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PARENTS AND EDUCATORS OF A SPECIAL SCHOOL: THEIR PERSPECTIVES ON INCLUSIVE EDUCATION FOR PEOPLE WITH DOWN SYNDROME IN NAVI MUMBAI, INDIA

Jennifer Peterson
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PARENTS AND EDUCATORS OF A SPECIAL SCHOOL:

THEIR PERSPECTIVES ON
INCLUSIVE EDUCATION FOR
PEOPLE WITH DOWN SYNDROME
IN NAVI MUMBAI, INDIA

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SIT Study Abroad

India: Public Health, Gender, and Community Action

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1. Abstract

The topic of this study is centered on students with intellectual disabilities; in particular, its focus is on those individuals who have Down syndrome. One of the primary debates revolving around the treatment of people with intellectual disabilities is whether or not they should be educated in separate, special schools. According to the current academic consensus, and the government of India's new policies, inclusion within mainstream schools is the most beneficial practice for students with Down syndrome to grow socially and academically; however, the perspectives of parents and staff is often left out of the equation when determining the impact of such schemes on local communities. Thus, this paper will utilize these perspectives through a three week period of interviews and observations at a special school located in Navi Mumbai, India. A total of eleven parents and five staff members were consulted. The results point toward aspects of special education that make it necessary in India's current climate of integration and less specialization. Simultaneously, the findings also indicate how inclusive education needs to change in order to become beneficial for families, who are so often left out of the discussion.

2. Acknowledgements

There have been several people who have aided in the completion process of this study. The author would like to acknowledge and thank, first of all, the SIT staff in New Delhi. To Azim Khan and Abid Siraj for their continued expertise in the field of public health, in addition to their guidance in the researching phases that made creating this paper possible. To Gautam Merh for helping with travel arrangements and logistical assistance. To Archana Merh and Bhavna Singh for their constant support and wisdom throughout the author's time in India. The entire SIT team was crucial to the completion of this project. Further thanks are due to Chris Kurian for her direction and instruction during crucial junctures of this undertaking.

The author would also like to acknowledge the counsel and hospitality provided by the special school and NGO in Navi Mumbai used in the study. Each individual at the facility was welcoming and ready to engage in helpful conversation. Specifically, the author would like to give thanks to the two founders and the vocational schools manager, who were instrumental in enabling contacts with parents, organizing interviews, and sharing information about their line of work and functioning of the school. The author is grateful to the parents and staff members who spared their valuable time for the interviews. Without their participation, this study would not have been possible.

3. Abbreviations & Acronyms

- * DRG: Disability Rights Group(s)
- * DRM: Disability Rights Movement
- * GoI: Government of India
- * IDEA: the Individuals with Disabilities Education Act, 1975, United States
- * IEP: Individualized Education Program
- * PWD: People with disabilities
- * PWID: People with intellectual disabilities
- * RTE: Right of Children to Free and Compulsory Education Act, 2009
- * SBP: Swami Brahmanand Pratishtan
- * UNCRD: United Nations' Convention on the Rights of Persons with Disabilities
- * WHO: World Health Organization

4. Introduction

Research Question in Context

The global movement for disability rights experienced a peak in the 1970s and 80s (Mehrotra, 65, 2011). This new phenomena resurrected the belief that individuals with disabilities, despite severity of conditions, were not to be divided into special schools. Rather, it was rationalized that all students should be taught together regardless of disability. One example of such transitions taking place is during 1975 in the United States. 1975 was also the years that the Education for All Handicapped Children's Act - now referred to as the Individuals with Disabilities Education Act (IDEA) - established a national mandate for mainstreaming special education (Murdick et al. 311, 2004).

The same discussions on education for people with disabilities (PWD) began to appear in India's policies and Acts only during the 1990s in the form of "integration" (Bhattacharya 18, 2010). Still, after years of advocacy and evolving laws, special schools remain prominent within the urban communities. Less than 1% of children with disabilities are educated in inclusive schools (Das and Shah 574, 2014). Majority of the parents are sending their children to special schools despite the push for change. Thus, the purpose of this study is to look at the framework of a special school in Mumbai, an urban setting, and analyze the perspectives of parents and staff in order to better understand their beliefs and experiences. Only by comprehending such information is it possible to create public health interventions and legislations that best fit the needs of people with intellectual disabilities in India.

The research question being posed is the following:

How do the perspectives of parents in special schools affect the debate on inclusive education for students with Down syndrome?

In order to make the results more meaningful, the context of the paper will analyze the question from the position of one intellectual disability type, Down syndrome. This consideration was made to keep in mind that the definition of disability is too broad, and for a study with limited time as this one, there is a need to keep a specific focus. The struggles faced by an individual with Down syndrome will be entirely unique from that of an individual with a different intellectual disability. Furthermore, under this inquiry, additional questions to explore are:

- ***How might mainstream schools be conducting themselves that makes inclusion difficult?***
- ***How are the educational and developmental needs of people with Down syndrome being met in special schools? What are the benefits of special schools?***
- ***Why and how should India move toward inclusion?***

What is Down syndrome?

Down syndrome in biological terms is defined as a “genetic condition that is usually caused by an extra copy of the twenty-first chromosome,” and can therefore also be called Trisomy 21 (Ohio Department of Health 1, 2015). Down syndrome is one of many forms of an intellectual disability. Among this diversity, Down syndrome itself has several manifestations in its conditioning and appearances. There are health complications which may arise as a result of this disability, such as thyroid issues or heavier-set bodies (Ohio Department of Health 1, 2015).

Adolescents with Down syndrome can experience learning difficulties that lead to developmental delays. These delays may also be the result of certain health conditions, as mentioned. For example, a hearing impairment in a child with Down syndrome will affect the developmental processes regarding speech, language, and communication (Layton 2, 2004).

Nonetheless, while these factors could impact the educational and developmental outcome of a child with Down syndrome, they are not meant to be used in a stereotypical manner. Several myths about what it means to have Down syndrome should be avoided. For instance, people with Down syndrome can develop early reading skills. They are capable of comprehending both spoken and written words. They are entirely able of learning alongside their peers who may not have Down syndrome (Cologon 1, 2013). Besides physical and intellectual dimensions, the disability has other social and economic facets which influences the quality of education received, and by consequence, the opportunity for a proper education in a mainstream school.

Defining Disability in India, The United States, and the WHO

The definition of disability has many extensions to its meaning, as it is interpreted independently across international organizations and countries. In India, the definition was first notably stipulated under the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995. This legislation was a landmark in the rights of people with disabilities and charged the government with ensuring that all children with disabilities had access to “free and appropriate” education until they were 18 years old (Das, Ajay; Shah, Rina 570, 2014). The conditions which were interpreted as a disability, as appointed in section 20 of

the Act, is: “(i) blindness (ii) low vision (iii) leprosy-cured, (iv) hearing impairment, (v) locomotor disability, (vi) mental retardation, and (vii) mental illness” (V., Sudesh 224, 2008). Only seven disorders were included in the Act, which created limitations for many PWD, including social, economic, and political exclusion. After years of championing for change by Disability Rights Groups (DRG), this definition was upgraded in the Rights of Persons with Disabilities Bill, 2016. The number of afflictions recognized by the government were increased from seven to twenty-one. They are listed as the following: Blindness, Low-vision, Leprosy Cured persons, Hearing Impairment (deaf and hard of hearing), Locomotor Disability, Dwarfism, Intellectual Disability, Mental Illness, Autism Spectrum Disorder, Cerebral Palsy, Muscular Dystrophy, Chronic Neurological conditions, Specific Learning Disabilities, Multiple Sclerosis, Speech and Language disability, Thalassemia, Hemophilia, Sickle Cell disease, Multiple Disabilities including deafblindness, Acid Attack victim, Parkinson's disease (Ministry of Social Justice and Empowerment 21, 2016).

In addition to these twenty-one disabilities, the Bill also stated that “Person with disability” (PWD) refers to, “A person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others” (Ministry of Law and Justice: Legislative Department 3, 2016). The acknowledgement of social factors as having the ability to create inequalities in the rights of PWD, and not assuming the disability itself establishes limitations, is a positive step forward in acknowledging economic and social injustices pressed upon this demographic. But the existence of a list, while lengthier than the last, could still provide restrictions as it is not a broad understanding of what it means to have a disability.

The World Health Organization (WHO) describes “disability” as “an umbrella term, covering impairments, activity limitations, and participation restrictions,” and an impairment is “a problem in body function or structure” (“Disability” 1, 2018). With this extensive approach to its meaning, disabilities are interpreted as more than just a health issue. In the Americans with Disabilities Act, 1990, United States citizens are covered if he or she satisfies any one of three possible descriptions, which are: “(i) has a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (2) has a record of such impairment; or (3) is regarded as having such an impairment” (V., Sudesh 225, 2008). A wide assortment of persons with disabilities are incorporated under this rendering and it is not being limited to those who have apparent or current impairments. In the light of interpretations such as these, it was understood when conducting this study that any definition of disability should recognize the unending forms of different abilities, as well as the barriers that exist for the people who possess them. Only then will proper and impactful interventions be created to reduce the effects of those impediments, or barriers, and improve quality of life.

Models of Disability

To best understand disability-targeted public health interventions - their motivations and overall effectiveness - the models of disability should be employed. These models are methods of approaching disability-related topics and issues. The views of each model can be applied to interventions in order to determine its goals and efficacy. The five categories are disclosed in Sudesh’s publication called “National and International Approaches to Defining Disability” and are as listed:

The Religious Model: This model's viewpoint is that disability is a retribution for actions committed in a previous life. It is viewed as a punishment inflicted upon an individual or family by God. Equally so, it could be viewed as an accepted blessing (221).

The Charity Model: This explanation looks upon PWD as dependent upon the society. It has an emotional appeal towards PWD as "helpless victims needing 'care and protection'" or "deserving pity." It has the effect of painting PWD out to be powerless individuals rather than empowering them" (221)

The Medical / Bio-Centric Model of Disability: This model states that disability results from an individual's "physical or mental limitations." The individual takes on sick role in which they need to be cured from (221).

The Social Model of Disability: This model believes that PWD are "not stereotyped as individuals who are unable to function, who deviate from the normal, or who naturally have a poor quality of life, but they are accepted as citizens who are prevented from realizing their personal and civil rights that are supposed to be common to all" (222). A downfall to this approach is that it fails to address environmental or social shortcomings, and compel PWD to depend upon state machineries for their participation in the social sphere (222-223).

The Disability Rights / Human Rights Model: Interventionists under this model "positions disability as an important dimension of human culture regards disability as a normal aspect and disabled are equally entitled to rights as others." It focuses on equality and accessibility, breaking down barriers, inclusion, and private and public freedom (223).

The concept of special schools historically falls under the charity model. The disability rights model, however, is the desired outcome when approaching disability in any country and needs to be advocated for more openly. Special education can be developed in a way as to advocate for inclusive policies while still offering the specialized aid that these schools so often provide and mainstream schools have yet to include.

Inclusive Education

According to the Rights of Persons with Disabilities Act of 2016, “inclusive education” in the Indian setting refers to “a system of education wherein students with and without disability learn together and the system of teaching and learning is suitably adapted to meet the learning needs of different types of students” (Ministry of Law and Justice: Legislative Department 3, 2016). In Chapter Three of the Bill, the Government of India (GoI) said it would endeavor that all educational institutions funded or recognised by them should provide inclusive education. Non discriminative opportunities in sports, accessible facilities, early intervention, and transportation, among many other provisions, are all precautions made to ensure the success of this national undertaking.

Inclusive education is seen as instrumental in creating a non-segregated environment for students with disabilities. These individuals are often kept excluded from society and unmentioned in most contexts, whether it be in the academic or social realms. They are described as being “hidden away in shame or embarrassment” (Chittooran et al 313, 2004). Particularly in the Indian context, the responsibility of caring for children with disabilities is left to family members who lack physical or emotional resources to do the task (Chittooran et al 313, 2004). With global stigmatic resolutions such as these, the argument put forward by scholars is that inclusive education can dispense sensitization toward these children and allow equality in all sectors of a community, not excluding access to employment.

As it relates to academics and Down syndrome, inclusion policies in schools has shown through research to nourish optimal learning environments for children with Down syndrome

(Hughes 1, 2006). Mainstream schools have proven, especially, to be beneficial in developing language skills over time. This statistic is particularly important because speech and language is crucial for cognitive and social development (Hughes 1, 2006), which could otherwise be difficult for parents to address for a child with learning difficulties. However, these statistics are based abroad and not in the country of question, India.

The Disability Rights Movement (DRM), as well as laws on inclusive education, have been largely introduced in India through international organizations (Addlakha and Mandal 62, 2009). The latest 2016 Act for PWD and its terms of inclusive education was in response to the 2008 United Nations' Convention on the Rights of Persons with Disabilities (UNCRPD). As a signatory of the international legislation, India created the Act to fulfill its obligations to the UNCRPD. Other global conventions, such as the Declaration of the Full Participation and Equality of People with Disabilities in the Asia Pacific Region (2000), also played a role in the introduction of inclusive education in India. Therefore, even though this approach has proven to be favorable, there are limitations in place at the grassroots that make international ideals practically challenging to follow through when applied to local Indian communities.

Intellectual Disabilities and Education in India

The origin of special education in India began with Christian missionaries in the 1880s. This pattern introduced the charity model of disability and focused mostly on the visual, hearing, and cognitively impaired (Das and Shah 561, 2014). However, once it achieved independence from Great Britain 1947, the GoI began gradually moving toward inclusive education. Under this mission, the 2009 Right of Children to Free and Compulsory Education Act (RTE) proposed free

and compulsory education to all children between six and fourteen years of age. The Act also made it regulation that all schools, both public and private, must reserve 25 percent of classroom seats for children with “disadvantaged sections.”

Intellectual disabilities, including Down syndrome, are often receiving even less assistance than other disabilities and are subject of much discrimination. The Disability Index, a tool that measures the deprivation suffered by PWD, is highest for individuals with intellectual disabilities (Mishra and Gupta 4026, 2006). This distress most noticeably applies in the sphere of scholastics. For example, illiteracy is highest among persons with an intellectual disability (PWID), a problem that reflects inadequate educational facilities for these individuals (Mishra and Gupta 4029, 2006). To combat such statistics, the GoI has incorporated provisions to allow early intervention and inclusion of people with intellectual disabilities into mainstream schools. In 2012, the GoI even allowed students with autism, cerebral palsy, intellectual impairment, and multiple disabilities to be able to choose a “home-schooling” option (Das and Shah 573, 2014). This decision, however, is not meant to be undertaken as an excuse for not educating one’s child. Instead, it allows those who cannot access schooling to opt for ways of educating at home, if jobs and other resources make it convenient.

5. Methodology

Overview

This study is the culmination of three weeks of observations and interviews in Mumbai, India. The location was centered around a special school in Navi Mumbai. With the help of the facilities available there, eleven parents of people with Down syndrome were interviewed in a semi-structured manner. The children were a range of ages from six to twenty-eight, plus two who were in their early thirties. However, the data was still considered relevant due to the insight that an elder population can provide in the ongoing changes of this policy, as well as an indicator for the outcomes of their educational history. These participants were able to better give a comprehensive opinion based on their child's entire academic career. Likewise, the NGO under question continues education for elder populations under their vocational programs, which teach skills for employment and implies that discussions on education do not end with adolescence.

Five of the eleven children whose parents were interviewed were females. The remaining six were male students. The parents themselves were a relative mix of five mothers and four dads, along with two who were sisters but frequently acted in a caregiver role. To respect identities, these individuals will be anonymously called "Parent" followed by a number in sequence up until 11 (i.e. Parent 1, Parent 2, Parent 3, etc.). The distribution of this information, for purposes of clarity, is addressed in the following table.

Figure 1.1: Age-Sex Distribution of Participants

Participant	Sex of Participant	Sex of Child	Age of Child
Parent 1	Female	Male	6 years
Parent 2	Male	Male	8 years
Parent 3	Female	Male	23 years
Parent 4	Female	Male	23 years
Parent 5	Female	Female	19 years
Parent 6	Male	Male	34 years
Parent 7	Male	Female	28 years
Parent 8	Female	Female	33 years
Parent 9	Male	Male	22 years
Parent 10	Female	Female	18 years
Parent 11	Female	Female	22 years

Some interviews were conducted in English, while a few were communicated through Hindi and required an interpreter's presence. Verbal informed consent of the participants was obtained. The results of the recorded sessions were then transcribed to allow for analysis of data collected. For purposes of ethics, no individual under the age of 18 was interviewed. Likewise, no individual with any intellectual disability was interviewed. In their places, parents and caregivers were instead asked questions. Some of the interviews were undertaken in the participant's homes, but a majority occurred in the school facilities itself, with only the translator present.

Along with the parents, five additional staff members were also interviewed to get a holistic understanding of special schools in the Indian context. Nonetheless, it is important to note that the data collected showcases results from one special school in all of India and is in no

way taken in a manner to stereotype all schools of this nature. Rather, it is a summation of applying a broad concept to a single, local context and analyze its effectiveness.

During the three week period, the school was mostly non functional due to its month-long and yearly recess, hence, classroom activities could not be observed; However, the staff was present and undergoing teacher training and engaged in annual planning for the impending academic session. The meetings and discussions that took place on these topics were observed, allowing for an understanding of how a special school may formulate curriculum, how special educators are trained, and therefore, how inclusive schools could also train its teachers.

Introduction to NGO and Location

The study was located, as indicated, in Mumbai, India. In particular, the central ground of the project took place in Navi Mumbai outside of the main Bombay area. The NGO there, called Swami Brahmanand Pratishthan (SBP), is a special school for multiple disabilities and was founded in 1990 (Founder, Interview). The founders of the school and a member of the teaching staff provided points of collaboration to contact parents of children with Down syndrome and conduct interviews. Along with these tools of guidance, the NGO proved to be a helpful source of information and contact in the community. Mumbai was the chosen location because the city has a history of NGOs that have addressed the issue of disability. Moreover, an urban environment will allow for a plethora of opportunities to observe the organized institutional effects of special education in the locations where it first began, the cities.

The NGO Swami Brahmanand Pratishthan provides a holistic, community-centric method within their schools for special needs children. It contains a vocational school for adults

to be trained in skills which is designed to help them enter into the job market. SBP has also built a secondary school in a rural location outside of Mumbai and is currently working on a hostel for students who might not otherwise have access to homes and education. Utilizing their years of expertise on this topic will allow for further understanding of the complexity of this issue. They will highlight an Indian perspective to comprehend policy questions which are so often discussed on the international level.

Brief Statement of Findings

The findings added with current knowledge about education of PWD indicate that, while inclusive education should be the goal for students with Down syndrome, there are changes which first need to occur in order to make it effective. As of now, due to a lack of efficient public institutions, special schools are a better option for people with Down syndrome in India. Mainstream facilities, according to the experiences of parents and staff at a special school, are lacking in their abilities to provide an inclusive educational environment where children with Down syndrome can learn alongside their peers. There exists a lack of proper support staff, sensitization, and holistic approach to learning. In order for inclusive education to move forward successfully, this study will showcase advantageous traits which can be gleaned from a special school in Navi Mumbai based on the perspectives and needs of the parents.

6. Results

Switching from Mainstream School to Special School

A majority of the students (54%) had previously gone to a mainstream, or inclusive, school before being transferred by their parents to a special institution. The six out of eleven parents who chose to do so were questioned on their reasoning behind the decision. The answers given were then split into five categories, which are: education, social pressure and problems, lack of progress, resources, or health and independence. Out of all six participants, 12 replies were given for basis of switching schools. These 12 responses were divided into the five groupings presented above and calculated into their corresponding percentages to create a pie chart for visual (Figure 2.1).

The “education” classification refers to displeasure with the syllabi available in mainstream schools. Their child may have had difficulty coping with the pace, material, or regimented schedules of the academics. “Social pressures and problems” were often in suggestion to other parents in the mainstream school. Some of the other parents felt that children with Down syndrome should not be educated in a mainstream school and therefore applied coercive strategies in order to encourage their leaving. Parent 4 shared her experience on this, saying, “The parents were complaining [. . .], ‘He is also a special child, so you should not come to such school.’” Concurrently, the pressure could also be from classroom peers who did not treat the child kindly. “Lack of progress” is directed toward the dissatisfied parents had with the the pace of improvements being made in the mainstream school, either developmentally, academically, socially, or otherwise. “Resources” were often in reference to the lack of trained

teachers or necessary facilities in the mainstream school. “Health and independence” applies to parents who were using education as a means to satisfy a desired growth in independence of their child’s everyday activities, or chose the special school out of a medical recommendation.

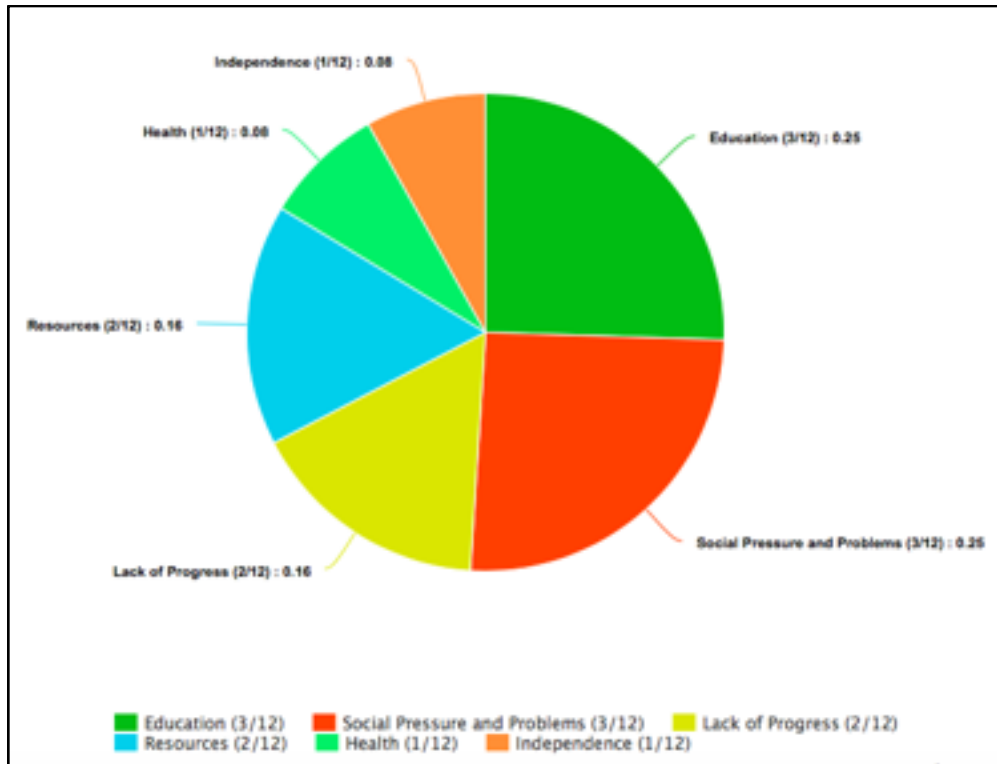


Figure 2.1: Pie Chart; Reasons for Switching from Mainstream School to a special school. 6 out of 11 parents switched. 3 out of the 6 referred to education and social pressures as being a factor, while only 2 indicated resources and progress, and only 1 for both health and independence.

The most cited motivators for switching to a special school were related to the rigorous educational syllabi in the mainstream institution, as well as social issues and pressures that were arising. Three out of the six parents who had changed schools specified these two factors as being instigators for doing so (Figure 2.1). Other influencers, such as lack of both progress and resources in the mainstream school, also led parents toward special schools, but on a slightly

lesser scale with only constituting two out of 12 responses. A desire for independence, in addition to health complications, were the lowest indicators with only one reply. In one scenario, the teacher at the mainstream school had recommended for the student to switch into a special school, going against a change for inclusive policy.

Furthermore, alternative issues related to inclusive education came up during discussions with all eleven parents, including the following: regimented schedules, lack of sensitization, learning material without emphasizing comprehension of the material, large number of students, and lack of life skills education. These elements were often added under the five broad classifications mentioned above and were discussed under the less formal portions of the semi-structured interviews.

Having the knowledge to know why parents decided to make the switch is influential in understanding what needs to be addressed in this education policy change to make it effective. What are parents experiencing that government officials or public health interventionists are not addressing? Why are special schools still sought after in local Indian communities despite the international and national agenda for inclusive education? How could mainstream schools change in order to include these children in the manner that is most beneficial for families and the student? These parents provide important perspectives, and the concluding results will allow such questions to be answered.

Improvements

When analyzing the effects that special schools have on children with Down syndrome, it is also essential to decipher why parents choose to not only enroll in the school, but also to stay.

Consequential improvements must take place in the student that culminate in parents believing special schools to be the best choice when given an option. What are the improvements that special schools are providing these students? What do these improvements say about the needs of the parents? Are they wanting to see a boost in educational knowledge or a boost in independence for daily activities? Is the goal employment or sustainability? Being able to distinguish these aspirations and needs will be able to put sense to much of the existing knowledge about inclusive education internationally, but more importantly, in India.

The parents were asked what kind of improvements they had witnessed in their son or daughter since his or her enrollment in the special school. Five out of eleven parents answered with issues related to speech and motor skills (Figure 2.2). The same number mentioned enhancements in comprehension and retention of their child. Other areas included eating properly and educational landmarks. “Comprehension” often infers that the student is now able to pay attention to instructions more effectively and for longer periods, whereas before the school, he or she might have been struggling to do so. As a consequence, the student can now perform activities that were once perhaps confusing. “Motor skills” typically concerns the ability to perform certain actions, such as holding a pencil and developing grip. To do these operations is crucial for any individual, but can particularly be difficult for individuals with Down syndrome in their early stages of life (Occupational Therapist, Interview). The least of all mentioned were advancements in the child’s behaviors, which includes increases in confidence as well. Overall, it is interesting to note that the developmental progresses - speech, motor, and cognitive skills - were discussed at a higher rate than the educational improvements.

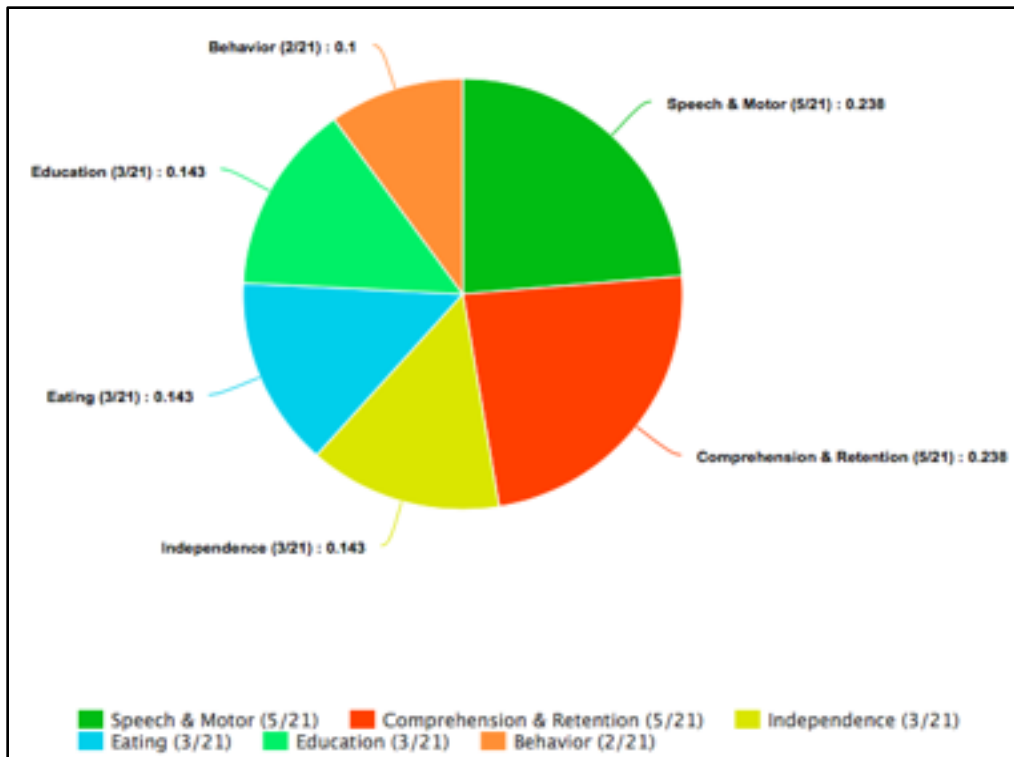


Figure 2.2: Pie Chart; *Eleven parents responses indicating the improvements they witnessed in their children after enrollment in a special school. 5 parents answered with speech and motor skills, as well as comprehension and retention. 3 parents answered with independence, eating, and education. And only 2 parents mentioned behavioral improvements in their son or daughter.*

Physical activity was pointed out by several parents as a necessary component to help bring forth improvements. In the special school physical education mentioned as the one of the most valuable features. Likewise, occupational therapy was cited as having the same unmistakably beneficial effects on the developmental and cognitive capabilities of the students. Parent 4 gave her experience, saying, “So all those children were much developed than him, so I was wondering what it is that he cannot do, when I underwent therapy. After four weeks of physiotherapy and all, there was a lot of changes in him - movement of his body, crawling” (Parent 4, Interview). In a special school, occupational therapy sessions are government appointed; but in mainstream schools, it is a position which is rare to come upon.

Community and Family Support

The respondents were also questioned on whether or not they felt the impact of community and family support. Almost every individual declared there was family support. Only one mother, Parent 1, verbalized that her family was inquiring why she kept the child and showed fear of having another baby with Down syndrome. Both of these statements were indications that family support was low. This participant was also of a lesser income status. On the subject of community support, four out of eleven people noted a lack in prominent support from the society. The explanations given for this answer demonstrated various experiences of going to a public place and receiving unwanted gestures toward their child, verbal or otherwise. Parent 3 said, “People stare at him. If you go outside in a mall or somewhere, they literally keep staring at him, and small children get scared maybe. Even the elders, they don’t understand [that] we are feeling bad about it, but then they don’t stop staring.”

Through similar stories to this one, participants who said they did not have community support were expressing the existence of stigma toward PWID. Out of these four, three of the parents were mothers. In almost every scenario, regardless of their response, neighbors and close friends were seen as supportive. It was specified as “the outside community” which was not benevolent. For example, Parent 11 stated, “No, [there is not community support]. I’m very fortunate that in the apartment where we are staying, people are very understanding. Otherwise, there have been incidents. I am very shocked at how people come up to me and will ask, ‘Why don’t you go to the doctor?’” The communities that are closely associated with the student, who have more sensitized firsthand experience with him or her, are generally depicted as more

approving and supportive. On the topic of stigma, Parent 11 also expressed, “Here, if you tell someone [my daughter] has a mental problem, it is a taboo kind of a thing.” She voiced a desire for people to understand that her daughter is not aggressive and there is nothing to be apprehensive about.

Parent 4 showed acknowledgement toward the fact that people will even scoff at her desire to send her son with Down syndrome to a special school. The mother said, “Even in malls and places [. . .] there are parents who feel that he should go to a normal school. They feel that the children are in special schools because you don’t accept your child. [They say], ‘Unless we accept them universally, we cannot actually think of sending them to a special school.’ I tell them, these are the problems [I] undergo [in a mainstream school]. Cause there they will tease him. And [in the special school], he will enjoy his life, and we will enjoy seeing him.” Even when the participants were aware of the push for inclusive education and faced stigma because of it, they still believed in, and preferred, the framework of a special school.

Gender

Women were more likely to disclose that the biggest educational and developmental challenges they were confronted with were related to personal matters. Essentially, women, more often than men, felt they were a negative factor in raising their child correctly. At the same time, this statistic also reveals that women had greater difficulties with accepting their child as Down syndrome in the beginning; Whereas, the father figures were presented in the interviews as being more welcoming to the idea from the start. Participants who had daughters with Down syndrome

were also more inclined to say the most notable challenges, or improvements, that occurred in their development and education were related to the student's health.

The Outliers

As stated, Parent 2 divulged a peculiar situation regarding the educational route for his son's education. He had disclosed that, starting the following semester, half of the day was to be spent in a special school and the remaining half in an integrated school. His son is now only eight years old and will begin this routine in the coming year. When asked why he made this decision, the father said, "This is not my decision. This is a decision from the school and I do respect whatever the teachers are learning and whatever they are telling me. So we give more importance to that because they know to teach and how to progress of the child." The respondent's reply demonstrates a high level of trust in the educators at the special school.

This educational path is one only few could take in practicality, as it requires logistical time and resources to move his son from one location to another every day. Thus, there is financial standings to take into account. In the interview, the father also was forthcoming about his child's interest in both studies and participating in activities. His son, according to the father, is unwilling to leave school and would rather be interacting. It is also worth mentioning that the only participant to uphold this schedule is a boy child; alternately, he is the only participant to be of 8 years, which could indicate an ideal age to start such a program.

Another outlier evident in the results was, as discussed, one mother whose responses suggested she did not have support from her family for her child with Down syndrome. The most striking difference between this mother and the other parents interviewed is how she showed

more concern about her child's abilities to perform routine functionings which would enable him to grow in his personal, everyday needs. The need for developmental progress overshadowed that of educational desires. As an example, when asked under what circumstances this mother would consider enrolling her child in a mainstream school, Parent 1's response was, "[My] first major priority right now is that [my son] should be independent in his personal needs. When he is able to learn things, or retain them, that will all decide whether he would be able to join the mainstream or not. [. . .] The major stress right now is not academics. The major stress is personal development, personal needs" (Parent 1, Interview). Concurrently, Parent 2, whose child is only two years older but holds a higher socio-economic status, was the father who revealed the plans to enroll his son into a mainstream school for the following academic year. This parent also communicated that his son has a particular interest in academics, which was not seen as the first priority for Parent 1.

7. Discussion

Educational Needs of Children with Down syndrome

Learning from the responses by both the parents and staff, it is crucial to first identify the educational needs of children with Down syndrome in order to know what areas are obligatory to focus on moving forward. The most prominent academic-related delays for students with this disability tended to be in speech and language development (“Development and Learning,” 2018). Due to this trend, such features should be included in schools to accommodate for the educational needs of students with Down syndrome. Visual aids can also be one of the best resources for teaching these pupils (“Development and Learning,” 2018). Majority of mainstream schools, however, will be heavily speech or lecture-based, which can make it difficult for people with Down syndrome or other intellectual disabilities.

Many respondents turned to special schools to aid the developmental and cognitive progress of their child. The yearning by parents for growth in these areas can take attention away from - and thus, inhibit - a focus on educational improvements. This trend can negatively affect future employment and continue the cycle of social inclusion. By doing so, people with Down syndrome will continue to be viewed at large as “dependents,” going against the target laid out in the desired disability rights model. For special schools to become better advocates of both the disability rights model and the inclusive policies by the GoI, they must implement programs for early intervention and employment. These attributes are elements of education that SBP has already been tapping into. They wish to avoid making the main objectives of special education focused on developmental processes, which, as explained, could contribute to further exclusion.

Challenges of Inclusive Education in India

The respondents of the study showcased many challenges that could hinder a successful inclusive policy for children with Down syndrome in India. To start, there exists a consensual truth that teachers are not being trained in high enough volumes to make inclusion successful. As evident in the results, one of the parents had changed from a mainstream school to a special school at the recommendation of the mainstream teacher him/herself (Parent 6, Interview). This action is representative of a wider problem. According to prior research, teacher's in India do not have supportive attitudes for inclusive education (Das, Ajay; Shah, Rina 575, 2014).

Additionally, educators in mainstream schools do not confidently believe they are qualified to teach adolescents with intellectual disabilities. This viewpoint is not entirely uncalled for, as lack of proper training is a reality. It is unfair to ask someone to perform a task which they have not been adequately taught how to do (Das, Ajay; Shah, Rina 576, 2014). It is as equally unfair to the students, who deserve to be educated by confident, professional, and properly trained teachers.

Along with academic instruction, the teachers and peers are not guided in sensitization practices to eliminate the social pressures and stigmas which result in parents deciding to switch to a special school. As one of the co-founders of SBP said, "Awareness has to increase among children at the grassroot level" (Founder, Interview). Upon changing schools, many parents expressed gratitude toward the fact that their child will be educated alongside students who are similar. And while exposure to others who are similar is still important, it should not escalate to the point of total separation. If so, then the idea that having Down syndrome makes someone "other" or "not normal," and hence should not be included in the masses, will remain. This

concept is referred to as the “perception of otherness” which has “led to the belief that the differences imparted by the individual’s disability contribute more dissimilarity than actually exists” (Murdick, Shore, Gartin 310, 2004).

The size and regimented schedules in inclusive schools also causes much concern for parents of people with Down syndrome. On this concern, Parent 10 voiced, “In a mainstream school there is a huge number of students, and one teacher, though the teacher was giving full support, [my daughter] was not able to cope up well. So that’s how I decided to switch to a special school.” Education in such a framework can be difficult to follow for any child, regardless of having an intellectual disability. In this demanding setting, only children with mild Down syndrome are recommended to be educated in the mainstream schools, and would still require a shadow teacher (Occupational Therapist, Interview). The necessity of shadow teachers is another resource that can be difficult to provide with a low number of trained professionals in India. For this reason, it will also feed into the slow implementation of inclusion in India.

Furthermore, children in integrated schools are grouped based on age more often than capabilities. Especially with India’s new policy of not failing students under 9th grade under the RTE Act, the emphasis on comprehension is pushed aside. In SBP, the institution has implemented Individualized Education Programs (IEPs) for each student. A special educator at the school, claims, “Grouping is based on their IQ level, their educational level, age group, and capability. [. . .] In a mainstream school, a single training program is made. Here, for each student you have to make one. For whatever I want to teach, though the topic is one, I have to think of different ways to teach every student. Because each student’s level is different” (Special Educator, Interview). By creating programs like these, the focus is on the students’ learning

outcomes rather than age brackets or graduating onto the next level. As Parent 4 said, “At the normal school, [my son] was just writing and he just copied things which he was not learning. And when he came to this [special] school, slowly he started learning about small maths, like five minus three. Then his understanding level increased.” Inclusive schools need to begin to accommodate for teaching every individual child as they need to be taught in order to see the best results in children with Down syndrome.

What we can Learn from Special Schools

Including the IEPs that were already mentioned, there are positive aspects of special schools which can be taken into account when moving forward with the future policies on educating PWID. The first to address is the plethora of resources often available in special schools which is still widely unobtainable in mainstream institutions in India. The position of an occupational therapist is one of such resources. This occupation is provided by the government to special schools, along with a sports teacher (Founder, Interview). Therapies, as mentioned in the results, have proven to be beneficial for these students but are uncommon to find in mainstream schools. This factor forces parents to either look for private sources, to not seek therapies at all, or to choose the option of special education. Therefore, in order to encourage the growth of mainstream schools in inclusive policies, these positions are necessary.

The sports program at SBP puts a large emphasis on enrolling students in competitions, which gives them opportunities to explore the country or even compete in the Special Olympics. Sporting programs are entirely different in integrated schools. In these establishments, children with Down syndrome would often not be trained to compete due to a lack of facilities and

physical activities that suit their needs (Sports Educator, Interview). Having a reliable sports program in a school that caters to children with Down syndrome is often taken for granted, but can be undeniably advantageous. A government study on the 2011 Census and disability in India said, “The contribution of sports for its therapeutic and community spirit is undeniable. Persons with disabilities have right to access sports, recreation and cultural facilities. The Government has taken necessary steps to provide them opportunity for participation in various sports, recreation and cultural activities” (Ministry of Statistics and Programme Implementation Government of India 50, 2016). Though the GoI has recognized the importance of these programs, the implementation needs to be more widespread and as advantageous for students as the initiatives currently available in special schools.

Implementing degrees and universities for special educators in India has been in the works for years. The hope is to increase the number of mainstream schools that have experts in the field. However, most of those professionals now work in special schools. They have knowledge which is important to educating children with Down syndrome. One of the crucial points of understanding is the saturation point. This is described by an occupational therapist as the limitation point to the student’s physical capabilities, saying, “Identifying that point is very important. Because [. . .] If the child doesn’t understand what he has done or what is expected from him, then he starts to go into a shell. And coming out from the shell becomes very much difficult. So [parents] have to accept that [point]. And sometimes it becomes very difficult for parents” (Occupational Therapist, Interview). Along with recognizing the saturation point, the specialists know ways in which to improve motor skills that can help the student to develop valuable abilities such as handwriting. Parent 11 said, “She was never too keen to write. So I

think her motor skills were a little weak. But in this [special] school, they had this system, the way of teaching, you could use fingers. You know, finger paints, play with the sand and all that. So she got to be able to write.”

Together, these examples point toward a system of holistic learning. Students do not simply sit in a classroom, listen to someone speak, and hope the information sticks. For this particular special school, the content is much more rounded in what the students participate in. The range of activities spans from integrated academics, to physical education catered to every child’s needs, as well as crafts and music to stimulate creativity. The students learn important developmental and life skills, which are further deepened by a low teacher-to-student ratio, kept by the government at 1:8. This proportion provides for more communication time between parents and the teachers and for more intense focus on each individual student’s progress. Such characteristics are needed for children with Down syndrome in educational environments, but more than that, they are also useful features that could be included into every school for all students to benefit from.

Employment

An economic aspect should always be considered in any education and legislative policies for PWD. Economic inequality is felt by PWD across the globe and is signified by “equity, equality of outcome, equality of opportunity and life expectancy” (P. Singh 65, 2014). Employment is a substantial facet to human existence, not only as a means for earning a living, but also as a source of empowerment, change, and status in society (P. Singh 70, 2014). Due to limited opportunities to engage in mainstream social, political and economic activities, PWD are

thereby entitled to less empowerment and reduced status. Even in the context of this study, parents did not aspire for ultimate employment of their children, despite several of the respondents' children being well into their adult lives. This fact demonstrates an apparent exclusion of PWD from the job market. However, disability is not the only component to the loss of employment for people with Down syndrome. In India, gender and caste play a considerable role. Unemployment rates in developing countries for women with disabilities is close to 100 percent (P. Singh 75, 2014); and exclusion from the market is a trait which is also common among the Dalit population.

These social characteristics could explain why, for low income and Dalit families, life skills training is more important for their children with Down syndrome than academics, and why special schools are sought out. The government should work to provide such guidance for families who struggle to have the time or resources necessary for proper development of their differently abled child. When interviewed, some of these individuals did not even know what Down syndrome was, or if they did, having access to early intervention is a privilege that few can afford. Lack of early intervention can be damaging because it is pivotal for any child's development and has proven to help build necessary critical learning, social, and physical abilities (Sharma 1, 2018). The education system can often play into the role of economic dependency for PWD and need to encourage higher level learnings, as well as employment opportunities, in order to fully include PWD into society in the equal status to everyone else.

Moving Forward with Inclusive Education

Engaging with these results in the real world is about moving forward with inclusive education in a manner that is best suited for the local Indian context. Special schools like the one in this study have much to offer as far as aspects that can be beneficial for a student with Down syndrome, and may still find a place of importance for people with high support disabilities. However, in order to make inclusive education in India meet its true potential, there is a need to distinguish between “integration” and “inclusion.” As explored in an article by Tanmoy Bhattacharya called “Re-examining Issue of Inclusion in Education,” the term “integration,” which was used by the GoI during the 1990s and first half of the 21st century, lies just outside of inclusion (Bhattacharya 18, 2010). Integration has the same concept regarding assimilation of students with disabilities into mainstream education. The difference is, under integration, the emphasis on the student fitting into the school by integrating him or herself. This is opposite to inclusion, which entails the need for the school system to change in order to better include PWD.

While these are the supposed issues of the 1990s and early 2000s, the conclusions of the study show there still exists the ideas of integration in India. The mainstream schools are slow to change, teachers are largely untrained, and the use of “shadow teachers” are still mentioned as vital for a child with Down syndrome to be enrolled in a mainstream school (Occupational Therapist, Interview). PWD in inclusive schools are subjected to being educated outside of the main classroom, confirming the segregation that inclusion policies are supposed to avoid. This was the case with Parent 11, who said her daughter was taught alongside students with disabilities and did not interact with other peers in the school (Parent 11, Interview). PWD are still being expected to integrate, while little efforts are being made for inclusion.

This larger issue needs to be addressed, but with it, there is a call for more resources put toward mainstream schools to make them inclusive for all. There should be specialists, support staff, sensitization, and assessment of individuals on a personalized basis. A member of the staff at SBP phrased it best by saying, “[Assessing students] is most important. Until they understand what the child can do, and the particular interest for that child, they cannot make a program” (Vocational Instructor, Interview). Moreover, staff members with disabilities should be hired. This characteristic is another contribution that had been observed during the study at SBP. The NGO places past students, who are familiar with the community and the people, into jobs in the school. When these establishments hire staff with disabilities, they will be battling the issue of stigma by creating sensitization while additionally providing jobs for PWD and including them into the job sector.

Certain facilities that need to be encompassed by mainstream schools, as mentioned, are physical education programs which cater to adolescents with Down syndrome in a meaningful way; thereby allowing them to partake in the compulsory physical activity that is recommended for people with Down syndrome. The buildings must be accessible for any health condition associated with Down syndrome, but also every other disability. All schools should aim for employment of their students and not just the students without a disability. PWD should not be separated from their peers and classrooms should incorporate activities that are more visually-based. As a whole, education could profit from becoming more holistic to better suit the needs of every student with different learning abilities and needs.

8. Conclusion

Summary of Findings

Overall, the study has aided in the existing knowledge about inclusive education in India. This policy, while not entirely new to the country, is still in its infancy with implementation. The current information about it and its potential gains is created mostly by international organizations and outside entities. However, the consensus that inclusive education produces positive outcomes for students with Down syndrome is correct. Down syndrome is an intellectual disability, but it does not inhibit an individual from being successful in a mainstream school when these individuals educational needs are properly being addressed. Establishing programs that cater toward visual learners and are more holistic in nature are just two ways in which mainstream schools could change in order to be inclusive.

There are, however, other factors which need to be considered when moving forward with the institution of inclusive education in order to make it functional, which can partly be gleaned from the perspectives of parents and staff at an NGO that works with these students. Such components can be found within parents rationale for changing from a mainstream school to a special school and the improvements that are considered satisfying enough to make them stay. Using this approach, the study has found that parents are dissatisfied with the progress being made in mainstream schools, due to various reasons such as class size or lack of facilities. They value the improvements in developmental abilities and daily life skills, as these elements can be difficult to address outside of the special school umbrella. The concept of accessibility needs to be addressed in inclusive policies. A person's socioeconomic status, as well as their

gender, could potentially play a role in what academic options are accessible and what aspects of education the parents deem more important. Community and family support, as analyzed in this paper, can also shine light on the existence of stigmas and the attitudes that can influence whether or not the public will be inclined to welcome inclusive policies.

Taking into account the results of these studies and considerations, there are discussions which need to be had about the benefits of special education and how to move forward with incorporating it into every institution. Facilities and faculties need to be improved to produce the values of inclusion not integration. Schools should not be expecting students to change in order to fit the “norm.” Keeping this determinant at the forefront of legislative changes and public health interventions will instill a most effective inclusive policy that caters to the local Indian communities and the disability rights model approach.

Limitations

The intent behind this study is to contribute to the understanding of how to appropriately tackle the issues of economic, health, and social disparities linked to the education of people with Down syndrome. As a whole, this is a specific and pervasive problem within the field of public health that is often overlooked in academic literature, which made discovering secondary sources related to the topic at hand troublesome. The study was also limited in scope. Only 11 parents and staff members of one special school were interviewed and observed. This paper is not to generalize the reality of every special school, but it takes a specific look at a single institution. Moreover, while this project is certainly contributing to the existing knowledge on the subject of education and intellectual disabilities, it simultaneously suffers from time constraint of less than

one month. For this reason, the interviews collected were kept limited and the school studied was only focused on one. Truly impactful academia would call for longer investments in time and resources, as well as a more holistic look at various schooling institutions within India. It is worth noting that, due to the limitations on time and resources, the group studied was focused on Down syndrome and could benefit from being expanded. The debate on inclusive education affects people with all types of intellectual disabilities. Thus, in the end, the research conducted and the conclusions being made will be unable to have any significant impact on the field of public health.

9. Recommendations for Further Studies

In order to produce a better understanding of the issues raised in this study, the field of public health research could benefit from further analysis into the perspectives of individuals most affected by the inclusive policy in India. If educators are unwilling or unconfident in the change taking place, how could inclusive education possibly be effective? What do teachers in mainstream schools think about the change? What are the perspectives of parents in mainstream schools? How will their beliefs affect the outcome? This study could further be split into rural and urban areas, as each community will have different needs. Some localities may be more inclined toward inclusive policies and are already seeing results of the legislation, while other domains might not be as far along in the process. Some communities in India may require first a focus on access to education before the full effect of inclusion can even be discussed.

More research needs to be done on people with Down syndrome in India. There is a significant lack of academic material surrounding this demographic, which is excluding a large number of individuals from the discussions taking place. Additionally, this study only concerns people with Down syndrome, but the influence of inclusive education will be felt by children from backgrounds of all different abilities. Future studies on how they are most affected by education policies for PWD should be conducted to ensure the quality of outcome. More of these types of studies should also be conducted by PWD as to not exclude their expertise, perspectives, and firsthand experiences. Legislation and academia on the subject should concern PWD so as not to again exclude them from the decisions that are most affecting their livelihoods.

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11. Appendix

A. Questionnaire for Parents (11 parents)

- a. Family Background
 - i. What is your name?
 - ii. What is your child's name?
 - iii. How old is your child?
- b. Financial Background
 - i. Do you have a nuclear family or a joint family?
 - ii. How many children do you have?
- c. Health
 - i. How was your child diagnosed with Down syndrome?
 - ii. Other health-related factors?
 - iii. What challenges have you faced with their development?
 - iv. Have you noticed any emotional or behavioral changes in your child upon enrollment?
- d. Education
 - i. How did you come to know about this school?
 - ii. Has your child previously attended another special school or a mainstream school?
 - iii. Why did you decide to pursue special education?
 - iv. How is your child progressing in his or her education?
 - v. What challenges have you faced with their education?
 - vi. Under what circumstances would you, if at all, consider enrolling your child in a mainstream school?
- e. Capabilities and Activities
 - i. What is his/her daily schedule of activities?
 - ii. What are your child's strengths? (What are they good at?)
 - iii. What are his/her food preferences?
- f. Family and Community
 - i. How would you describe the perspectives of Down syndrome in India?
 - ii. How is the family support?
 - iii. How is the community support?
 - iv. How would you describe Down syndrome to somebody who does not know what it is?

B. Questionnaire for School Founder and Managing Trustee

- a. History
 - i. What is your educational background?
 - ii. How did this school come to open?
- b. Education
 - i. How is the classroom curriculum created?
 - ii. How are education and health related?
 - iii. Is the goal of special schools to help the child to learn life skills or to help them move into the workforce?
- c. Framework
 - i. Does the school receive any government funding?
 - ii. Outside of the government, how is the school funded?
 - iii. How does federal and state government regulations affect the school?
 - iv. How do you determine which students are able to be enrolled?
- d. Accessibility
 - i. How much does it cost for attendance?
 - ii. Are students ever turned away due to cost?
 - iii. How can special education become more accessible?
- e. Inclusive Education
 - i. In your experience, why are special schools important?
 - ii. How are special schools in India different from mainstream?
 - iii. What is your opinion of the Indian govt's push for inclusive education, which is largely influenced by international organizations?
- f. Down Syndrome
 - i. How does special education meet the developmental needs of students with Down syndrome?
 - ii. How many Down syndrome students are enrolled?

C. Questionnaire for Occupational Therapist

- a. What is your educational background?
- b. How would you describe the work of an occupational therapist?
- c. How do you interact with the students?
- d. How often do students receive occupational therapy?
- e. For how long have you been an occupational therapist?
- f. Why should people with Down syndrome receive occupational therapy?
- g. How does occupational therapy affect their developmental process?

- h. What is the availability of occupational therapy? In mainstream schools?
- i. What is your interaction with the parents?
- j. How do students react to, or receive, the therapy?
- k. What improvements have you noticed in a student prior to therapy?

D. Questionnaire for Sports Teacher

- a. What is your educational background?
- b. How long have you been a physical education teacher?
- c. How often do you interact with the students?
- d. What is the age range of students you work with?
- e. What type of activities do you plan for students with Down syndrome?
- f. How do the activities at a special school differ from a mainstream school?
- g. How does sports affect the health of people with Down syndrome?
- h. How willing are students to participate?
- i. What challenges do you face as a sports educator?
- j. What is the central focus of physical education?

E. Questionnaire for Special Educator

- a. What is your educational background?
- b. How long have you worked in the field?
- c. What does the daily school schedule look like?
- d. How are the students assessed upon enrollment?
- e. How are the students grouped in the classrooms?
- f. How does grouping based on these factors benefit the students?
- g. How is your job different from a teacher at a mainstream school?
- h. Under what circumstances would it be possible for students with Down syndrome to be in inclusive education?
- i. What challenges do you face being a special educator?
- j. What improvements have you seen in students with Down syndrome after enrollment?
- k. How do special schools help in the development in children with Down syndrome?

F. Questionnaire for Vocational Instructor

- a. What is your educational background?
- b. How long have you worked in the field?
- c. What does the daily schedule look like?

- d. What activities do students perform?
- e. How does vocational training impact students with Down syndrome?
- f. What challenges do you face as a vocational instructor?
- g. Are students eager to participate in the activities?
- h. What improvements have you witness in students with Down syndrome?
- i. What is the goal of vocational training?
- j. Are students employed after?