

Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: A Qualitative Study from Rural Villages and a Poor Urban Settlement of Bangalore, South India

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ABSTRACT

Purpose: *Children with developmental disabilities, if given skilled early intervention, have the potential to lead productive lives and can contribute to the social and economic development of their communities. This study explores the barriers to early diagnosis and intervention for children with developmental disabilities who live in rural and urban areas of Bangalore city, India.*

Methods: *The study was conducted in selected villages of Devanahalli Taluk in Bangalore Rural District, and in Devara Jeevanahalli (DJ Halli), a shanty town in Bangalore city. The qualitative study design consisted of in-depth interviews and focus group discussions (FGDs). Parents of children with developmental disabilities, doctors practising in the area and school teachers were interviewed using a purposive sampling framework. An inductive, data-driven thematic analysis was carried out.*

Results: *The physician-related barriers were identified as lack of skills and understanding of children with developmental disabilities, lack of knowledge and resources, lack of specialist back-up services, and communication difficulties with regard to conveying bad news to clients. Parent-related barriers were financial constraints, delay in accepting the diagnosis, and prevalent myths, beliefs and stigma pertaining to disability. The teachers viewed children with special needs as an additional responsibility, and were also apprehensive about the attitudes and interaction of other children at school with children with disabilities.*

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Limitations: *Although the conditions are more or less similar in the different shanty towns and villages in South India, inclusion of more such settlements and villages using probability sampling would have increased the external validity of the study.*

Implications: *Better understanding on the part of parents, doctors and teachers can influence rehabilitation policy and practice, thereby facilitating early diagnosis and rehabilitation of children with developmental disabilities.*

Key words: *children with developmental disabilities, childhood disability barriers, inclusive development, CBR, accessing disability care, inclusive education*

INTRODUCTION

Developmental disabilities are disorders of the developing nervous system that manifest during infancy or childhood as developmental delay or as limitations of function in one or multiple domains, including cognition, motor performance, vision, hearing and speech, and behaviour (Solarsh & Hofman, 2006).

In India, 35.29% of all the people with disabilities are children. There are other estimates that India has 12 million children living with disabilities and that only 1% of them have access to school (Childline India Foundation, no date). Studies have reported a prevalence of 1.5% to 2.5% of developmental disability among children under five in India (Nair & Radhakrishnan, 2004; Nair et al, 2009).

Children with developmental disability face a number of barriers and challenges. They need to be identified early, assessed and stimulated in order to achieve their full potential. The people who can play a crucial role are parents, doctors and teachers.

For several years, the Bangalore Baptist Hospital has been delivering preventive, promotive and curative health and community development services to 50 villages of Devanahalli Taluk and to DJ Halli, one of the shanty towns in Bangalore. In the course of their work, the health team came across children with developmental disabilities who had different problems: some were diagnosed late, others had developed contractures, some were left neglected in their households, a few had died due to neglect and associated malnutrition, and many had dropped out of school. These observations were a cause for concern and became the basis of this action-oriented research.

Objectives

1. To identify barriers to early identification, appropriate treatment and rehabilitation of children with developmental disabilities, as perceived by parents
2. To determine barriers to diagnosis and provision of appropriate care to children with developmental disabilities, as perceived by doctors.
3. To identify barriers in providing inclusive education to these children, as perceived by teachers.

METHOD

Definition of terms

Taluk: A subdivision of a district, consisting of a group of several villages organised for revenue purposes.

Community: A group of people living in the same place or having a particular characteristic in common.

Study Setting

This study was undertaken in DJ Halli, one of the shanty towns in Bangalore city, and in 5 villages of Devanahalli Taluk, a sub-district. DJ Halli is a densely populated and overcrowded area, where the majority of the people are engaged in construction work or small-scale industries like making garments and *beedis*. Other features are the high pollution levels, high crime and infant mortality rates, prevalence of infectious diseases, non-communicable diseases and deaths due to malnutrition. Devanahalli, which is part of Bangalore Rural District, is a predominantly rural area with a small semi-urban population. It is sparsely populated, and majority of the people are engaged in agriculture and animal husbandry.

Study Design

A qualitative study design was chosen to elaborate on the multi-dimensional aspects of the stated problem and to better understand the experiences of the critical 'influencers', namely, parents, doctors and teachers, in dealing with children with developmental disabilities. The research questions were broad,

so as to accommodate inductive, data-driven thematic analysis. The strategies of Corbin and Strauss (2007) for qualitative research were used to guide data collection and analysis.

Study Population and Sampling

The Community-Based Rehabilitation (CBR) field team had conducted household surveys in the selected villages in the rural area and in the shanty town. As a part of this CBR programme, children with developmental disability were identified and community-based rehabilitation services were initiated. Information about parents of children with developmental disabilities was taken from the CBR programme register and they were contacted by the research team. The team, which consisted of a doctor, an occupational therapist and social workers, visited these households to establish rapport, explain the purpose of the study and to conduct the interviews. The parents were interviewed at a time convenient to them, using a semi-structured questionnaire which was largely a list of open-ended questions. With permission from the parents, the research team also looked into the medical records available.

The semi-structured interview guide contained the following prompts:

- Can you describe your child's condition?
- Can you describe the events leading to the diagnosis of your child's condition?
- Who told you about the child's condition? How did you feel?
- Can you tell me about the treatment suggested?
- What were the challenges faced regarding the treatment of your child?
- How did you respond to these challenges?

Parents of 32 children were interviewed; of them in 18 children, both parents were present during the interview, and in the other 14 children, only the mother was present. In cases where both the parents were interviewed, it was noticed that mothers were able to remember and share the experiences more clearly than fathers. Therefore the interview was conducted if both parents were present or if the mother was available. The questionnaire referred to demographic details, age, educational qualifications, occupation of the parents and family income. Parents were encouraged to share their experiences in getting to know about their child's condition, their interactions with the doctors, and the social pressures and stigma

that they experienced. All the interviews took place at their homes, for a duration of 35 to 90 minutes (average 46 minutes). In accordance with the conventions of thematic analysis, recruitment ceased when no new information emerged from the interviews (Corbin and Strauss, 2007). Thematic saturation was attained after conducting 30 interviews; however, an additional two interviews were conducted to confirm saturation.

All the doctors, including indigenous practitioners in the proximity of the selected areas, were identified and contacted for interviews. Though all the 41 doctors were willing to be interviewed, due to unavoidable circumstances 3 of them were not available on the date of the interview (one was out of town, one had a family emergency and the other did not give any reason). In-depth interviews were conducted using a semi-structured questionnaire. Apart from their qualifications and number of years of experience, the doctors were asked about the challenges they faced in dealing with diagnosis and management of children with developmental disabilities.

The interview guide contained the following prompts:

- In your practice, do you see children with developmental delay?
- Can you describe the challenges you face in diagnosing developmental delay?
- Once you get a clue that the child has developmental delay, what do you do?
- In your experience, what are the challenges in treating a child with developmental delay?

Doctors were encouraged to speak about their competence in identifying children with developmental delay, as well as their ability to provide appropriate management and referral. They were assured that their identities and the information they provided would be kept confidential and used for academic purposes only.

All the schools in the selected geographical area were mapped on the basis of information provided by the education department at the sub-district office. Using the lottery method, 8 schools from the list, 4 each (2 private and 2 government) from rural and urban areas, were chosen at random for the study. After obtaining permission from the school officials, the research team conducted focus group discussions with teachers and school children. The teachers who were available

and were willing to participate were selected. Focus Group Discussions (FGDs) were held with 31 school teachers and 39 children without disabilities; four FGDs with teachers and four FGDs with students. Each FGD had 6 – 9 participants and the duration varied from 90 to 130 minutes.

As part of the school visit, the research team also conducted an environmental analysis. Environmental analysis consisted of an audit of the school infrastructure, to assess whether the school conformed to a minimum set of barrier-free provisions which are essential for facilitating children's accessibility and independence. These barrier-free provisions are a necessary part of Sarva Shiksha Abhiyan (SSA), a government initiative for achievement of Universalisation of Elementary Education (UEE).

All the interviews and FGDs were conducted in the respondents' first language (either Kannada or Hindi). The research team built rapport with the respondents to promote open and honest communication. It is claimed that most researchers have organisation and institutional power compared to the participants (Henry, 2003; Karnieli-Miller et al, 2009). However, in this instance, the power effect was nullified by the fact that the researcher had been working in the area for more than 2 years and had developed a certain level of rapport and trust with these communities and the participants. Also, the research team had experience in dealing with children with disability, and sharing these experiences became a unifying factor.

The study was approved by the Institutional Review Board.

Analysis

Inductive thematic analysis, whereby themes are generated from the data as opposed to a pre-existing thematic framework, was performed concurrently with interviews until thematic saturation was reached, in accordance with the methods described by Corbin and Strauss (2007). Journal entries and memos were included in the analysis. Thematic analysis took an iterative approach, whereby as new themes were identified and added to the thematic framework, earlier transcripts were recoded (Corbin and Strauss, 2007).

In-depth interviews and focus group discussion tape-recordings were transcribed and translated verbatim. A preliminary analysis was conducted to get a general sense of the data and reflect on its meaning. The data was then open-coded in a systematic fashion, on the basis of repeating words and concepts. Each data item

was given equal importance in the coding process. Constant comparative analysis was performed repeatedly; data was compared to the categories to determine consistency in coding. Each code had to have a supporting sentence, extracted from the one-to-one interview or FGD transcript, and a relevant comment added by the evaluator. The coding was done until no new categories emerged from the data. In the next stage, the codes were collated into potential themes, by gathering all data relevant to each theme. Themes were repeatedly checked against each other and against the original data set, to ascertain that they were internally coherent, consistent and distinctive. The themes were then analysed to explain the core phenomenon, causal conditions, strategies and consequences through axial coding by connecting themes. Rigour was addressed by repeated coding of transcripts by different team members to ensure a comprehensive themes list and framework; an iterative process of constant comparison between the existing framework and new data; detailed documentation of the analysis process; and, discussion of emerging and final themes with all authors. Guided by the triangulation protocol of Farmer et al (2006), the data was triangulated further to validate the findings. A summary of the triangulated results was sent for review to a senior researcher who concurred with the results.

RESULTS

Demographic Details and Diagnosis of the Children in the study

The oldest child was 15 years old and the youngest was 2, the mean age being 7.6 years. 62.5% of the children in the study were males. Their medical conditions were cerebral palsy (43.8%), mental retardation (28%), cerebral palsy and mental retardation (12.5%), spinal muscular atrophy (6.3%), blindness (3.1%), seizure disorder (3.1%) and Treacher Collin syndrome (3.1%).

Parents

Among the parents interviewed, 40.5 % belonged to the rural areas while 59.5 % were from the shanty town. Almost three-quarters (75%) of the households had an average monthly income of Rs. 4000. Majority of the mothers (90.6%) were housewives; around 28% of them were illiterate and 28% had completed high school.

The dominant themes that emerged from the interviews are described below.

1. Delay in diagnosing the problem by the doctors

Even though the health-seeking behaviour of the selected population was relatively good, the most important barrier that parents reported was that the doctors failed to spot the problem early. One parent said, *“I had taken my child to the doctor 10 - 12 times for loose stools, breathlessness, allergies, etc., but no doctor told me my child has a problem at that time. After three years, one doctor told me my child is different”*. Similar experiences were shared by majority of the parents. 75% of them agreed that the doctors did not do everything in their capacity to help them.

In their first year of life, most children (87.5%) had been taken to a physician at least once in three months and the others once a month. Despite frequent visits, the doctors treated these children for infections only. They seemed to ignore the disabilities the children presented. Lack of competency of the health professionals emerged as a major barrier in these communities.

2. Confusion regarding where to seek help for their child’s condition

The parents faced many challenges in deciding what was best for their child. The doctors failed to give them proper directions. All that was communicated was that the child had to be taken to another hospital, but no information was provided regarding where to go and whom to meet.

“Doctors don’t seem to know about my child’s condition. The first 6 doctors gave us a vague explanation and told us to go somewhere else,” one parent stated. *“Even after telling our child’s problem, the doctors failed to inform us where to go, what to do and what will happen to our child in future. All of them left us confused.”*

Almost all the parents had made multiple visits to different hospitals and wasted a lot of time, energy and money.

“We have asked many, but no one seems to know; we tried different places and wasted a lot of money. We lost hope and the child is at home.”

Most parents were frustrated because they had no idea where to go for help and no one helped them.

“We are poor, where can we go and find out? There is no one to help”, a parent stated angrily.

Lack of education, financial constraints and large family size made matters worse.

3. Treatment options are expensive and require dedicated time with the child

When poverty and disability intersect, the expenses associated with children's care have important implications for their families. Childhood disabilities impose very high costs on poor families. The analysis of parents' expenditure revealed that they had spent an average of Rs. 1,80,000 on their child's treatment. Parents may be forced to make trade-offs between the needs of their child with developmental disability and the basic needs of their family. Majority (90.6%) of the interviewed parents used the words "too expensive" and narrated how they could not provide optimal treatment to their child.

"There are no services provided by the Government and private treatment is expensive. There are no facilities available nearby and we have to travel at least 40 km to go to the town. The treatment is very expensive, 350 rupees for half an hour. We can't afford it."

"If we have to sit with him every day, there won't be food on the table", said the father of one child.

4. Myths and beliefs

Many myths and beliefs prevalent in society pose a threat to children with developmental disabilities and their parents.

"This is due to our family's past sins, nobody can do anything about it and we have to go through this suffering," one parent said.

"We have to pay the price for the bad karma which we might have done in the previous birth," added another mother.

There is a strong conviction that only sinners in a previous birth are born with disabilities in this life.

These beliefs also caused distrust of medical and rehabilitation services.

"Even if doctors provided treatment, the child is unlikely to improve. This is God's curse," a young mother remarked.

A few of them revealed that they had taken their child to traditional healers and faith healers.

The frustration of social exclusion was evident. One mother said, *"We have suffered enough because of this child. Many of the relatives do not call us for any functions. Even if someone calls us, they talk behind our back that we had this child because God wanted to teach us a lesson."*

5. Delay by the parents in accepting the diagnosis

Some parents (18.8%) were in denial regarding the diagnosis for a long time, and had multiple physician consultations hoping to hear that their child was normal.

“Our child was normal, just like her sister when she was born,” said one parent.

“There was nothing unusual about my child. It’s just that he is not as smart as other children,” another parent said.

These respondents were younger (mean age was 23.1 years) than the rest of the mothers. 66.6% of them belonged to rural areas. Even when faced with severe developmental delay, these mothers were in denial.

There is a widespread dislike of the doctor who first diagnosed the child. One parent even blamed the doctor for causing the child’s disability.

“Our child was okay, but the doctor gave some medicines for cold. After that only he started getting all the problems. He must have given wrong medicines. We no longer go to that doctor,” a mother said.

6. Caregiver burnout

A child with special needs requires constant care and support, which results in excessive stress and strain for the parents.

“He needs a lot of attention. Someone has to sit with him all the time, the roads outside are busy, he will run out if we don’t prevent him,” said one.

“No matter how much I explain, she likes to play with water. All the water which is kept for drinking is wasted. I get very angry. I am tired of telling her,” another mother said.

“We tried everything; we spent more than Rs. 4,00,000 on our child. We are tired of taking him to different places. We have no hope,” a parent lamented.

Though many parents expressed their frustrations in dealing with their children, the researchers did not probe to explore the possibility of abuse.

Table 1: Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: Parents' perspectives

<p>Concepts basic (Open codes) Illustrative quotes</p>	<p>Organising theme</p>	<p>Global theme</p>
<p>Lack of knowledge and skills <i>"It's not that we did not go to show our child...S had diarrhoea when she was 3 months, many times fever...but no doctor told me that S has other problem."</i> (G, mother, 11th Oct 2013)</p>	<p>Competency</p>	<p>Provider related</p>
<p>Lack of information <i>"S has a problem, Doctor told us, but did not tell where to go and what to do. He did not tell what to do next."</i> (N, mother, 11th Oct 2013)</p>	<p>Information deficiency</p>	
<p>Expensive <i>"350 per treatment session, that too for many days... expensive."</i>(G, 44 years old)</p>	<p>Financial drain</p>	<p>Environment</p>
<p>Non-availability <i>"N has to be taken to town, in this village...uh... doctors said they can do nothing... it is difficult...town is unfamiliar...costly..."</i> (U, 24years old, 25th Sep 2013)</p>		
<p>Chronicity <i>"G will not become okay...I do not think it is like cough or fever... He has to be taken to the doctor for treatment.. how many times I can...um... you know...it is difficult..."</i> (N, 32 years old,11th Sep 2013)</p>		

<p>Dedicated time <i>"I cannot work, have to sit with A every day... I am not able to provide for my other children..."</i> (G, 30 years old, 12th Oct 2013)</p>	<p>Energy drain</p>	<p>Caregiver related</p>
<p>Burnout <i>"With other three children, it's tough to take care ... treatment is difficult... I am so tired... lose temper too..."</i> (Z 26 years old, 15th Oct 2013)</p>		
<p>Hopelessness <i>"We are tired of taking the child to different places... when we ask whether N improves, always they give a blank look... We have no hope."</i> (M, 22 years old, 13th Aug 2013)</p>		
<p>Stigma <i>"We do not want to go...they will talk...you know... behind our back... that why we are cursed..."</i> (S, 24 years old, 24th Oct 2013)</p>	<p>Social avoidance</p>	
<p>Lack of faith in therapy <i>"It is due to our family's past sins, nobody can do anything about it...it is beyond medicine...next birth... maybe we will all be healthy..."</i> (M, 23 years old, 15th Sep 2013)</p>		
<p>Need for suffering <i>"It is God's curse upon us...what treatment can make a difference...we have to go through pain...uh...umm... suffering...to cleanse..."</i> (L, 22 years old, 10th Sep 2013)</p>		
<p>Denial <i>"I do not believe that something is wrong... I do not want others to know... it's a false thing... why should others spread a rumour... my child is ok..."</i> (P, 25 years old, 12th Sep 2013)</p>	<p>Lack of adaptation</p>	

Doctors

Thirty-eight doctors were interviewed, of whom 13.2% were from the rural area and the rest were from the urban area. With a mean age of 38 years, their experience varied from 1 - 25 years. While 70% of them held a post-graduate degree, one doctor was an *Ayush* (indigenous medicine) practitioner.

Three major themes emerged.

1. Breaking bad news is difficult

Many physicians, both GPs as well as specialists, reported feeling considerable anxiety while conveying “bad news” to parents, due to factors such as fear of a negative reaction and a sense of powerlessness from not being able to provide a cure. This was more pronounced among doctors with less than 5 years of experience.

The doctors demonstrated a lack of confidence in handling emotional issues.

“It is a very sensitive issue, what if they overreact? I don’t know how to handle such situations.”

The doctors also showed hesitation in conveying the diagnosis of a child’s developmental disability, though it was not such a problem to break bad news to an adult.

“I don’t have a difficulty in telling a 40-year-old patient that we are suspecting cancer; they take it better when compared to a parent of a child with developmental disability. Parents are very emotional regarding their children.”

“If the parents are uneducated, the matter becomes worse. They overreact and blame us.”

Uneducated parents and time constraints are the major barriers in explaining a child’s condition to the parents.

“I see hundred patients a day, all kinds of patients; I can’t afford to spend so much time with the parents.”

Many doctors felt there was no need to explain the diagnosis to the parents because they believed that since most parents were uneducated, they would not be able to understand.

Another interesting concern that was pointed out was the stigma towards the doctors who diagnosed these conditions.

“One child’s mother did not speak to me for five years because I was the first to break the news. The whole family stopped coming to me. I have become a bad omen for them. I learned my lesson. Now I refer all such children to another centre, let them deliver the bad news.”

“They won’t take it in the right sense. Parents don’t want to hear anything bad about their child.”

Though this experience was not common to all, the doctors who were involved had taken it too personally and had vowed never to take the risk again.

2. Lack of competency

Majority of the doctors (76.3%) expressed difficulty in diagnosing children with developmental disabilities. Only 9 doctors rated their competence in dealing with this issue as satisfactory.

“I am not very confident that I can identify children with special needs. We were not taught about all this in detail. I can pick up these disabilities at a later age, if it is moderate to severe. Only a specialist can pick up subtle signs.”

“Though not a specialist, I do come across these types of children. I am confused most of the times.”

The paediatricians, psychiatrists and the neurologist showed confidence in diagnosing children with special needs. All of them expressed their desire to attend training programmes to build capacity.

3. Referral

Even though many general practitioners often dealt with children with developmental disabilities, they had no information and showed no interest in finding out about referral hospitals and institutions that provided specialised services for diagnosis and rehabilitation. They referred such children to medical college hospitals, assuming that all the facilities were available, and did not follow up.

“I usually tell them to go to a medical college or a big hospital” one doctor stated.

“I know it will be difficult for parents to find the right doctor and right place but I don’t know either” exclaimed another doctor.

Table 2: Barriers to Early Diagnosis and Management of Children with Developmental Disabilities: Physicians' perspectives

Concepts basic (Open codes) Illustrative quotes	Organising theme	Global theme		
<p>Difficulty in breaking bad news</p> <p><i>"Any problem regarding child...parents do not take in the right sense... Too much for me to handle... No time to sit and talk and manage their feelings..."</i></p> <p>(Dr. V, 7th Dec 2013)</p>	<p>Physicians' avoidance of diagnostic disclosure</p>	<p>Provider related</p>		
<p>Lack of time</p> <p><i>"Crying...sadness...takes a lot of time to console the parents... Deal with them...I can't afford to spend so much time with the parents...there are other patients waiting..."</i></p> <p>(Dr. G, 12th Dec 2013)</p>				
<p>Fear of blame</p> <p><i>"I have become a bad omen for them because I first broke the news of their child...the whole family stopped visiting me... Its too much of risk to take...easy to refer...let others say it..."</i>(Dr. G, 22nd Dec 2013)</p>				
<p>Lack of knowledge and skill</p> <p><i>"I am confused most of the times... With the current level of understanding, hard to identify early..."</i></p> <p>(Dr. R, 22nd Dec 2013)</p> <p><i>"Not very confident... The child can be normal, but slow compared to others... But it may be pathological too..."</i></p> <p>(Dr. M, 14th Jan 2014)</p>	<p>Competency</p>			
<p>Specialist domain</p> <p><i>"Only a specialist can pick up subtle signs... Is there any screening test...I mean,other than looking at the milestones...it's difficult ...we are not specialists..."</i></p>				
<p>Lack of information regarding referral</p> <p><i>"I usually tell them to go to medical college or a big hospital. The specifics I do not know, I assume that in medical colleges the treatment will be available."</i></p> <p>(Dr. M, 8th Dec 2013)</p>	<p>Inappropriate and incorrect referral</p>			

<p>Expensive <i>"It is expensive... They have to go to the advanced centres... Travel, treatment...most of the parents cannot afford... Initially there is hope and they will shell out money... Then the enthusiasm slowly diminishes."</i> (Dr. M, 8th Dec 2013)</p>	<p>Financial drain</p>	<p>Environment</p>
<p>Caregiver burnout <i>"The condition is not curable... The parents also get tired carrying the child to different places... Difficult to manage at home also. .parents give up, it's difficult to motivate them...the situation is different from western countries...We can't totally blame the parents..."</i> (Dr. N, 14th Dec 2013)</p>	<p>Energy drain</p>	<p>Caregiver related</p>

Teachers

While more than half (54.8%) of the interviewed teachers belonged to the shanty town, the rest belonged to the rural area. 87% of the teachers were females. About 75% of them were in the age group of 20-43 years. 51% of the teachers were from government schools and the rest from private schools. An important observation was that 71% of the teachers did not have any training in managing children with disabilities.

Most schools lacked trained personnel, special materials and resources to aid children with developmental disabilities in their basic learning and daily activities. Consequently, children with developmental disabilities were not getting appropriate, specialised attention and care, and the education of regular students was frequently disrupted.

Four themes emerged.

1. Extra burden

Teachers showed reluctance to include and manage children with developmental disabilities in the same class alongside normal children. They looked on it as an extra burden.

"With normal children alone, we are finding it difficult to cope; children with developmental disabilities, unthinkable!" one teacher exclaimed.

2. Pressure to perform and obtain good school results

Most schools were understaffed. Teachers felt that a lot of time had to be dedicated if there were children with developmental disabilities in the school.

"We are being evaluated by our students' performance. To maintain a reasonably high pass rate, we need to put in a lot of effort."

"We do not have enough staff and there is pressure to produce good results. Having a child with disability in the class is a distraction."

3. Lack of trained manpower

There was considerable anxiety among all the teachers with regard to managing children with developmental disabilities.

"What if they get fits or something like that?"

"What if they fall and injure themselves?"

"Who will accompany them always?"

4. Concerns about the interaction between normal children and children with developmental disabilities

The other concern which the teachers raised was the interaction and relationship between other school children and the children with special needs.

"I don't know how the other children will accept them. It's complicated. We are not ready for such things."

Children without disabilities

Focus Group Discussions were conducted among school children. All of them used the words 'deaf', 'dumb', 'blind', 'handicapped' to describe children with disabilities. The school children were ready to accept them and voluntarily promised their wholehearted cooperation to help in any way they could. They were eager to make friends with them. The responses from these children were: "I will teach him", "I will help him with the homework", "I will carry her", "I will teach her to walk", and "we can sing together".

Environmental analysis of the schools showed that the facilities were not designed to accommodate children with disabilities. None of the schools had accessible toilets. There were a lot of steps and no ramp access to many classes.

“We can’t construct ramps for these five children. These are only on paper for government to show, it’s a waste to do all these things,” one school principal stated.

DISCUSSION

The value of early identification of children with developmental delays has been well documented (Ramey et al, 1992; Shonkoff et al, 1992; Brooks-Gunn et al, 1994; McCarton et al, 1997; Hollomon & Scott, 1998; McCormick et al, 1998; Campbell et al, 2002). Not many studies in India have explored the barriers in providing early intervention services so as to facilitate inclusive development of children with disability. The delay from the doctors’ side has been reported in a few studies which concluded that there is lack of knowledge and skills in this area, which requires emphasis and training (Campbell et al, 2002; Ryzd et al, 2006). Other physician factors include attitudes, awareness, or interest (Esposito, 1978); insufficient training (Thorburn et al, 1993); doubt about the value of early detection or non-acceptance of early treatment (Mousmanis & Watson, 2008); uncertainty about how or where to refer (Desai & Nohite, 2011); time limitations of the clinic visit and inadequate reimbursement (Ertem et al, 2009); and cost factors (Dobrez et al, 2001). In some cases, practitioners might be legitimately concerned about unnecessarily alerting a family and would prefer to wait until the problem is too obvious to ignore (Shevell et al, 2001). The appropriate education and training, and issues affecting professional interest, motivation and health-provider acceptance, need extensive study in the context of local geographic and cultural conditions.

Some studies have explored the myths and beliefs related to disability that prevail in different parts of the world. A World Health Organisation report (Promoting the rights of children with developmental disabilities, 2007) states that in cultures where guilt, shame and fear are associated with the birth of a child with disability, the children are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development. As a result of discrimination, children with disabilities may have poor health and education outcomes; they may have low self-esteem and limited interaction with others; and they may be at higher risk for violence, abuse, neglect and exploitation (UNICEF, 2007; WHO, 2011).

The National Sample Survey (NSS) 58th round (Ashappa, 2013) reported that nearly a third of Indian children with mild disability were out of school, despite the fact that they needed no assistive device to be able to attend school. Yet, irrespective of the levels of disability - mild, moderate or severe - they rarely progress beyond the primary school level. Lack of knowledge and negative attitudes of the teachers and school authorities play a major role in this outcome.

Delay in early diagnosis, and failure to provide timely interventions, inclusive education, rehabilitation and social integration among children with developmental disabilities, are almost universal in India. A better understanding of the critical barriers in early intervention and inclusion of children with developmental disabilities as perceived by parents, doctors and teachers has been accomplished through this study. The recommendations made here can influence rehabilitation policy and practice, thereby facilitating early diagnosis, appropriate interventions and rehabilitation for these children.

Table 3: Barriers for Early Diagnosis, Rehabilitation and Social Integration for Children with Developmental Disabilities: A conceptual framework

	Contextual conditions • Resource constrained settings		
Causal conditions • Lack of competency • Inappropriate referral • Cost of treatment • Caregiver burn-out • Myths and stigma in the community	Phenomenon Diagnostic, therapeutic and rehabilitative delay	Action/interaction strategy • Multiple doctor consultations • Depletion of resources • Energy drain • Social withdrawal	Consequences • Irreversible progression of disease • Poor Quality of Life • Neglect/Abuse • Poverty
	Intervening conditions • Attitude / education of parents		

Table 4: Recommendations put forward by the Stakeholders to overcome the Identified Barriers

Key Stakeholders	Key Recommendations
Parents	<ol style="list-style-type: none"> 1. Provision of a help desk or hotline for information 2. Facilities for counselling and support for the families 3. Services to facilitate financial as well as treatment entitlements to children with developmental disabilities
Doctors	<ol style="list-style-type: none"> 1. Demystification of diagnosis and simplified algorithms for doctors and healthcare workers 2. Increasing the technical pool, and short orientation courses for health personnel 3. Publicising referral centres and establishing a systematic and organised referral system 4. Establishing centres in all district hospitals with government providing incentives to specialists who are willing to visit and help in early diagnosis and intervention. 5. CME programmes for doctors including communication and counselling skills
Teachers	<ol style="list-style-type: none"> 1. Reorientation of teachers in simplified ways to manage a differently abled child at school 2. Organising sensitisation workshops before implementation of the policy 3. Providing support with trained manpower and disability-friendly facilities

Limitation of the study

Though the conditions of different shanty towns and villages in South India are more or less similar, inclusion of more poor urban settlements and Taluks through the use of probability sampling methods would have increased the external validity of the study.

CONCLUSION and RECOMMENDATIONS

The study throws light on the various challenges faced by parents, doctors and teachers in dealing with children with developmental disabilities in India. It reveals that parents felt there was a delay in diagnosis, and lack of access to correct information about where to go for help. Treatment options, when available, were inaccessible and unaffordable. Myths and misconceptions about disability, added to their woes. The doctors felt their competency levels were not optimal to diagnose and manage disabilities among children. They also felt that there was insufficient information on where to refer such children. In addition, they lacked communication skills to deliver 'bad news' to the parents. The teachers, in general, had a negative attitude towards children with special needs. They viewed them as an additional burden and responsibility. They lacked the knowledge and skills to care for such children. They were also apprehensive about the attitudes and interactions of normal children at school with children with disability.

Primary care doctors and general practitioners need training to increase their skills and confidence. Simple algorithms to facilitate this should be made available. There is also a need for specialist services to assess and treat children with developmental disabilities. Referral centres within a district should be widely publicised and a systematic chain of referral needs to be established. All Taluk / district government hospitals should be supported by visiting specialists. Doctors need to be given special inputs on communication skills. Reorientation for teachers, enabling them to address the needs of children with disabilities, and provision of barrier-free environments at schools would help in promoting inclusive education.

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