



Schooling children with disabilities: Parental perceptions and experiences



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ABSTRACT

Schooling of children with disabilities has become an important development agenda, as also emphasized in the SDGs. This paper examines how parents of children with disabilities from low income families living in a rural community in India understand and experience the schooling of their child with disabilities. Data were collected through semi-structured interviews with mothers. Findings suggest that mothers greatly valued schooling both for its short and long term benefits; however they were acutely aware of the poor quality of schooling on offer. While parents emerged as strong enablers in supporting their child's schooling they were seemingly devoid of agency to enable their child with disabilities to access meaningful education.

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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 et al., 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 and 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 and 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

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Table 1
Overview of the sample children.

Name	Gender	Type of disability ⁴	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

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 and 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. Its '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).

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

⁴ Descriptors used are those provided in the field by mothers or teachers.

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