's part to learn to deal with the child and take the responsibility for her training and development. Moreover, the training parents undergo, allows them to take care of the child's needs at home, lessening the family's expenditure on rehabilitation.

There are inherent benefits derived by an organization through parent involvement.

As stakeholders, parents act as measures of checking the following:

- ❑ Quality of the program: The work is in response to an ongoing need
- ❑ Perception: The organization enjoys goodwill of the community it works with

With direct parental involvement, it is possible to maintain an adult: child ratio of 1:1, at the same time reducing the cost of hiring more personnel. This translates into better pay packages for the employees, increasing security and the prospect of longer association.

6. Summary and conclusions:

Early intervention is assuming a lot of importance because of its implications on 'prevention' and further 'regression' of a disability. Most organizations desirous to offer early intervention services overlook the fact that to be effective, the whole development needs to be addressed. The cost of offering such an intervention is quite high.

On the other hand, getting funds is becoming increasingly difficult. In recent times, the emphasis has shifted to development and capacity building. The amount of funds diverted, typically goes to other large organizations that may have the basic capacity to utilize these funds. This leaves the small and upcoming organizations out of the race, leaving them to implement other indigenous practices for reducing expenses in order to survive. A majority of these cost management measures end up doing more harm than good, endangering the very objective they were implemented for- survival!

Finally why should we not look for a more beneficial and viable option in the form of parent involvement that on one hand works towards a more empowered client group and on the

other hand reduces the cost to the organization by almost half? E. g., Setu, which has 32 children, incurred expenditure of \$ 9296/- towards running the early intervention centre and saved \$ 331/- in FY 2002-03.

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Web Resources:

<http://www.cdipage.com>

<http://www.censusindia.net>

<http://www.givefoundation.org>

<http://www.globalissues.org/TradeRelated/Poverty/NGOs.asp>

<http://www.isar.org>

<http://www.healthlibrary.com/reading/disability/extent.htm>

<http://www.nichd.nih.gov>