Parents' Concerns on Home Based Education

Is it in the best interest of their child?

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Abstract

Home Based Education (HBE), a programme was initiated by the Sarva Shiksha Abhiyan (SSA) for children with disabilities as a result of adopting a Zero rejection policy for all children. It became a legitimate right through the Right of Children to Free and Compulsory Education (Amendment) Act, 2012. The aim of this programme was to provide intensive specialised support to children with severe and profound disabilities at home so that they could be mainstreamed at a later stage, if possible. As a result of this Amendment, the number of children under the HBE programme have been increasing over the years. In the present study, 62 parents conducting such interventions in the States of Rajasthan, Uttarakhand, Goa and Karnataka were interviewed on issues like parents' satisfaction with the programme, the problems faced by them in rearing up and educating their child with disabilities at home, the benefits they derived and the suggestions they can make regarding the improvement of the programme for better development of their child. Analysis revealed that although parents welcomed the interventions being provided and were also coping with the problems after consulting the resource teacher/ volunteer/caretakers, they felt that the training given to them or also to the resource provider was not adequate, the financial and other provisions were not sufficient, the frequency of visits of the resource provider needed to be increased and the child should get the opportunity of going to a school after building up the basic skills. The parents also had very low expectations from their child and showed a lot of pessimism in spite of the interventions.

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INTRODUCTION

Although estimates vary from State to State, the number of children with disabilities in the Home Based Education Programme (HBE) of the *Sarva Shiksha Abhiyan* (SSA) has risen over the years. While the number of children with special needs (CWSN) under HBE programme was 1,38,133 in the year 2009-10 out of the total of 30,42,053 identified (MHRD, 2010), it was 2.06 lakh out of the 27.16 lakh till March 14 (SSA data till March 14 as presented in the expert group meeting in 2014).

The practice of HBE, however, has its roots in the year 2001, when *Sarva Shiksha Abhiyan* (SSA) was launched by the Government of India as an answer to implementing the Zero Rejection Policy. The SSA framework stated (MHRD, 2006) that "SSA will ensure that every child with special needs, irrespective of the kind, category and degree of disability, is provided education in an appropriate environment. SSA will adopt zero rejection policy so that no child is left out of the education system." Further "the thrust of SSA will be on providing integrated and inclusive education to all CWSN in general schools. It will also support a wide range of approaches, options and strategies for education of children with special needs. This includes education through open learning system and open schools, non formal and alternative schooling, distance education and learning, special schools, wherever necessary, home based education, itinerant teacher model, remedial teaching, part time classes, community based rehabilitations (CBR) and vocational education and cooperative programmes."

In the year 2012, in the month of June, the Government of India made HBE a right for children with disabilities through the Right of Children to Free and Compulsory Education (Amendment) Act, 2012. The Act stated that:

"Provided that a child with multiple disabilities referred to in clause (h) and a child with severe disability referred to in clause (o) of section 2 of the National Trust Act for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 may also have the right to opt for home based education."

The Amendment gives children with severe and multiple disabilities the choice between school and HBE. The idea behind this option was that there may be children with severe profound disabilities who may require intensive individualised support and attention which is not possible in a regular school system.

DEFINITION OF HBE

HBE is operationally defined by the SSA (SSA, 2006) as the education of children with severe intellectual/ physical disabilities, who can be educated in the combination of home-based and alternate educational settings to enable them to achieve independent living skills. HBE aims at school preparedness and preparation for life. Alternate educational settings provide opportunities for learning of social skills, vocational skills and implementation of life skills.

Benefits

The major reason given for including HBE as an option under the SSA and RTE was that a large proportion of children with disabilities were still out of school. According to the twelfth plan document, the proportion of disabled Out-of-School Children (OoSC) in 2005 was 34.19 per cent and remained slightly changed at 34.12 per cent in 2009. The twelfth plan noted that the maximum number of OoSC are those with mental disabilities (48 per cent), followed by children with speech disabilities (37 per cent). The need for highly specialised skills to be taught by special educators, incapability to access the regular academic curriculum, requirement of additional time and attention, strong need for better parental involvement, need for support of peers who are more like them, and teaching of specially tailored curriculum are some of the other reasons given by the SSA for adopting HBE as a viable option for some children with disabilities (SSA, 2006).

There have been very few researches on HBE in India. Studies done in the west have spelled out the benefits of HBE for children with disability. For example, an exploratory study that involved two male and two female elementary students with attention-deficit/hyperactivity disorder (ADHD) was carried out in home schools and public schools by Steven (2004). The general purpose of the study was to determine whether parents could provide instructional environments that facilitated the acquisition of their children's basic skills over time. The results indicated that home school students were academically engaged about two times as often as public school students and experienced more reading and math gains. The key variable appeared to involve student to teacher ratios that existed between the two settings.

Using a less intensive intervention model of approximately 20 hours per week, Birnbrauer and Leach (1993) found that mothers in a treatment group (N = 9) reported less stress than control group mothers (N = 5) after 2 years of the intervention programme, although they were similar at intake. Cattell-Gordon and Cattell-Gordon (1998, p.82) in a report of their experiences conducting an intensive home-based programme stated that "there were also the more subtle but stressful problems of having one's home invaded for months at a time with team members who came and went." Research by Hastings and Johnson (2001) shows that comparisons with other samples suggested that UK parents involved in intensive home-based behavioral intervention for their young child with autism reported no more or less stress than other parents of children with autism. Their data suggested that parents of severely affected children are more pessimistic regardless of coping strategies used by the family. However, believing that the intervention being used is effective at ameliorating even severe autism does result in reports of less pessimism.

The launching of HBE programme under the SSA and then being made as a legal option by the Government of India was in the best interest of the child. It was clearly stated that resource teachers/ specially trained teachers, or a para-resource teacher located in the village as a part of their job, could also visit the homes of CWSN to impart pre-integration training to them or even to do parental counselling. Severely disabled children, as a part of their HBE programme, would also require services like physiotherapy (PT), occupational therapy (OT) and speech therapy. The National Institutes, District Rehabilitation Centres, District Disability Rehabilitation Centres and Composite Resource Centres offer these services. Further, the National Trust Act under the Ministry of Social Justice and Empowerment, also trains caregivers, who provide specialised services to disabled persons within their families and communities. These caregivers are being trained through various organisations throughout the country. It was planned that convergence could be established with all these organisations to provide such support to CWSN being educated at home (SSA, 2003).

METHOD

Participants in this research were 62 parents of children with disabilities under the HBE programme who were interviewed for the study. The parent who was primarily responsible for the care of the child with disability was asked about the HBE. Only one respondent from each family was interviewed. The States visited were Karnataka, Uttarakhand, Goa and Rajasthan. Initially, visits to only 3 States were planned. However, a fourth State, Rajasthan was added because of its difficult terrain (desert areas).

TOOLS

Open ended interview schedule with 14 questions was developed with the help of experts. The instrument included open ended questions seeking answers on parents' satisfaction with the programme, the problems faced by them in rearing up and educating their child with disabilities at home, the benefits they derived and the suggestions they can make regarding the improvement of the programme for better development of their child.

RESULTS

The following are the results obtained based on the interviews held with the parents.

Parents' satisfaction with the programme

Majority of the parents (92 per cent) expressed satisfaction with the HBE programme as shown in the figure given below.

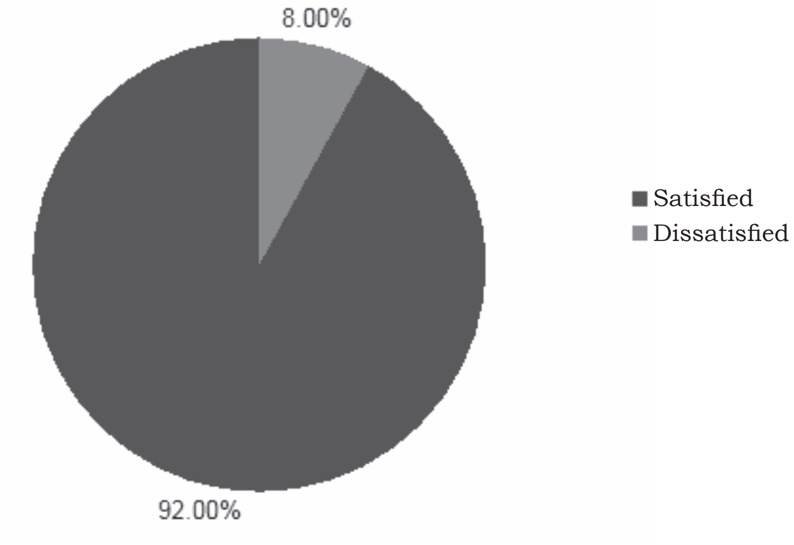

Figure 1: *Parental satisfaction with HBE*

Ninety two per cent of the parents thought that the programme was good and appreciated the government's efforts. The parents said that it is a useful programme since many children being bedridden or had multiple disabilities and were not able to attend the school. Since the teacher/volunteer/caretaker comes home, the child does get some basic inputs/therapy. If this was not so, their child will learn nothing and would just be isolated. A few of them also felt that when the teacher came home, they got useful information from her/him regarding how to handle their child's high support needs and their child really looked forward to the teacher coming home to teach her/him. Some parents felt grateful for the therapy and the support being provided to their child in the learning of daily living skills. The gratitude reflected parents' pessimism regarding the future of their child. However, some parents were unhappy with the programme as they wanted their child to actually go to school as she/he does not learn much at home.

REGULAR SCHOOLS

When asked whether parents wanted their child to go a school rather than learning at home, majority of them showed willingness to send their child to school (84 per cent) with other children. One of the reasons given was that in the absence of proper resource support at home, it is important that the child should go to the school. However, some of the parents realised that it was not possible because of the severe disability conditions of their child (bedridden, no control of urination etc.) and felt helpless and unhappy about not being able to send their child to school. There were also parents who conveyed that their child was not interested in going to school. Most of the parents, however, felt that their child needed to pick up the basic skills before she/he is sent to school. Some of them wanted their child to go to a special school and not the regular school, go for only a few hours and not full time and have proper transport for travelling to school. The following figure gives the percentage of parents wanting or not wanting their child to go to school.

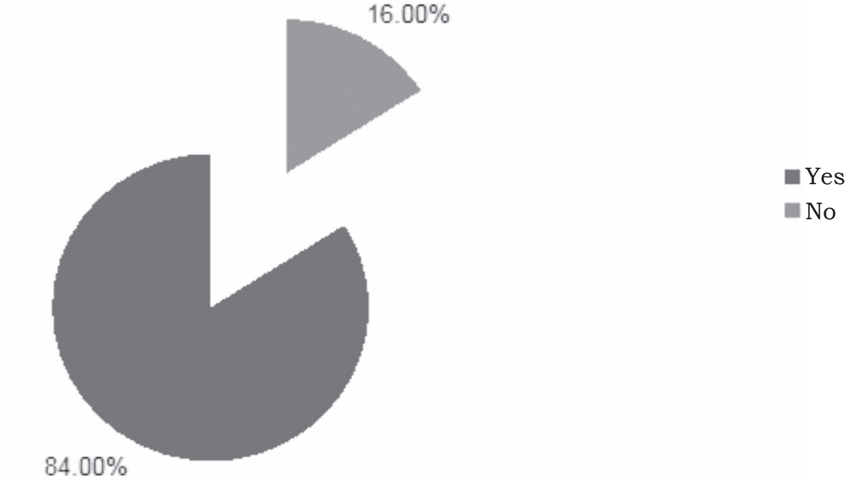

Figure 2: *Percentage of parents wanting/not wanting their child to go to school*

Figure 3: *Benefits from HBE*

BENEFITS

The following figure shows that 74 per cent of the parents felt that the HBE programme is beneficial for their children.

The benefits pointed out by the parents included:

Medical facilities and other devices

- Guidelines for medical treatment and physiotherapy.
- Mental Retardation (as conveyed by the parents) kit, cerebral palsy (CP) chair, CP stand, learning-aid.
- Information about the medical camps for physiotherapy and other facilities.

Teaching related assistance

- Learning of simple words, numbers and poems, simple addition/subtraction, tables, time and colour concepts.

However, 24 per cent of the parents felt that there was no benefit of HBE for their child. The reasons given for this were infrequent visits of the teacher, severity of child's disability condition and lack of training of the teachers/volunteers.

ADDITIONAL INPUTS

In spite of the benefits being derived from the HBE programme, the parents were asked about what additional inputs they expected to be provided in future, under the programme. Many parents conveyed the need for the following additional facilities:

In addition to above, many parents felt there should be more frequent visits of the resource teachers/volunteers. There were also parents (5 per cent) who did not have any comments because they felt that since very little inputs were being provided for their child at present, so

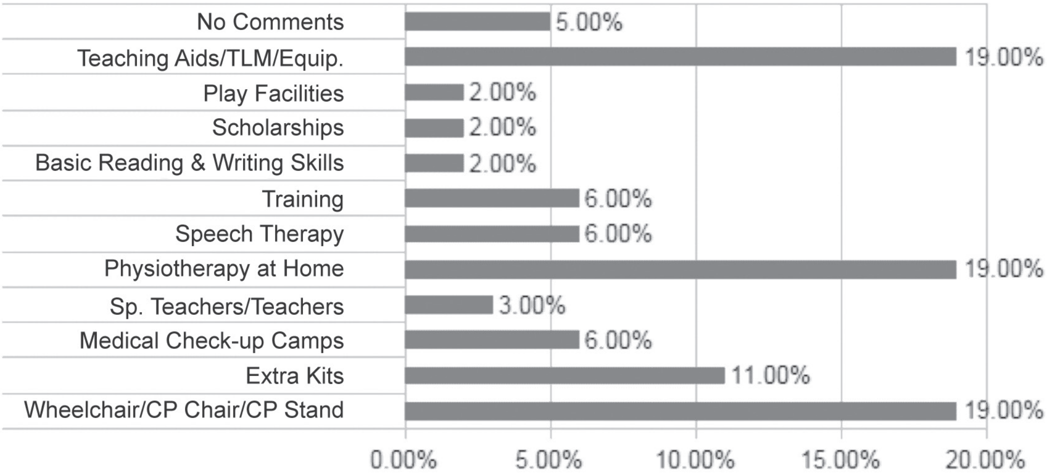

Figure 4: *Parents' response to additional inputs*

they are in no position to comment upon additional inputs required for their child.

Training of Parents

Seventy-three per cent of the parents have got some inputs on taking care of their child with disability at home. In States like Karnataka, Uttarakhand and Goa, the parents have been given training and awareness programmes like *Samudaya Jagriti, Kala Jatha*, etc.

The number of training programmes given to each parent ranged from 1 programme to 5 programmes. However, most of the parents expressed the need for more training. In the State of Rajasthan, the parents expressed that they have not been given any training. This was because of the remote distance (training camps situated at 50 kms. away), lack of transport facility and difficulty in travelling because of difficult terrain etc. Some parents had taken 1-2 days parental counselling sessions which they thought was not helpful in taking care of even the daily routine care of their child.

Resource Teachers

Eighty-one per cent of parents expressed their happiness with the involvement of the resource teachers in HBE. However, most of them had problems with the frequency of teachers'/caretakers'/volunteers' visits (only once in one or two months), lack of training (as in the case of volunteers/caregivers) and negative attitudes of some teachers who did not want to spend much time with the child.

Problems faced by Parents

The following were the problems faced by the parents in HBE:

Problems Faced by Parents of Children Under HBE Programme

- Carrying a grown up child with disability to the toilet
- Need for surgery
- Need for mobile medical facilities
- Resource support
- Hyperactivity and lack of concentration in the child
- Attending to daily routine and health issues
- Need for one-to-one caregivers because of severity of disability condition
- Inadequate provisions for speech therapy
- Lack of transport
- Need for better financial help
- Poverty conditions and illiteracy of parents
- Inability to understand, write and communicate (even to the volunteer)
- Untrained volunteers
- Lack of time as parents have to go for work. This affects the education of their child

Financial Provisions

Only 4 parents out of 62 were happy with the financial provisions being provided under the HBE programme. The remaining said either the financial provision was not sufficient or there was no funding at all even when the child was enrolled in the school. They felt that medicines, equipments etc. and the health issues associated with the child's condition required finances that are not being provided by the government. Some parents were getting a small amount from the State welfare department which was barely enough to meet their needs. Some of the parents also expressed the need for transport allowance for taking their child regularly for treatment or therapy.

Improvement after HBE

While 84 per cent of the parents said there was improvement in the child, the degree of improvement ranged from mild, moderate to sufficient improvement. Parents expressed the need for more physiotherapy. Some parents felt that there would be more improvement if teachers/caregivers/volunteers came more frequently to visit the child.

Following Suggestions of Teachers

Majority of the parents (80 per cent) expressed that they liked to follow teacher's suggestions and also got the opportunity to learn from her/him in carrying out day-to-day routine activities for their child. The teachers explained to them about various provisions available like relaxation in admission procedures, scholarships, availability of bus and railway passes and physiotherapy services. Some of the parents also felt that their child is happy when the teacher visits home to teach her/him. Teachers also prepared IEP and recorded the progress of the child. They provided physiotherapy, and took their child regularly for resource support and medical check-ups to the Block Resource Centres (BRCs). On the other hand, the remaining parents felt that they were not able to gain much from the teachers. The reasons given were that the teachers came very infrequently or came once only and did not come after that at all. Some also stated that they were busy with their own work and did not have much time to interact with the teachers.

Involvement of Siblings /Other Children

The following figure shows that while 69 per cent of the parents felt that there was involvement by siblings and other children of the family and from the neighbourhood, 16 per cent expressed their unhappiness regarding the same.

Majority of the parents who said yes to the involvement of siblings/other children stated that the contribution of other children was in the form of providing support

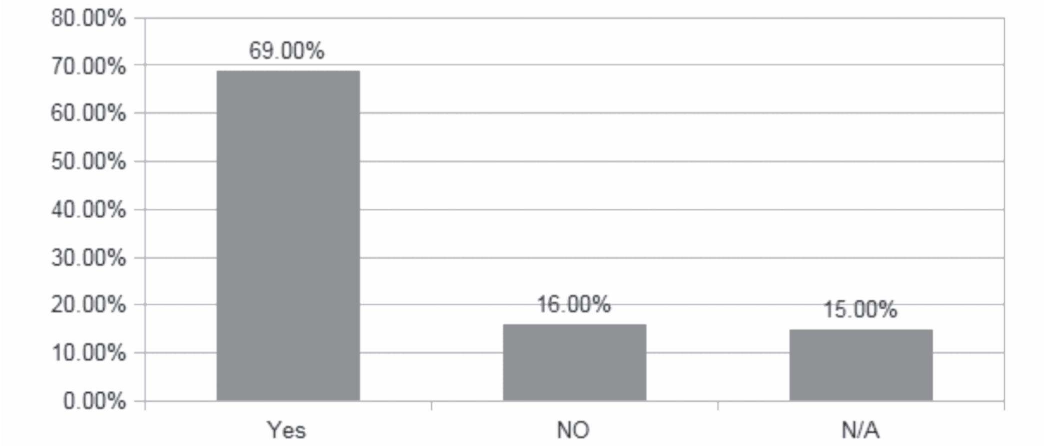

Figure 5: *Involvement of siblings/other children in the education of the child*

for daily living skills, school work/ studies (reading and saying some words), movement from one place to another, and entertainment (telling stories, playing some games). Some parents also expressed their dependence on their other children in looking after the child with disability because of their daily work routine. For these parents, earning a daily living would have been a challenge if the siblings did not look after this child. Children told stories, played with the CWSN and also took her/him out on a wheelchair. The parents who expressed non-involvement of other children stated that their child is sometimes completely isolated even when she/he is amongst other children. The reasons given for non involvement of other children were the other child being younger to the child with disability or inability of their other children to communicate with or handle the child with disability. Fifteen per cent of the parents had no comments as there were no other children in their family to look after the child with disability.

Resource Facilities

Majority of the parents expressed that the HBE Programme has resulted in making them aware regarding the various provisions available for their child. The different facilities available as expressed by the parents are given in the following figure:

However, the many parents pointed out that most of the provisions were being provided by the State Welfare Department and not by SSA. Some of them also said that though they knew about these facilities they were unable to take benefit of these because of procedural hurdles.

Further Suggestions

Finally, the parents had a number of suggestions to offer regarding

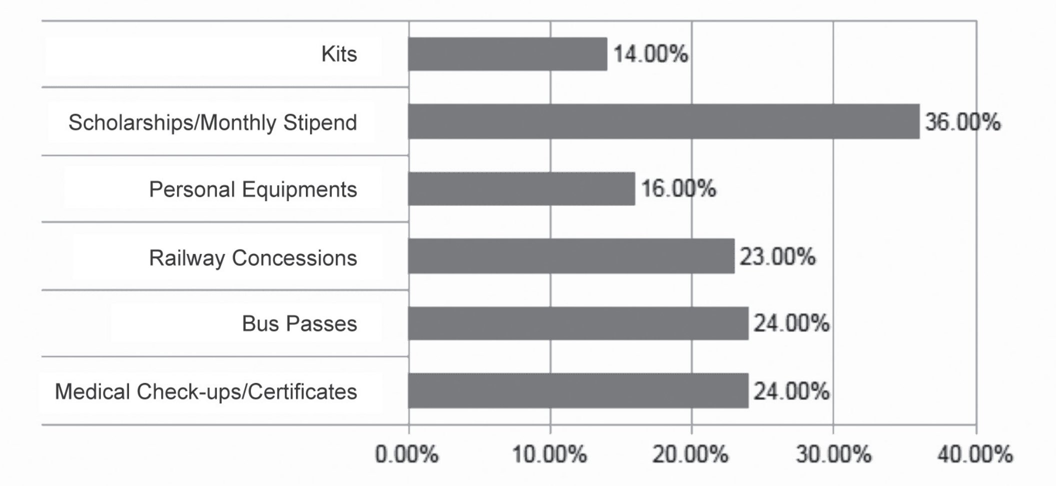

Figure 6: *Percentage of parents having information regarding facilities/concessions*

the HBE Programme. Some of these suggestions are:

- The HBE Programme should be carried on continuously and special teachers should be appointed permanently by the government for this.
- More training and orientation opportunities for teachers and parents should be available.
- Transport facility should be given to parents to take their child to school and for health check-ups.
- More TLM, kits and assistive devices are required.
- Individual teacher/caregiver for each child should be provided.
- Teachers should visit more frequently (throughout the week) instead of once/twice a month.
- Free medical check-ups, medicines, physiotherapy and other therapies should be provided.
- Once a while, some field visit/trip should be arranged for all students in a group.
- Child should be taken to a nearby special school at least once a week.
- Regular visits by doctor at home should be provisioned.
- Crèche facility should be provided so that we can go to work leaving the child behind.
- Financial provisions need to be given by the Government.
- There should be a provision for admitting the child in a nearby regular/special school.
- The child should get some quality education inputs along with care and rehabilitation inputs.

DISCUSSION

Most parents of children with severe and profound disabilities, in the present study, reported satisfaction with the programme, and majority of them felt grateful for whatever was being provided. In particular, parents were using adaptive coping strategies, informal social support sources in addition to the Government support in looking after their child with severe disability. The particular study, however, did not find any parent talking about educational interventions. The efficacy of the interventions was judged in terms of concessions/facilities being provided, frequency of visits of the caregivers/ resource teachers/ volunteers, financial provisions, moral support and support in carrying out daily living activities. It appeared that resource support and visits to Block Resource Centres (BRCs) tended to reduce the pessimism, especially when the disability was very severe and parents had hard time coping with the child's condition.

It was also seen that parents having children with disability under HBE in areas that are remote and not easily accessible felt helpless as the teachers/caregivers/volunteers could visit their children and the medical and training camps were arranged at a distance far from their house. Some of the parents had more than one child with disability at home and found it extremely difficult to meet the needs of these children on a daily basis.

The inclusion of HBE in the RTE and relative public acceptance of HBE has brought a number of consequences. The legitimacy of HBE as an educational practice has led to many children with disabilities being pushed out of the regular system of education. Children who can even go to regular schools are now being put under HBE for the convenience of school authorities and teachers. For example, parents of children with visual impairment under the HBE in the State of Uttarakhand expressed that their child could easily attend regular schools if given the opportunity.

On the other hand, most of the parents interviewed valued the idea of services/information being provided at home so that they are able to build their own ability and that of their child having high support needs. Some of them stated that their "child was incurable and HBE was a ray of hope for them. These children were bedridden, or had no urine control or did not understand anything etc. and therefore unable to attend regular schools". They expressed the benefits in terms of medical camps, physiotherapy, kits, equipment and information regarding the concessions available. However, many of them also felt that this should not be the only option available for the education of their child. Their child should get the opportunity for attending regular or special school whichever is available in the neighbourhood. Keeping the child at home, fosters social isolation and exclusion from society, even if other children in the family and from the neighbourhood are interacting with this child, These children, they felt, are also deprived of many entitlements available to other children in the school like regular teachers, mid-day meals, etc. However, high support needs of these children demand fundamental systemic changes in the educational scenario. If inclusive education has to be a reality then the system that promotes inclusion needs to be flexible, extending to all kinds of diversities that exist in our society.

It was also seen that there was no clarity regarding the labelling a child as severe and profoundly disabled. Labelling is generally based on a medical model and a child who is blind (considered to be a severe disability by many) can still be easily included in regular schools. Parents of many children in the study felt that they were grateful and satisfied by what was being provided to their child even if the teacher/untrained volunteer/untrained caretaker visited the child only once in two months. This is because the parents believe that their child is not educable and had low expectations from her/him. Finally, the study also revealed that children under the HBE Programme living in backward, remote areas with difficult terrain are further deprived of interventions and require more intensive support measures. This has implications for future research.

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