

1. Introduction

The position of parents of children with disabilities within the larger discourse on education can best be described as tenuous. Various international declarations, such as the UNESCO's Salamanca Statement (UNESCO, 1994), which was seminal in focusing attention on the need for educating children with disabilities, conceptualised parents as "privileged partners" (p: 38) in the education of their child. It noted their inherent rights to be consulted and promoted their participation in the planning and provision of their child's educational needs. While such intentions are commonly seen in international policy discourse, their translation in practice is far more complex, and has been addressed differently in various national contexts. Even in England, where special educational needs (SEN) legislation positions parents as partners in the education of their child (Department for Education, 2014), research highlights how parents are more likely to be seen as customers or a problem by the local education authorities and schools (Macleod, Pirrie, McCluskey, & Cullen, 2013). Additionally, studies exploring parental decision making on school choice have concluded the lack of real choice for parents, particularly those from minority ethnic groups (Crozier & Davies, 2007; Byrne, 2013). These research insights are from a context where educational provision for children with disabilities is well spread. However, issues relating to the role and position of parents in contexts where state education is still not as wide spread and schooling provision is at an early stage of responding to the needs of children with disabilities, are of equal, if not more, importance.

In this article, my focus is specifically on India, which provides the basis for a useful analysis because of two main reasons: firstly, in 2009 The Right of Children to Free and Compulsory Education (RTE) Act was passed, which legislates the provision of free and compulsory education till completion of elementary education in a neighbourhood school for all children, including those with disabilities. Secondly, India is seen as having an enabling and positive disability legislative framework, which places the education of children with disabilities (referred to as Children with Special Needs, CWSN, in official documents), as a central concern under the *Sarv Shiksha Abhiyan* (the SSA). SSA is the country's current flagship programme aimed

at improving access and quality of provision for all children between 6-14 years (SSA, 2007).

Over the last decade or so, there has been a marked increase in the visibility of disability in the Indian context. This is not only in relation to the growing media interest and focus on disability issues as reflected through televised debates, but also the significant rise in the portrayal of characters- both children and adults- with disabilities in mainstream Indian cinema (Rao, 2015). In more recent years, in order to include all out of school children, state governments have started organising door-to-door surveys before the start of the new school year to identify and enrol all such children (Jeffery & Singal, 2008). Teachers, who usually conduct these surveys, are specifically instructed to inquire about children with disabilities. National data sets, such as the District Information System for Education (DISE) now collects information on school enrolment for children with disabilities. Therefore it is useful to examine how in these changing times, when no longer an assumption holds that their child with disability is best hidden away, parents belonging to low income groups are making sense of the role, purpose and nature of schooling for their child with disabilities.

Interestingly, while globally education of children with disabilities is getting more attention as in the Sustainable Development Goals (United Nations, 2015), there is little research exploring parental experiences of engaging with the education system. It is important to stress here that in many developing education systems, such as India, parents from more affluent socio-economic groups, in the absence of state funded educational provision for children with disabilities, have taken on the role of service providers by setting up special schools or other community outreach programmes for children with disabilities (Alur & Bach, 2012). Parents have also played a central role in setting up advocacy groups and lobbying for the rights of children with disabilities, such as Action for Autism which is one powerful example (Johansson, 2015). However, the scenario is very different for parents of children with disabilities living in poor communities, who are more likely to have limited financial resources and truncated social networks.

The main aim of this paper is to examine how parents of children with disabilities from low income families living in a rural community in South India perceive and experience the schooling of their child with disabilities. In order to do so I draw on data gathered from semi-structured interviews conducted with mothers to identify factors that shape their decision to send their child to school and their perceptions and reflections on their child's experiences in school.

I contextualise these findings not just within the growing and visible official discourse around disability, but also by drawing contrasts with research studies which have engaged with how parents from low income families understand and make decisions regarding the education of children without disabilities. My reasons for doing this are not merely shaped by the lack of research insights on parents of children with disabilities, but also to draw out contrasts (and similarities) between the two groups. This wider body of literature also provides helpful conceptual insights for framing my broader analysis. Here I particularly draw on the work of Hirschman (1970), who proposed the concepts of exit, voice and loyalty to understand the behaviour of individuals in organisations that operated under the rules of the market. Hirschman's framework has been adopted in education to analyse how consumer behaviour affects the quantity and quality of education. In recent years, it has been extended further to respond to the realities of countries where educational provision by the state is still not universal (Fennell, 2010). Even though this framework is primarily used in relation to understanding choice making between public and private schools, I will use it to explore what it means for parents of children with disabilities who are not necessarily making a decision between sending their child with disability to a public or private school but how to access education. I will examine the costs of exit (Hirschman, 1980) and factors that continue to maintain a child's presence in a system which they know is not delivering good quality education.

2. Research approach and sample

This research was carried out with mothers of children with disabilities living in a rural community in Chamrajnagar District of Karnataka. Karnataka is one of the few

states to have a state policy on inclusive education. It's '*Draft Policy on Inclusive Education*' notes:

...there is a need to look into the issues of education of children with disabilities in the larger context of education in the state especially in terms of their retention and quality of education.... Karnataka needs to develop a cogent policy, strategy or an action plan on Inclusive Education of children with special needs that can address the state specific needs and realities with a long-term vision (p. 4). (SSA, 2006a)

While the policy covers a range of areas, such as emphasising the need for multi-sectoral working, special focus on girls, developing a localised understanding of inclusive education etc., it is interesting that it does not engage with or highlight the role of parents and communities in the education of children with disabilities.

Data reported in this paper was generated through one-to-one semi-structured interviews with mothers. This data collection was part of a larger project on '*Role of inclusive education in enhancing children's personal, social and educational well-being*', funded by CBM (International), and adopted a qualitative approach to examining the impact on schooling on the academic, personal and social wellbeing of children with disabilities in this community. This project involved multi-method approaches to data collection which included interviews with district officers, heads of school, teachers in government primary schools, Inclusive Education Resources Teachers and Inclusive Education Specialist Teachers- a cadre of professionals set up under the SSA, community leaders, and activities conducted with children with disabilities. In addition to this narrative observations were conducted at the school and classroom level. A large part of the time was also spent in the community interacting with a local Non-Governmental organisation working with children and young adults with disabilities, which also facilitated researcher access to a large number of Self Help Groups (SHGs) set up in various villages in this district. As the primary focus of the project was on children of school going age, eight in-depth case studies of children with disabilities were developed (see Table 1 for details).

Table 1: Overview of the sample children

Name	Gender	Type of disability¹	Educational status
Mahesh	M	Physical	Passed class 8; dropout
Lalit	M	Physical	Enrolled in Class 6
Subhash	M	Learning	Enrolled in Class 7
Meena	F	Hearing	Enrolled in Class 3
Champak	M	Cerebral palsy	Was enrolled in class 4
Adesh	M	Cerebral palsy	Was enrolled in class 3
Anu	F	Learning	Was enrolled in school, but now enrolled in home based education
Priya	F	Cerebral palsy	Was enrolled in school, but now enrolled in home based education

Conducting interviews with mothers was crucial in developing a holistic appreciation of their child’s schooling journey. While invitation to participate in these one-to-one interviews was given to both parents, not surprisingly, it was the mother that was ultimately interviewed in each case as she was the primary carer for the child and was present at home. The central role of mothers in child rearing in India is also noted by many researchers, such as Sriram and Sandhu (2013). While Chakravarti (2013) based on her research examining the experiences of caregiving among families of young people with cerebral palsy in Delhi (India), discusses how the ‘burden of caring’ (p. 134) is more specifically on mothers.

These interviews were conducted at a time convenient for them and in the official state local language, Kannada, which all the participants were fluent in. The lead researcher who conducted the interviews was supported by a locally based

¹ Descriptors used are those provided in the field by mothers or teachers.

translator, who had basic training in interviewing styles and had developed a good knowledge of the themes outlined in the semi-structured interview schedule.

The semi-structured interviews with mothers explored themes related to the child's diagnosis, experiences related to school enrolment, rationale for sending their child to school, experiences of interacting with teachers, and other similar issues. All interviews were audio recorded after due permission had been obtained. The interview data were then transcribed and translated to English and checked by a third party for accuracy of translation. The data was then analysed using both deductive and inductive processes, this was largely framed by the analytical steps proposed by Neuman (2009). An open coding scheme was undertaken to allow for the emergence of descriptive codes and enable a low level abstraction to help flag key themes from the data. This was then developed further by a second pass through the data, which involved the organisation of themes and ideas in a more coherent manner, allowing for the identification of core ideas which have been used in framing the findings presented below.

3. Findings of the study

Analysis of interviews conducted with mothers clearly highlighted the immense value that they placed on schooling for their child with disabilities. However, they also noted a range of structural and other barriers that compromised the quality of schooling that their child received.

3.1 Parental motivation for schooling: long and short term gains

Contrary to commonly held assumptions, in majority of cases, parents of children with disabilities were investing significant personal time and energy in ensuring that their child was attending school. In one case the mother spoke about how she used to carry her son to school, in another instance, a mother recalled how she would sit idle for hours outside her child's classroom so that she could help him go to the toilet when required.

When mothers were asked why they were sending their child with disabilities to school, they unequivocally spoke in terms of the value of schooling in improving the quality of their child's future. Lalit's mother summed up a recurrent theme which emerged in all interviews when she equated schooling with 'insurance' to her child's future wellbeing. She stated, *"If he has education, at least he would have a job"*. When asked that even though she was aware of his disability "who encouraged you to send him to school?" she responded by reflecting on her personal experiences, *"We never went to school so we wanted that at least our child goes to school. He shouldn't suffer the way we are suffering"*. It is interesting here that she reflected on education as a panacea for alleviating suffering, and was arguing that irrespective of her son's disability, education will help him overcome future barriers. Mahesh's mother reflected on the fact that if her son could learn to read and write there would be long term financial benefit which would have a direct impact on him and his family's well-being.

If he is able to sign, he stands by himself; he would be ready to earn money. The benefit is he would be able to earn his living in the future. He can't go alone anywhere, we are homebound because of him; someone has to take care of him every day.

These arguments were very similar to those put forth by parents of young adults with disabilities in Dewas when reflecting on their rationale for sending their child to school. Singal et al., (2009) noted that an overwhelmingly motivation driving parents to send their child to school was to enable them to be employed later on. It was common for parents to describe their child's education in terms of future wellbeing. Parents strongly equated the purpose and value of education with future employment.

Not only did mothers in Chamrajnagar equate schooling with long term benefits, they were also aware of the more immediate rewards of sending their child to school. Mahesh's mother talked about the financial benefits and assistive aids her son had received from school. The government, under the SSA, provides a range of incentives for children with disabilities, such as allowances for transport; hostel and children (with and without disabilities) are all provided with free school uniforms and

mid-day meals. During interviews it was clear that parents whose children were currently enrolled in or attending school were aware of, and accessing, many of these benefits. It was common for parents to point out that their child's school attendance resulted in some monetary returns (e.g. government scholarship given to the child for attending school) and other material rewards (e.g., free books and uniforms provided to the child). For instance, Subhash's mother, who was disappointed with the quality of schooling that her child was receiving, accepted that schooling was simply a way of accessing government sanctioned benefits. Reflecting this perspective, she noted: *"Instead of sitting at home, he should go to school....if he stops school they will stop all the other things as well like scholarships"*.

It is important to note that these scholarships, however small they were, seemed to be making a significant contribution to the functioning of these poor households. Subhash's mother when asked what she did with the money, noted the following:

We have deposited that money in the bank and started an insurance scheme. We pay the premium once in 3 months, which is around Rs. 500 for post office account...If we spend all the money on him, how will we fill our stomach?

Mothers' also referred to the benefits their child received in terms of getting free clothes to wear (uniform) and food as part of the midday meal scheme.

Nonetheless, it is interesting to note that across the sample group, mothers seemed to have internalised the benefits of schooling- sending the child with disabilities to school was discussed with a certain degree of naturalness. Schooling itself took on a more normalising feature, where parents did not really question it despite the lack of quality education, as discussed later. Rather they continued to value education for a range of different reasons and were willing to invest personal time and energy. This naturalness of schooling could be attributed to the changing socio-political scenario in India where education has become so integral to the common discourse (De *et. al.*, 2011). What is particularly interesting here is how this is impacting the educational inclusion of children with disabilities, who have historically been excluded from mainstream participation.

3.2 Enrolment, attendance and learning: contested spaces of engagement

Not only did parents value schooling, none of them recalled any difficulties in getting their child enrolled in the government run primary school. Adesh's mother narrated how she and her husband were keen that their son attended school and how the *"father went to the government school and got his name registered"*. Similar experiences were shared by others who noted how easy it was to get their child with disabilities enrolled. Parents also spoke about the door-to-door surveys that were undertaken by school teachers. For example, Chameli's mother noted that it was during such a survey that she met the school teachers, and they put Chameli's name on the school register. When she explained to the teacher that her daughter could neither sit or stand, the teacher responded that it did not matter and *"her name needed to go in"*.

While mothers noted the ease with which their child had been enrolled in school, the real arena of struggle and dissatisfaction emerged after the child had been admitted. Mothers' discussions in this regard were illustrative of despair, helplessness and frustration. Anu's mother in recounting her child's experiences at school narrated:

We admitted Anu to school as she had crossed 6 years of age. We thought that we would go and tell Anu's problem to the teacher. The teacher hadn't seen Anu before we took her to school. The teacher let her attend class for one week....then she told me not to send Anu to school. She said that whatever benefits they will get from the government in school like clothes, would be sent to her at home. She has got two sets of uniform. But she does not attend school now.

Thus, while the child was initially allowed to attend school, soon the teacher felt unable to respond to the child's needs and according to the mother *"the teacher asked us to take her back"*. The teacher complained that Anu did not let anyone study and this was disturbing for the whole class. *"I can't teach like this. If she (Anu) is able to sit silently then it is okay for her to come to school. Otherwise we can't let her attend"*. The mother concluded by noting that the teacher felt Anu could come back to school only if, *"some special facility comes to school where she can study. In*

that case we will call her back to school. Also, you can send her back to school if her thinking capacity improves". Thus, even though Anu's name was on the school's register, she was not attending school. As it emerged later, this was the case for a number of children with disabilities, who were enrolled but not attending school on a regular basis (and sometimes not at all). They were being provided the state benefits, such as school uniforms and the free mid-day meal, which was delivered to their house by someone in the village.

Similar to Anu's mother, Meena's mother, who had herself completed elementary schooling, showed a great deal of involvement in her child's education. When her daughter started attending school, she went and met the teacher regularly to find out what was happening in class and how the teacher was supporting her child. However she acknowledged that apart from her daughter simply copying what the teacher wrote on the blackboard she had no way of making sure that the child was understanding what she was being taught. The mother also expressed reservations about the behaviour of other children and the lack of support provided by the teacher:

Friends' don't allow her to play with them they sometime complain to the teacher and she (the teacher) supports them. She dances at home. Whatever the friends do at school, she comes back home and does that.

The mother recounted how Meena after a few days of attending school, was asked by teachers to stop coming to school because they felt that "*she can't speak, hence we can't teach her!*"

While enrolment had seemingly become a natural step, regular attendance and participation in the learning accorded in these classrooms were determined by a range of other factors. Anu did not attend school because of her teacher's reluctance to teach her, but for other children like Mahesh and Lalit, their attendance was determined by the availability of support in reaching school, such as a wheelchair or sometimes even a willing friend who could accompany them and carry their school bag. More pertinently, the biggest barrier, especially as children grew older, was their inability to use the toilet independently and/or the lack of disabled friendly toilets in

school. This issue emerged as the single most distressing feature for the mothers. Mahesh's mother expressing her concerns noted:

Toilet is a big problem with him...I don't know if he will be able to read and write...The main reason we can't let him go to school is that he expresses his toilet need only to meHis friends took him to the toilet in school but sometimes he had to be sent home.

This resulted in Mahesh being kept away from school as it lacked the appropriate facilities. In a similar vein Champak's mother mentioned:

The teacher has said that I have to come to school and take care of him. But if I spend more time with him I cannot do other things in the house. The teacher does not have any problem with his coming but if he dirties the place then it's a problem for me and the teacher. It is also a problem for other children.

Some children, like Mahesh, had a requirement of a special toilet so that his wheelchair could be accommodated. However, the three government schools the research team visited did not have any such facilities. In one of the school's, over a year back, a government subsidy had been provided to construct a special toilet but till date no initiative had been taken in getting it constructed. In other cases where disabled friendly toilets did exist, such as at the learning resource centre at the block level, their upkeep was a problem. In the block resource centre (BRC) that was visited the entrance to the disabled friendly toilet had been blocked with a big metal frame. On being asked why this was the case, the official noted that there was a tendency for children and others to vandalise it. Thus, the irony of the situation is that while efforts of a grand scale are being made within educational policies to make schooling accessible for children with disabilities, basic needs and concerns remain neglected.

Another interesting observation worth making here is that while majority of parents were themselves not well educated, they were acutely aware of the low quality of schooling that their child with disabilities was receiving. This was evident in a range of conversations. Meena's mother shared concerns about the poor quality of

schooling when she noted that her daughter only copied things from the blackboard, but had no comprehension of what was written.

Thus, while learning outcomes of these children were not encouraging, as many could not do simple arithmetic or recognise words², parents though aware of this lack of learning were unable to address these concerns. In five cases mothers justified the continuation of schooling in terms of the positive impact on the child's social skills and the fact that the child made friends and had fun. Subhash's mother noted:

He goes to school every day with his friends....we are unaware of the school routine or what he learns. The only thing we see him do is that he plays with his friends.he doesn't even hold a piece of chalk and he doesn't write. He doesn't open any book from his bag.

However, such positive experiences were not common across children with different types of impairments. Anu's mother spoke about how her daughter felt isolated and did not have any friends, "*She plays alone. Sometimes she pumps the bore well or walks around here.... if someone plays around here, she doesn't join them. She is always alone*". Similarly, Meena's mother noted that her daughter did not play with others, not because she preferred being alone, but because other children were unable to communicate with her and hence did not include her in their games.

While positive social relations with peers were important for parents, they remained aware of the poor quality of schooling their child was receiving. Consequently during interviews when asked why their child was not learning in school, mothers tended to argue that teachers had not been trained to teach children with disabilities. In such instances, it was common for parents to emphasise that their child should be provided support from specialist teachers.

Even though special schools are not very widely spread in rural India, and most of the parents had relatively little or no access to 'experts' in their immediate neighbourhood, they frequently reflected on the value of having someone teaching

² While this was a common problem for many children without disabilities, with whom we used the same tests, it was even more acute for those with disabilities. Particularly given that we were comparing children with disabilities with children without disabilities who were identified by the teachers as already being below average in their learning.

their child who was specifically trained in responding to their child's particular needs. For instance, Meena's mother regarded schooling as having a central role in improving her daughter's life and was very clear in her suggestions of what was needed. She noted:

M: Education we need first, someone has to encourage her to speak. She doesn't understand in a regular way as other children but she needs some special ways. We will have to think about those ways. We have to cooperate with her.

R: In which ways do you think they have to cooperate?

M: Special class....she is unable to understand anything in regular class, so we need a special class. In special class they teach in a special way... In class they teach all students and she can't gain anything, but if someone works with her alone...with her on an individual basis that would be very helpful.

Two mothers noted that there was a special school in the neighbouring city but they could not afford to send their child because of financial constraints. In majority of the cases parents were aware of the presence of specialist support in the form of Inclusive Education Resource Teachers (IERTs) under the SSA model. However, they felt that this support was inadequate and highly infrequent in nature. Interestingly, while the policy documents assume that IERTs will support teachers by equipping them with pedagogical skills to respond to diverse needs in their classroom, in reality it was clear that there is very little interaction between teachers and these professionals.

It is useful to highlight here that Singal *et al.*, (2011) noted similar discussions around mainstream and specialist provision in interviews conducted with poor parents in Dewas (Madhya Pradesh, India). Parents, particularly of young people with visual impairments who had achieved very high levels of education (some of them even had College education) due to the availability of both specialist and mainstream provisions, were more forthcoming in arguing for targeted specialist support.

4. Discussion

Undoubtedly times are changing, discussions with mothers noted the importance placed on schooling, even for children with disabilities, highlighting the impact of official rhetoric on the private landscape of family life and disability in India. However there are also interesting points of departure in these official and private discourses. While increased efforts are being made at the state and national levels to include children with disabilities into mainstream schools through the provision of specialist para-professionals, building of ramps etc., many parents continued to voice very basic concerns in relation to their child's well-being at school. It is in examining these disjunctures' that one becomes aware of how policy proclamations need to be made more responsive and accountable to ground realities.

4.1 Parents as enablers

The growing visibility of disability in education and broader official discourses and popular media are shaping how children and young people are being positioned in their families. While no clear answers are evident, positive inferences in this regard can be drawn based on the fact that there was an absence of accounts of anger, deficit, stigma or frustration directed towards children with disabilities in the household. In referring to their child's disability mothers generally drew on a range of different interpretations and explanations, which spanned the breadth of the metaphysical to the medical. This resulted in a scenario where mothers were not simply blaming their karmas (destiny) and not doing anything for the child, rather they were more interested in providing for their child. Similar observations were made by Lang (2001) in his ethnographic work with rural communities in South India.

On one hand, research has shown that parents can be barriers in the education of their child with disabilities, due to reasons such as being overprotective of their child's safety, not understanding the value of education, or being neglectful of their child (Plan, 2014). On the other, recent years have shown an increase in educational enrolment figures for children with disabilities, which one could argue is also a result of growing parental motivation to send their child to school. Hammad and Singal (2014) in their sample of high achieving young women with disabilities in Pakistan found that the single most important factor in their educational success was the

support they received from their mother. Another such example of positive parental support is Botts and Owusu's (2013) study in Ghana. As discussed later in the paper, Johansson's (2014) findings from her work with middle class families in urban India with a child with autism also support a similar view.

However, government discourse does not seem to recognise the potential of working with parents. Under the Rights of the Persons with Disabilities Bill (2011) parental engagement is discussed only in terms of a child/young person with disabilities right to a home and family. It is interesting that unlike the RTE Act³, the PWD Bill does not acknowledge the role of parents in their child's education. Rather it is under the SSA that parents of children with disabilities are given a more prominent place, but are framed as recipients of services. SSA (2006b) views parents as needing information about their child's condition, counselling to help cope with the demands of having a child with disabilities and raising their awareness in relation to the benefits of sending their child to school. Thus, within the Indian policy arena parents are more likely to be positioned as carers or recipients of service, rather than partners in their education.

4.2 Parental motivation for educating a child with disabilities

Mothers in this research strongly believed in education as a mechanism for economic mobility. They had aspirations of a better life for their child and argued that being schooled would help their child gain employment and financial security. These findings are more in line with Krishna's (2004) research with poor families living in rural Andhra Pradesh (India). As a result of focus group discussions with a range of community members, Krishna concluded that people living in poverty identified four stages of progress. These in the order of importance are: (1) buying food to eat; (2) sending children to school; (3) possessing clothes to wear outside the house, and (4) returning debt in regular instalments. Thus, schooling for parents was a high priority even when resources were scarce, as also noted more recently by De *et. al.*, (2011).

³ It shall be the duty of every parent or guardian to admit or cause to be admitted his or her child or ward, as the case may be, to an elementary education in the neighbourhood school" (Point 10, RTE Act)

Also important to acknowledge is that over the last 20 years or so there has been a significant increase in educational attainments of individuals and in intergenerational educational mobility in India, as suggested by Maitra and Sharma (2009). Based on analysis of the 2005 Indian Human Development Survey and household level interview data collected across different states, these researchers concluded that education attainment of the next generation is largely not constrained by the endowments, preferences and opportunities provided by the previous generation. Rather state policy and programmes on education have been successful in severing this link.

Both the above observations seem to hold true even for children with disabilities. It was clear that parents valued schooling for their child with disabilities for the same reasons as children without disabilities. They drew strong links between schooling and future employment. Furthermore, they were not constrained by their own lack of schooling. Even though most of the mothers were not literate they desired schooling for their child with disabilities. Additionally, developments at the policy level were having a clear positive impact on educational enrolment of children with disabilities. This is most evident when one draws on insights gathered from Singal et al's (2011) work with parents in Dewas (Madhya Pradesh, India) whose children had attended primary school over a decade back (in early 2000s). Parents in Dewas noted reluctance amongst school heads and teachers to admit their child in government schools. In contrast, mothers in Chamranjangar, with children of school going age, highlighted how they had been actively encouraged by school teachers to get their child enrolled. Thus, access simply construed as school enrolment, was much easier a decade later.

While the above discussion helps us examine closely reasons as to why parents are willing to send their child with disabilities to school, wherein increased government impetus and greater realisation that schooling facilitates short term and long term, direct and indirect benefits was evident. Nonetheless we remain unclear of why parents even though aware of the poor quality of schooling their child was receiving continued to remain in the system, or simply let the child drop out. This being the case even when they remained convinced about the need for their child with

disabilities to be educated. In order to shed some light on the mechanisms which might be at play here, I draw on Hirschman's model of exit, voice and loyalty.

4.3 Notions of exit, voice and loyalty

A significant body of research on parental decision making in relation to schooling of children without disabilities draws on Hirschman's model of exit, voice and loyalty. Succinctly, 'exit' in an educational setting is regarded as an economic response to deteriorating educational quality whereby parents take their children out of a poorly performing school and transfer them to a better school. 'Voice' is a political response from within the school that can work to improve the quality of provision, and 'loyalty' is the affinity that an individual has for a particular school. These three mechanisms have been regarded as a useful method for mapping how households in poor countries make schooling decisions in a context where new providers are entering the educational environment, and also how these three mechanisms operate for households with very different socio-economic status, resulting in different social and power hierarchies (Fennell, 2010). Even though this model has not been used to examine decision making in relation to parents of children with disabilities, I would argue that it holds potential in highlighting the multitude of additional complexities that are at play for parents of children with disabilities.

As noted in the findings, mothers' acknowledged the immense value of schooling and in some cases actively supported their child to attend school. However they were also acutely aware of the poor quality of schooling that their child was receiving and talked openly about how their child simply attended school but did not learn anything. They even talked about how their child was simply promoted from one grade to the next because of the no-detention policy at primary level. However none of them discussed exiting from the system or raised their voice to challenge the inadequacies of the system. This non-exit could be explained as a result of two interrelated aspects:

Firstly, the lack of exit due to the absence of any real choice. As James and Woodhead (2014) note 'the very notion of choice assumes- to a certain extent- the making of informed decisions between viable alternatives' (p: 4). In this research, mothers did not have any such viable options. While government schools are

mandated to include children with disabilities, there is no such regulatory pressure on private schools; hence they do not have to include children with disabilities. Additionally, these mothers were not necessarily wishing to choose between private and public schools, rather their focus was more on the nature of support offered by the schools in relation to children with disabilities. Mothers expressed desire for a school which responded to the specific needs of their child, and hence for them a more viable choice was that between a mainstream school or a specialised provision, wherein the later was seen as more accepting of their child's needs.

Similar findings were noted by Vaidya (2014) in her research with families with a child with autism, living in urban Delhi (India). Vaidya noted that all the 20 families when presented with a choice between special and mainstream options for their child with autism were more likely to choose the special school. Mothers of these children not only spoke at length about the emotional support they received from the staff at special schools, but they also recounted how the mainstream school had failed them and their child. Parents made a choice to send their child to a special school because of the appropriateness of teaching support and acceptance amongst teachers in relation to their child's difficulties. These factors they felt were missing in mainstream settings.

Singal et al. (2011) also noted that when real choice did exist in terms of special and mainstream settings, parents even of low income families in rural Dewas, choose to send their child with disabilities to the special school. However, an interesting point of contrast is evident in the rationale underpinning parental choice of special school in the Vaidya and Singal *et. al.*, studies. In Vaidya's study the predominantly middle class parents expressed unhappiness that special schools did not focus enough on academics and were more aligned towards functional and prevocational activities, however these functional and pre-vocational activities were the one's which were immensely valued by the poor parents in Dewas (Singal et al., 2011), especially in the early years of a child's development. These contrasting perspectives might be reflective of the kind of health care facilities and other support that are more easily accessible to middle class families in urban India, in comparison to poor families living in rural settings. Consequently, it can be postulated that the nature of the educational good provided by a school, alongside parents' socio-cultural context,

plays an important role in decision making. However, in the absence of any such viable alternatives for parents in Chamrajnagar resulted in them not exiting the system.

Secondly, an additional factor which seemed to play a very prominent role in parental decision making is the social and political costs of exit that have been talked about in Hirschman model and expended upon by Fennell (2010). It is interesting to note that in many cases, parents regarded enrolment as an entitlement in itself. This was largely because once the child was enrolled they were able to access a range of state sanctioned benefits- such as school uniforms, mid-day meal and a disability allowance. While there is absence of any rigorous research on how such entitlements have impacted on enrolments levels for children with disabilities, it is useful to draw on the research findings of Jayaraman & Simroth (2011). Using a panel data set of almost 500,000 schools observed annually from 2002 to 2004 the researchers noted that midday meals resulted in substantial increase in primary school enrolments, even though there was no impact on increase in learning. This was also seen as a contributing factor for children with disabilities in this study, as noted in the findings.

Srivastava (2006) in her work on school choice noted that a parent's motivation for educating one child within the family may differ from the motivation for educating another as this is largely influenced by the child's entitlement to state benefits and her/his future wage earning prospects. The findings of the present study suggest that in the case of children with disabilities both short and long term benefits associated with schooling were important factors in influencing parents. However it is also useful to postulate how sending a child with disabilities enabled indirect benefits for families, such as releasing the mother or another member from caring responsibilities. While this issue was not discussed in this study, it can be regarded as a strong motivator for parents to send their child with disabilities to school.

While parents continued to remain in the system, either with their child attending school or simply being enrolled, they did not use 'voice' to improve the quality of provision through political action. What strongly emerges in the findings is an absence of voice, wherein even though parents had a grievance this was not

expressed and no attempt was made to change the status quo. This was not due to lack of parental interest as Harma (2011) notes, parents even those from poor families, desire quality schooling. However, what is more likely to be the case is that parents themselves were acutely aware of their own positions in the social hierarchy, and lack social power to complain. This was clearly an issue for the mothers of children with disabilities in Chamrajnagar, who felt that their complaints would make no difference, rather in majority of the cases, voicing their concerns was not even considered an option. Fennell and Malik (2014) note that parents of non-disabled children in their study did not use voice due to lack of adequate knowledge of systems, and due to fear of retribution towards their child. Findings emerging from this study highlighted that while lack of knowledge was indeed an important factor, more significant was the perception of their own low status, further corroborated by their status of being parents of a child with disability.

Parents of children with disabilities regarded mainstream schools as disempowered spaces of inaction. There was no evidence of collective voice or action for improving the schooling experience of their child with disabilities. This is interesting given that the community did have Self Help Groups (SHGs) for young people with disabilities and parents of children with disabilities. However, the focus of these SHGs was more on raising funds for self-employment etc., and not on improving the educational experience of the children with disabilities attending school.

Thus, in addition to being poor and not well educated, being a parent of a child with disabilities seemed to add another layer of complexity in relation to how parents navigated the schooling landscape. Here one can draw on the findings from a few recent studies which have examined issues of parental choice and participation in relation to children with disabilities in middle and upper-middle class urban families who send their children to (high and sometimes very high fee paying) private schools.

Research undertaken by Das & Kattumuri (2011), Hooja, (2009) and Singal (2008) clearly notes how parents from these social groupings also acknowledged that the educational needs of their children with disabilities were not being met in these schools. In order to address these concerns parents adopted various strategies,

such as employing a special educator to teach the child after school hours, or even negotiating with the school and employing a special educator to shadow and support the child whilst in school and paying for such support through personal finances. More recently, Johansson (2014) in her research with middle class families with a child with autism living in urban Kolkata (India) noted very similar findings. In her research study it was evident that even though highly educated (and economically well off) parents acted as strategic agents who actively negotiated a range of dilemmas and tensions to ascertain their child's admission and continuity in private school settings, their relationship with the school as highly precarious and fragile" (p:93). Based on her findings, Johansson rightly questions "why these agentic middle-class parents, who could be the impetus of greater change, seemed rather limited in how they sought the child's school to change..." (p: 93). Thus, the use of voice here did not fall into any of the four categories⁴ suggested by Fennell and Malik (2012), rather what was in operation was a use of voice for more strategic purposes, where the option to exit was not there but also the option to bring about improvement in the quality of teaching delivered through systemic change was not available. Thus, these parents sought to use voice strategically while being very careful about their boundaries, not tipping the existing status quo and not desiring for any long term change. Parents did not have real options and choices to either exit the system or indeed voice their apprehensions. The notion of loyalty in such a scenario was very weak and continuation in the mainstream government school was due to the costs of exit and the lack of real choices.

5. Conclusion

Current international and national debates on education and disability have focused on increasing access to schooling; however findings from this study highlight that in such grand narratives important details get overlooked in implementation. While there is growing awareness of the need for schools to include children with disabilities, they are not yet geared to respond effectively to increased diversity. This is not only in terms of the current lack of physical accommodations, such as disabled

⁴ Fennell and Maik (2012) identified four possible voices- V1- individual complaints; V2 parent teacher meetings; V3-participation in School Management Committees; and V4- no voice.

friendly toilets but also in terms of teachers' inability to respond to the learning needs of children with disabilities. Education has enormous benefits, both short and long term, as recognised by parents in this research. Their keenness to send their child to school was clearly evident; however policy discourse continues to overlook the potential of working with parents as partners. As we move forward, it is imperative that we involve parents of children with disabilities in discussions about education and schooling- the nature and type of support needed. Parental involvement is crucial for change. It is only when schools and families work together than children are likely to stay in school and learn.

Acknowledgement:

I would like to thank the participants in this study for their generous time and patience. The research was funded by CBM International and I would like to thank them for their support.

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