A Model Case: Specialized Group Home for Girls with Disabilities in India

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Abstract

The purpose of this intrinsic case study research was to better understand inclusion of girls with disabilities in Kolkata, India at a home and school for orphan girls. Non-institutionalized, inclusive, community-based care is rare in India, specifically for individuals with disabilities. This case study involved interviews (n = 32) with students, teachers and staff, observations, and document analysis. All transcripts were analyzed using structural and in vivo codes. A continuum of inclusion, designed to be culturally responsive, showcases different levels of integration. The end goal is true inclusion where individuals with disabilities are fully included in all aspects of their community such as education, employment and living. Once achieved, inclusion is embraced as the norm and can be a catalyst for growth. In this study, themes included: peer supports, creation of home, awareness of discrimination and staffing. Together, these embodied inclusive living at Shishur Sevay. Inclusive living serves as the foundation to build an inclusive education.

Keywords Case study · Special needs · Orphans · Disability · Inclusion · Non-Western

This case study illuminates the benefits of inclusive living for individuals with disabilities who are also true orphans—those who legally have no parental care (Belsey & Sherr, 2011; Chou & Browne, 2008)—in India. Related to terminology, there is an unfortunate systemic problem of orphans who may not truly be orphans receiving services and in some cases residing in orphanages that operate under the guise of serving true orphans (Bartholet, 2010). This phenomenon is seen in many underserved countries (Bartholet, 2010; Carpenter, 2015) and these "orphanages" often drive family break up as opposed to providing legitimate support for true orphans in need. A Save the Children report (Csaky, 2009) indicates that at least four out of five children living in institutional care have one or both parents alive and therefore are not actually true orphans. However, due to poverty and social exclusion, among other reasons, families often relinquish their children feeling like placing them into government run care is the only way to ensure they get access to education and enough food and other essentials. These children often end up in residential facilities because their parents are poor and cannot afford to feed them, Save the Children reports (Csaky, 2009).

In other cases, families are "coerced into giving up children in exchange for money by unscrupulous institutions and adoption agencies hoping to profit from either the residence or trafficking of children" (Csaky, 2009, p. 5). Some give them up because the children have disabilities, or belong to a marginalized ethnic or gender group, and these individuals are often categorized as true orphans because parental rights have been waived. Csaky further explains, "discrimination and cultural taboos also mean that in some countries a disproportionate number of girls, disabled children and children from minority ethnic groups are relinquished or abandoned into care institutions." (Csaky, 2009, p. vii). Children with disabilities in these orphanages are not inherently a bad thing, however, sometimes these children are used for fundraising efforts and exploited for personal gain by the leaders.

Generally, the options for orphans with disabilities in India fall under the following categories: institutionalized care, non-institutionalized care and unserved, meaning individuals not receiving any type of support services. The institutionalized care options for orphans with disabilities include government-run institutions, shelters, children's homes, observation homes or special homes that are licensed by law. The non-institutional

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care options in India for orphans with disabilities are scarce and have huge variability in terms of the level of care provided. There are non-governmental organization (NGO) run homes both segregated and inclusive that are licensed by law, and some that operate that are not licensed. There are also residential schools for persons with disabilities that are typically run by NGOs. Care options are few and far between due to, in part, the stigma surrounding disability and the lack of education on the topic.

Statistics

In India, there are no clear estimates nor consensus of the number of persons with disabilities. Deeply rooted social stigma results in exclusion and invisibility of individuals with disabilities, therefore even when explicitly asked, such as by a government survey, oftentimes individuals are reluctant to report or acknowledge disability. Additionally, Hiranandani and Sonpal (2010) explain that disagreement over definitions of disability also further compound the task of assessing prevalence rates of disability. The main sources of national disability statistics in India are the Census and surveys of the National Sample Survey Organization (NSSO). The 58th round of the National Sample Survey (NSS) reported there were 18.5 million persons with disabilities in 2002 (NSSO, 2003) compared with 21.9 million reported by the Census of 2001 (Registrar General of India, 2001) and 26.8 million reported by the Census of India (2011). Furthermore, CHILDLINE India Foundation (2016) reports that 35.3% of all people living with disabilities are children, or approximately 9.5 million whereas available information from the Census of India (2011) puts this number at 4.5%, or approximately 1.2 million.

The Census of 2011 sought to clarify definitions of disability, capture specific information on the type of disability expanded from five categories in 2001 to eight in 2011 and included information from individuals residing in three categories: normal, institutional and homeless (Saikia, Bora, Jasilionis & Shkolnikov, 2016). However, of the total households having disabled persons, about 99% households are normal households, 0.4% are institutional and 0.2% are houseless households (Government of India, Ministry of Home Affairs, 2015), which suggests a possible measurement and/or sampling issue, as this seems grossly underreported given the national statistics of institutional care and homelessness.

Departments and Policies Related to Disability

Combined, there is a systemic lack of systems of support for disability work in India. The topic of disability cuts across many sectors of government in variable degrees, but currently lacks a centralized or coordinated effort. Protections and oversight for children with disabilities mainly comes under the oversight of the Ministry of Social Justice & Empowerment, though several other ministry branches are also involved. This piecemeal approach is not sustainable; as such, it was stated in the 11th Five Year Plan that "The 'Disability Division' of the Ministry of Social Justice & Empowerment will be strengthened by converting it into a separate Department, so that it can liaise effectively with all the other concerned Ministries/Departments and fulfill its responsibilities towards the disabled" (Ministry of Social Justice and Empowerment, 2015). Given the specialized and cross cutting nature of disability as well as the influence of the UN Convention on the Rights of Person with Disabilities (UN CRPD), there is a call to action to address the inadequacy of existing implementation structure.

India ratified the UN CRPD in September 2007, and the convention subsequently came into force in May 2008 (Narayan, Narayan & Shikha, 2011). The UN CRPD highlights the importance of full and effective participation and inclusion in society and that individuals with disabilities should be inherently treated with dignity and individual autonomy. There are specific provisions related to living arrangements for persons with disabilities with an emphasis on inclusion and connectedness to one's community.

Related, though not solely about persons with disabilities, is the Juvenile Justice (Care and Protection of Children) Act of 2015 (JJ Act). Broadly, this act reinforces that there should be no discrimination against a child on any grounds including sex, caste, ethnicity, place of birth, disability and mandates equality of access, opportunity and treatment for all children. The act also doubles the penalties for any offense committed on children with disabilities. While there are other laws in India that specifically pertain to persons with disabilities, it is the combination of the CRPD and the JJ Act that relate most to inclusive living. Collectively, these pieces of legislation provide an important context for children with disabilities who are orphans in India.

Alternative Care Options

Another piece to this context is an understanding of the term, *continuum of care* (Better Care Network, 2015) that provides an overview of a range of alternative care options for children who have been separated from parental care. The continuum of care may also include short-term transitional residential care, small group homes, and—for older youth—supervised independent living, and/or inclusive living. Large-scale institutions caring for large numbers of children, including children with disabilities, are not recognized as a viable option in the continuum because they do not provide a safe environment that promotes the healthy development of

children (Better Care Network, 2015; Human Rights Watch, 2014). Building on this for persons with disabilities, Shishur Sevay is an example of a replicable non-institutionalized inclusive group home model of care for orphans with disabilities. Inclusive living in this context is a very understudied area, but has significant promise for individuals with disabilities, particularly orphans, in developing countries.

There are psychological benefits to inclusive living such as reduction in trauma and emotional maturity (Grunewald, 2003), benefits for adults with disabilities in the context of deinstitutionalization efforts (Chowdhury & Benson, 2011) and inclusive living for college students with disabilities (Hendrickson, Carson, Woods-Groves, Mendenhall & Scheidecker, 2013), but little other work in this intersectional space of youth and disability let alone orphans with disabilities. Specific to India, a Human Rights Watch report (2014) found that women and girls with disabilities are often forced into mental hospitals and institutions where they face unsanitary conditions, risk physical and sexual violence, and experience involuntary treatment, including electroshock therapy and pharmaceutical abuse.

Continuum of Inclusion

It is also possible that there is an additional continuum of inclusion that should serve as an overlay to the continuum of care. Inclusive living grew from the independent living movement within the disability community. In the early stages, the fundamental premises of independent living were that "Human beings, regardless of the nature, complexity and/or severity of impairment, are of equal worth, and have the right to participate in all areas of mainstream community life. Whatever the character and severity of an impairment, individuals should be empowered to make choices and exercise control in their everyday lives" (p. 529, Barnes & Mercer, 2005). However, activists rallied to push the community beyond too narrow of an interpretation of independent living and encouraged consideration of building relationships based on interdependence rather than independence. For some individuals with disabilities, independence is actually achieved through having a say over one's life and decisions, rather than, for example, completing all activities of daily living without assistance. Therefore, terminology evolved to refer to this as 'integrated' or 'inclusive' living (Barnes, 2003; Barnes & Mercer, 2005).

That said, a continuum of inclusion as seen in Fig. 1 may have differing levels of integration, and will also be subject to cultural definitions of disability. For example, in many parts of India, the term disability is used to describe individuals with visible disabilities, and there are often few organizations or homes that meet the needs of multiple disability groups. The end goal of this continuum is true inclusion, as outlined by the CRPD where individuals with disabilities are fully included in all aspects of their community and associated domains such as education, employment and living.
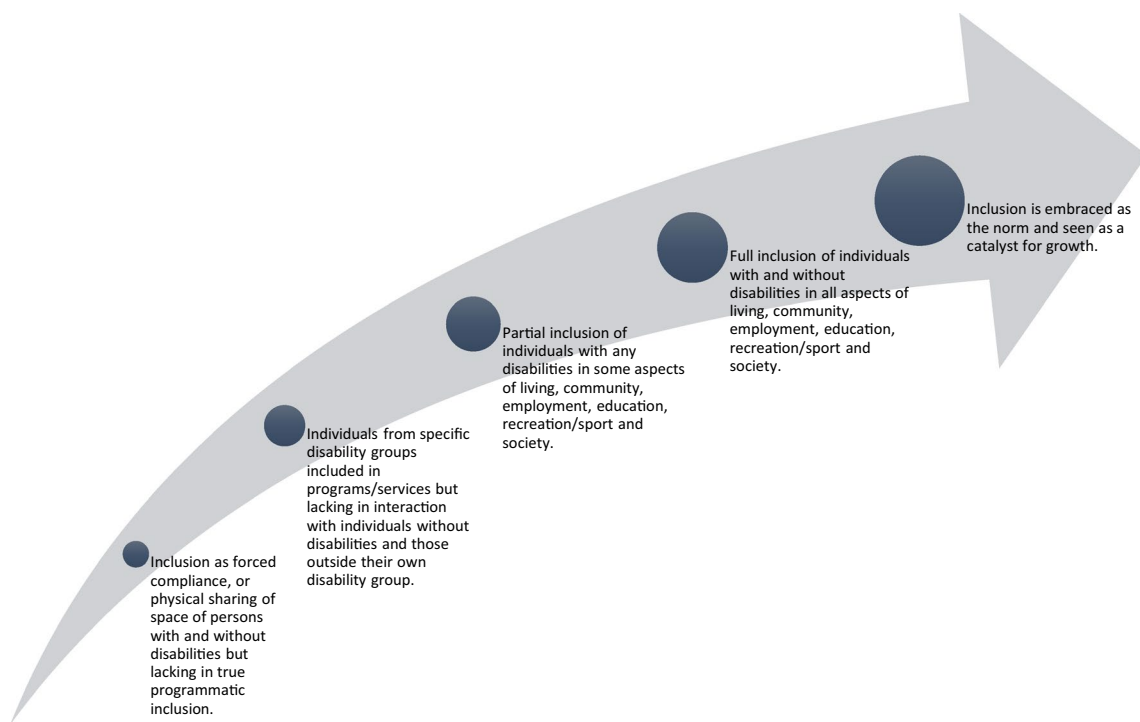

Inclusion as forced compliance, or physical sharing of space of persons with and without disabilities but lacking in true programmatic inclusion.

Individuals from specific disability groups included in programs/services but lacking in interaction with individuals without disabilities and those outside their own disability group.

Partial inclusion of individuals with any disabilities in some aspects of living, community, employment, education, recreation/sport and society.

Full inclusion of individuals with and without disabilities in all aspects of living, community, employment, education, recreation/sport and society.

Inclusion is embraced as the norm and seen as a catalyst for growth.

Fig. 1 Continuum of inclusion

Once achieved, inclusion is then embraced as the norm and can be a catalyst for growth. In the case study presented here, inclusive living serves as the foundation and catalyst to build an inclusive education.

Methods

Design

An intrinsic case study design (Stake, 1995, 2008) was used to examine inclusion at Shishur Sevay. An intrinsic case study is the study of a case (e.g., person, specific group, occupation, department, organization) where the case itself is of primary interest in the exploration. The exploration is driven by a desire to know more about the uniqueness of the particular case. Given that Shishur Sevay is an inclusive home and school in the middle of Kolkata, India, in its own right, this was intriguing in a place where inclusion and progressive rights for persons with disabilities are often not thought of. The heart of this method lays in the "researcher at least temporarily subordinates other curiousities so that the stories of those "living the case" will be teased out." (Stake, 2008, p. 136) The purpose is not to come to understand some abstract construct, but rather to explore the uniqueness of one particular case, in this paper, of Shishur Sevay.

While the overall project was designed to look at inclusion in the broadest sense at this site, the research question that guided this portion of the study was: In what ways has the development of this inclusive school permeated into inclusive living at Shishur Sevay? This design gives voice to previously orphaned students with disabilities and childcare workers whose voices are also often silenced in traditional Indian culture. This approach of interviewing and observing students, staff, teachers and workers affiliated with Shishur Sevay was empowering.

Setting: Shishur Sevay

Shishur Sevay was founded by Dr. Miriam Hahn—this name is a pseudonym—in 2006 in Kolkata, West Bengal and adopts an inclusive model of non-institutional care for orphan girls, some with profound disabilities. Inclusive living has had a profound impact on the children with disabilities as well as those more abled. In 2013, they established Ichche Dana Inclusive School for our children. From the beginning the more abled girls wanted to care for and teach more children. In the case of this particular non-institutional school and home, the girls in attendance are, on good faith, all true orphans based on available reports and inquiries from the founder. The mission of Shishur Sevay is to protect orphans and abandoned children, including those having differing abilities and disabilities, by providing a safe environment where they will be sheltered, nurtured, and educated in ways that build competence, confidence, independence and leadership. At the time of data collection, there were 17 full-time staff members (founder, house supervisor, teachers, child care workers, operations manager, accountant, guards), 8 part-time teachers, 9 Board of Director members, and 13 students living and learning at the home. The teachers' main responsibility is education of the students. The childcare workers, also known as massi's, are primarily responsible for helping with activities of daily living (i.e., feeding, dressing, toileting).

Participants and Data Collection

The Institutional Review Board at the lead authors' institution approved this study. For the archival data, all of Shishur Sevay's blogs from their website, and annual reports from December 2014 to December 2016, the year prior to and after in-person data collection were gathered. For the interviews and observations, consent forms were available in English and Bengali. For students under age 18, legal guardian signatures were obtained and students were read an assent statement. The consent and assent statements explained that pseudonyms would be used. The lead researcher spent 2 weeks immersed at Shishur Sevay. During this time, she worked with the founder to set up times to interview all staff, teachers, students and Board members who were available and to observe classes and everyday activities. All full-time and part-time staff with the exception of the guards were invited to participate in one-on-one interviews. Priority in scheduling was given to full-time staff members. All local Board members were invited to participate in one-on-one semi-structured interviews. The semi-structured interview "is a qualitative data collection strategy in which the researcher asks informants a series of predetermined but open-ended questions…there is no fixed range of responses to each question" (Ayres, 2008, p. 810). All students at Shishur Sevay participated in some way in interviews and/or observations. In total, 32 participants were interviewed and/or observed: 13 students (ages 3–16), 19 adults (ages 19–73) including—6 childcare workers, 7 teachers, 4 administrative staff and 2 Board members. Refer to Table 1 for a summary of participants, roles and ages of the students. Of the 13 students, nine participated in a one-on-one semi-structured interviews, with two using alternative augmentative communication (AAC) device as opposed to traditional verbal responses and four were not able to provide reliable verbal responses and were observed only. For more information regarding the interviews with the two students using AAC device, refer to Forber-Pratt (2019). It was unknown how many students ahead of time would need to be observed versus participate in one-on-one

Table 1 Participant Information

Role	Pseudonym	Age
Admin (house manager); full-time staff	Rochi	adult
BOD; part-time volunteer	Sevita	adult
Admin/Teacher; full-time staff	Padma	adult
Administrator; full-time staff	Miriam	adult
Dance Teacher; part-time staff	Samir	adult
Educator; full-time staff	Arushi	adult
Massi (childcare worker)	Punarnava	adult
Massi (childcare worker)	Champa	adult
Massi (childcare worker)	Kamana	adult
Massi (childcare worker)	Trupti	adult
Massi (childcare worker)	Matrika	adult
Massi (childcare worker)	Kalyani	adult
Special Educator; full-time staff	Aesha	adult
Special Educator; full-time staff	Sana	adult
Special Educator/Admin; full-time staff	Sudesh	adult
Staff (driver); full-time staff	Bimal	adult
BOD; part-time volunteer	Sharda	adult
Teacher; full-time staff	Gorma	adult
Teacher; full-time staff	Misha	adult
Student	Gitka	11 years old
Student	Priyal	15 years old
Student	Arianna	3 years old
Student	Selma	16 years old
Student	Kanaka	10 years old
Student	Bodhi	11 years old
Student	Maya	16 years old
Student	Premila	13 years old
Student	Komali	10 years old
Observed only (no interview)		
Student	Sabeena	10 years old
Student	Mareesha	5 years old
Student	Rugu	15 years old
Student	Siyona	9 years old

interviews, therefore a separate observation form was not used, rather, the lead researcher used the semi-structured interview guide as a structure for capturing fieldnotes from these observations.

A chart of the types of disabilities represented by the students is provided in Fig. 2. Many of the students have multiple disabilities; the terms used along the top of this chart came from within the organization, often reworded to convey more direct meaning to the teachers and staff working with the students. Worth noting, almost all the girls would likely qualify for disability services by standards in the United States, however, culturally in India disability is still often defined as those who can walk versus those who cannot or who have visible or apparent disabilities. Semi-structured individual interviews with consenting teachers, staff and

Board members lasted between 45 and 90 min. Semi-structured student interviews lasted approximately 20–30 min.

A native speaker of Bengali and Hindi worked with the lead researcher and translated during the interviews. Participants were given the choice of which language to use. All childcare workers (massis) and student interviews were in Bengali or Hindi. The majority (all but one) teacher and administrator interviews were in English. After the non-English interviews, a native Bengali and Hindi speaker performed a literal translation of them to written English and re-listened to the audio with the English text to verify the translation.

Then, another native speaker conducted back translation on 10% of each transcript for interviews not conducted in English. Only doing back translation on 10% of the transcript is a process recommended by Nakigozi and colleagues (2013) because, as Regmi and colleagues (2010) suggested, back translation of the entire transcript for all interviews can be costly and time consuming. The second translator took the English written transcripts and created an audio file of how they would speak portions of it in Bengali. Then the original audio file was compared by this second translator for consistencies and any inaccuracies or adjustments were then made to the resulting transcript. These transcripts were then used for the basis of our analysis.

Research-Subject Relations

The lead researcher collected all data in India and self-identifies as Indian and with a physical disability. The lead researcher did have a previous friendship with the lead administrator at Shishur Sevay. She had also met a few of the students and teachers in this study 7 years prior, though these previous visits were not for research purposes. Therefore, coming into this project, the lead researcher was sensitive to the fact that some may have perceived her as a friend and therefore may have been reluctant to share their true feelings however, she found the opposite was true because participants were able to see her a trustworthy ally. She did try to make sure that participants knew that she would not judge them based on their answers and that any existing friendships would not be jeopardized because of this study and reminded them that they could choose not to answer any questions. The other student researchers on this project participated in the early conceptualizations of the interview questions and later with the data analysis of the transcripts.

Data Analysis

We approached the data analysis through experience and careful reflection to come to understand the case (Stake, 1995) as well as using structural codes guided by our research questions (Saldaña, 2015) for our first round of

ID:	Autism Spectrum	Balance problems	Behavioral problems	Cerebral palsy	Chronic health conditions	Difficulty toileting	Difficulty feeding	Fine or gross motor problems	Hearing impairment	Intellectual/develop mental disability	Lack of impulse control	Language disorders	Learning disabilities	Mental illness	microcephaly	Paralysis	PTSD	Seizure disorders	Speech disorders	Unable to speak	Unable to stand or walk	Visual impairment	other
1																							
2				•	•	•	•	•		•					•	•		•	•	•	•		•
3	•					•	•	•		•					•			•	•	•	•	•	
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5				•		•	•	•				•				•		•	•	•			•
6				•		•	•	•				•				•	•	•	•	•			
7		•						•				•											•
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11	•	•	•			•	•	•		•	•							•	•	•	•		•
12									•			•							•				•
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Fig. 2 Chart of disabilities represented by students at Shishur Sevay

coding. The research team used Saturate (Sillito & De Alwis, 2009), a computer-assisted qualitative data analysis (CAQDA) tool to allow for multiple coders and memo writing across the research team in a collaborative format. For the first round of coding, structural codes in alignment with the research questions were used. For the second round, we used In Vivo coding to capture terms used by participants themselves and feelings or emotions. As Saldaña (2015) points out, In Vivo coding is useful when doing research that seeks to honor and prioritize participants' voices, particularly when participants come from a marginalized or previously silenced population. In India, the voices of persons with disabilities and that of childcare workers are often absent from discourse, therefore, this analytic approach seemed fitting. We collected data from people from all roles across Shishur Sevay to create a fuller understanding of inclusion. In conjunction with the In Vivo coding, subcodes were generated for the previously identified structural codes. For the third round of coding, for this paper, we focused on the inclusive living structural code and its corresponding subcodes and reanalyzed the in vivo codes to add examples based on these subcodes. Subsequently, all of Shishur Sevay's blogs, and annual reports from December 2014 to December 2016, the year prior to and after in-person data collection and researcher fieldnotes from data collection (including observations) were analyzed using the resulting structural codes and subcodes for inclusive living. As this was a part of a much larger project, only the subcodes focused on for this project are included in this paper. Interview data was analyzed first to develop these codes, then those codes were used to analyze the archival data and field-note data, including observation notes.

Data were independently analyzed by members of the research team, and then as a group we came together for clarification and confirmation of resulting themes. When any disagreement occurred, each member of the research team provided a rationale for their selection of a particular code and how they interpreted the segment. In these instances, we went back to the original audio file to re-listen for context and then a compromise or decision was reached among the research team. As codes were developed and themes, we consulted again with our translators to assess equivalence and congruence of themes across the two languages. This was done to improve the validity and to increase our confidence in the reliability of these data given the nuances of different languages.

Results

The research question guiding this portion of the study was: in what ways has the development of this inclusive school permeated into inclusive living at Shishur Sevay? In response, peer supports, the creation of home, staffing and awareness of discrimination were identified as key themes about how members of Shishur Sevay think about inclusion and in how they talk about inclusive living. The adult teacher, administrator and childcare worker (massi) interviews were richer than the student interviews, perhaps in part due to age, maturity and attention-span, however

examples across all types of participants are provided in the sections that follow. All quotes provided use assigned pseudonymns.

Peer Supports

This category deepened our understanding of the type of supports that students at Shishur Sevay encountered on a daily basis, namely peer supports. Broadly, peer support is defined as a system of giving and receiving help or assistance founded on principles of shared responsibility, and either implicit or explicit agreement of what is helpful. Peer support is unique because a 'peer' is someone who can offer support by virtue of either relevant experience or positional understanding. This type of support can take many forms, and this section illuminates what peer support was in the context of Shishur Sevay, and how and why it operated as a support for the students. The interviews with study participants revealed that, for Shishur Sevay, peer support manifested in the following ways: (1) the older students supported the younger students, (2) the students helped one another learn in school, and (3) the students supported each other simply because they were family to each other, and that was what family does.

A unique facet of peer support at Shishur Sevay were the ways in which the older students cared for and helped the younger students. Over and over again, in the interviews, the staff and students talked about the unique ways in which the older students supported and cared for younger students. The staff explained how impressed they were with the older students at Shishur Sevay, in many ways, among the older girls there was a shared sense of care for the younger students. For example,

> "So when she comes in the morning she'll say you know "everybody, get up, it's time to get up!" So they'll get up. [Maya] will take [Gitka], take her shushu then bring her to her to do the exercises. [Komali] will put [Bodhi] in the potty chair. So one massi is there, in the potty room. One massi is usually in the kitchen. So the kids do…the big girls also do a lot." *(Sharda, Staff Member)*

This support manifested in other ways too; for example, if a staff member was not paying close attention or completing another task and a younger student needs help- the older girls jumped right in and aided whomever was in need. Or if a staff member needed help holding, feeding, or bathing the younger students, the older girls jumped in the mix and helped the staff member complete that task. Also, the staff and students mentioned that not only was it helpful when older girls jumped in and supported the younger girls, but they understood each other in a way the staff cannot. For example, one staff member explained that she believed it

was beneficial for the older and younger girls to stay together because of the unique ways the students understood and supported one another:

> "I think it's good if the normal and not normal stay together. If they (the children with disabilities) need something then the big girls, the normal ones they'll be able to understand and will be able to look after them, will be able to help them." *(Trupti, Staff Member)*

Peer support was not only evident in daily living activities, but also in classroom activities. The students helped one another learn, assisted with classroom activities and, also, taught one another cultural and religious practices. For example, in the class, if the staff was teaching the classroom activity, and some of the younger students were having trouble either completing the activity or were having trouble understanding, the older students would jump right in and taught the younger students what to do in that situation.

> "One of the other big strengths that I've seen too is the peer supports that are being intertwined into the lessons too. Especially with the presentations, with [Gitka], and the other big girls, the fact that they're working together is really wonderful…so anytime that that can be continued to be supported will be important." (Researcher Field Note)

Also, the staff explained that not only would the students help one another but, in reality, everyone was always learning and supporting one another, this was one of the unique characteristics of Shishur Sevay as an organization. A student shared,

> "While teaching [Gitka] and [Bodhi] you have teach with more interest and make it more fun, if they see expression then they will enjoy it more, they'll understand better if they can understand or not. Get things, like a ball, put it in their hands then they'll understand." (Komali, Student).

Komali's quote illustrated the attention students gave to each other, as she understood specifically how to approach her peers so that they would learn more effectively. In many ways, peer support at Shishur Sevay just made sense to the community of students and teachers at the school. Because they all lived together anyway, many of the students explained that peer support was just a natural outpouring of their day-to-day life. A staff member explained that because everybody lives together, everybody can look after one another. For example, if there was a student crying, another student would console them because, in many ways, they operated as a family with one another. Peer support also felt natural to the students because, in many respects, Shishur Sevay had an "all hands-on deck" culture in place. For example, when a group of students and teachers took a trip outside

of Shishur Sevay and encountered accessibility snafus with a student's wheelchair, another student jumped in, without a prompt, and helped the staff member to maneuver the wheelchair. This was demonstrative of the ways in which peers at Shishur Sevay assisted one another, in many different ways, out of a shared common sense, or need.

Creation of Home

Inclusion at Shishur Sevay meant, first and foremost, being part of a family. It might seem odd to some that family and home were the priorities, when also being founded as a school. However, Miriam explained, "Academics would be the last thing. Because you can live without academics, you know? But without society, without people you cannot live." (Miriam, Administrator). The themes of family, home, and community were reflected in quotes from members from all types of participants (i.e., students, massis, teachers). Miriam was intentional about making sure that Shishur Sevay was created as a home. From the very beginning, she tasked herself with creating a family rather than an institution. Miriam spoke about adopting the first children saying:

"Who are these kids who get left behind? Who are these kids who are basically in storage, they're inventory, and in institutions, and living with them, being able to provide them a home and love and nurturing and family…bringing those children [with disabilities] made this place a home, not a shelter, not a hospital, not a dormitory, because older girls, at the age of 6, they had lost everything, including their younger siblings. And they had these little children to take care of." (Miriam, Administrator)

Teachers, staff, and students alike described the Shishur Sevay community as one that felt like home. Inclusion was being supported as part of a family, not just part of an institution. Sudesh (Teacher) commented that at Shishur Sevay you "feel that you are a part of it…everybody is thinking of [you]." Selma, a student, stated "Family is there." Samir (Teacher) also expressed that in the past in India, there were more multi-generational families where childcare was split among many adults. Shishur Sevay reminded Samir of that kind of community of care. Purnanava, a childcare worker (massi), stated that in other places she worked she, "will work, will stay quiet…here I am working with everybody, talking to everybody." There was an expectation of community, everyone was getting to know each other, rather than just performing their roles adequately.

Family at Shishur Sevay was also encouraged through how the students lived together. Aesha, the special education teacher, commented that the children "eat together, they sleep together, they play together, they go together, that is inclusion." This sentiment was echoed by Sharda, a childcare worker (massi) who said, "I don't see problem. The big girls sleep here and the little ones sleep here. No problem." There was also an overwhelming sentiment from the staff and students that together is what was meant to be, that they could not imagine it any other way. For example, Purnarva stated, "They have been together since the beginning, there is no separating them! Staying together is good." And several students had similar sentiments like, "should stay together". A few students were able to recall their lives prior to being at Shishur Sevay and were able to draw comparisons. Priyal reflected about her time at another home and stated, "They didn't like us and we didn't like them.". One student, Premila, had memories of the government run orphanage she was at before Shishur Sevay, and she explained:

"There, are kept separate. I had seen it in [name] home. The little ones used to sleep in the third floor, separate…[Rugu] used to be kept separately… far from the kids. On the second and third floor were all the crazy people. We were on the first floor. I wanted to know, why do they keep the kids separate? I could have slept with some of the kids but then we did not get to. I'm used to that from my childhood. I used to sleep next to my brother…Here [at Shishur Sevay], everybody together." (Premila, Student)

Komali had similar sentiments and shared,

"I was in one [home], before this home I was (at) another home, there [Gitka, Bodhi, Rugu and Siyona] were in another room and we were…That time I didn't know about disability, here I know what is a disability is. And sometime I feel bad for them that there I couldn't understand but here when I think about that place I feel bad." (Komali, Student)

Aesha further explained how living together as a family created a norm of helping, which connected to the peer supports discussed above:

"Because children are living together. Nobody thinks, they are all part of the family, of part of the whole group, nobody thinks they are different from them, in any way. And whatever they are not able to do, others are very happily rushing forward to help them. Which doesn't happen in other schools or outside. It doesn't happen." (Aesha, Teacher)

In looking towards the future, Miriam also wants to ensure that the space becomes more inclusive by creating a way to access the upstairs floors via wheelchair:

"It's just, it's not inclusive if you have to, if all a sudden all the big girls disappear upstairs, and whole conversations happen, and they practice music up there, because part of my interest and commitment to inclu-

sion is also for the kids who can't do anything, alright? I mean they can't walk, they can't talk, they're cognitively disabled, but humanly responsive" (Miriam)

In addition to living in close proximity and sharing meals, everyone was expected to contribute to the maintenance of the household. Children both with and without disabilities were assigned chores depending on ability. Miriam reflected on the initial surprised response she got from a child welfare officer when she expressed that she gave the children chores:

> "My kids wash dishes. I wash dishes. And then [a child at Shishur Sevay] said something about changing diapers, and [the child welfare officer] said, "You make her change diapers? Wait, you're saying that the handicaps [girls with disabilities] are with the girls? You've mixed them? How did you mix them? How did you do this?"

The themes of family and community were also evident in the ways that culturally relevant familial names were used for many community members within Shishur Sevay. Shishur Sevay also goes on vacation together like a family would, taking everyone with them. When asked about where she would like to go on the next vacation, Komali (student) stated that she wanted to take everyone to the hills. Many of the other students echoed this desire to continue vacationing with everyone.

Shishur Sevay also has a history of bringing children to cultural events. On the Shishur Sevay website, a blog entry from December 13, 2014 entitled "Shradh in the Village" described a trip that all the children and staff of Shishur Sevay took together to attend the Shradh Ceremony of a close friend of the institution, who was also a blood relative of one of the staff members. The Shradh Ceremony is part of the ritual that takes place after the death of a family member. Thus, in this instance, Shishur Sevay partook in a ceremony of devotion for an extended family member. The inclusion of all of the staff and children on this trip showed that the connections to each other extend beyond institutional roles, and into familial roles.

Staffing

Inclusive living was the foundation upon which inclusive education rested for Shishur Sevay. As previously mentioned, teachers, staff, and students routinely described the Shishur Sevay community as a type of home-like environment. Just like a home, Shishur Sevay was made up individual members that have worked to make the space functional.

The staff were one of the main reasons this institution functioned and felt like a home to the teachers, staff, and students. Unfortunately, at times, the limited number of employees prevented Shishur Sevay from reaching its full

potential. One of the critical, ongoing needs of this institution is a greater workforce. With an entire team, Shishur Sevay could give needed attention to each and every student; instead, they are not able to give the desired amount of attention to each of the students at Shishur Sevay.

When the school was short staffed, meals are rushed, and the big girls had to aid in lifting and carrying the students because there were not enough staff to aid in the process. A lack of staff can have serious ramifications for the long-term success of the students, and this section explores the everyday difficulties that arose from the current staff shortage at Shishur Sevay.

A staff shortage simply means less workforce. Many students at Shishur Sevay needed staff assistance to transition from one activity to another, or assistance with transfers from bed or toilet to their wheelchair or to other school activities. Additionally, as the girls are growing, it often took two staff members to safely transfer individuals. In one instance, there were not enough staff to help with student participation in dance activities. Samir explained:

> "I'm trying various ways I'm making them sit down after doing a little bit or if one girl was holding her now two are holding, for some just one girl holding them is enough. I mean this I have thought later that, she could be held up by one person now we need two people, this has come later." (Samir, Teacher)

For this teacher, staff helped the students participate in the dances. Miriam has looked at more elaborate harness systems that might aid in supporting students but still allow for movement. In other instances, the teachers and staff at Shishur Sevay needed more help to lift the students. In one example, an administrator, Padma, explained that:

> "They are getting bigger, now it's actually hard to sometimes just lift one of them. Even that should be the part of training that, it's important but you also need to know how to do that without injuring."

Not only are more staff needed for the current daily operations at Shishur Sevay but in looking toward the future, more staff is a necessity. This institution will not be able to grow without employee expansion. The need is evident to students, as Komali explained, "We need many special teachers for the kids and make the place bigger." (Komali, Student)

As an organization, Shishur Sevay was clearly established as a home, haven, and school for many students who might otherwise have been overlooked in Indian society. An apparent dream for the staff and administrators at this institution is expansion. They want these students to be able to experience the love, acceptance, and belonging that exists in abundance at Shishur Sevay; however, for this to happen, as a student, Komali, put it: "then we need more people to help."

Awareness of Discrimination

A rich portion of the student data was their perspective and awareness of the "little ones" experiencing discrimination. Some of the older girls expressed sadness at the discrimination faced by the little ones outside of the home. Others expressed wanting to spend more time with the little ones, and others discussed methods of teaching their sisters. Miriam was hyper aware of this awareness in the girls too and reflected on this. For example, Selma stated:

"Because the little ones actually can't go, [we] don't always go out sometime[s]. [Bodhi, Sabeena] they don't always go with us so I don't like that. … I would like to be able to go out with them more often… I feel very bad. no one listens…I'm ok, I can talk but [Gitka] can't talk." (Selma, Student).

This was echoed by Maya:

"[Gitka] [will] called me. I ask, anything? She says yes, then I understand what she want to… When they know and ask…The elders are seeing, the elders understand so when someone knows and still asks I feel very bad, they can see… It's very painful (I feel very hurt) when someone points like that …With everybody." (Maya, Student)

Miriam summarized the actions and feelings of the girls as unconditional love. She stated:

"…And the kind of unconditional love-I remember one of the girls, years ago, would say "I hope when I die my eyes can go to Somali". That's not what people generally expect kids to be thinking about. Another one used to say that she prays to God that God will give her the power to make them [the little ones] speak. And the first time one of them was asked what do you want to do when you grow up, she said "Well, I need to get a job because I have to take care of my little sisters." (Miriam, Administrator)

Discussion

Shishur Sevay is using inclusive living as a catalyst for academic inclusion. With true inclusive living serving as the foundation with a familial atmosphere of love and healthy sibling rivalry, these girls are provided with the chance to be girls. They are very typical teenage and pre-teen girls, who despite traumatic and challenging backgrounds, have learned what it means to thrive. Peer supports and the creation of a home allow the students and teachers at Shishur Sevay to work together interdependently to support all members of the community. Students help other students, but they also support teachers and other staff members. Students have gained awareness of the discrimination faced by some members of the community, and this awareness also spurs them into finding ways to support their fellow students, strengthening their commitment to interdependent support. Staffing also arises as part of the equation for a strong interdependent community of care. Without sufficient staffing, opportunities for some girls to be fully supported and included are limited.

Research indicates the importance of peer supports for inclusion (Carter, Sisco, Melekoglu & Kurkowski, 2007; Shogren, Gross, Forber-Pratt, Francis, Satter, Blue-Banning & Hill, 2015). In the case of Shishur Sevay, peer support was identified as a valuable asset, however, there are some complicating factors that ought to be considered. For example, at Shishur Sevay, this peer support potentially takes on a different meaning of sibling support because the girls live and go to school with one another in addition to being adoptive sisters. The older girls do worry about the girls with disabilities about their future care and caregiving. However, the literature on sibling support for individuals with disabilities looks different with the cultural and structural differences of this relationship in most research studies versus the climate at Shishur Sevay. It is known that siblings of persons with disabilities and siblings as caregivers need supports for themselves (Arnold, Heller & Kramer, 2012; Conway & Meyer, 2008; Naylor & Prescott, 2004) and it is important to include older siblings in the future planning for persons with disabilities (Heller & Kramer, 2009).

However, with the prevalence of institutional care and the societal barriers and structures in place in India along with the novelty of Shishur Sevay, it is not yet known the role that the older girls may play or be allowed to play in the future planning of the girls with disabilities. This is in part because of their own past experience with institutionalized care and they are not currently identified as guardians for the girls with disabilities. However, in the spirit of building advocacy, it is believed that for all the reasons mentioned above about the role of peer supports, that the older girls will advocate for their sisters with disabilities if and when the need arises. However, as Zuna, Brown and Brown (2014) point out, family relationships are important, as is earning trust and support from the broader community to expand the support network. This is currently an under-utilized method of support for the girls at Shishur Sevay; community outings are few, in part due to the complicated logistics because of inaccessibility. It is hoped that expanding ties with the broader community will help not only to provide further resources and supports for siblings who may find themselves in the future role of caregiver, but also to build on the notion of inclusion. Support from peers and the broader community can be particularly beneficial in reducing isolation and building community.

Deeply connected to the peer support issues mentioned above is the dedication of Miriam to create a home, not another institution. In the home of Shishur Sevay, all individuals' voices are valued. Inclusion is embraced and expected. Love and the potential to succeed are at the core. On the surface, this may not seem all that remarkable. However, given the context of India, all of these qualities are quite remarkable—extraordinary even. As mentioned earlier, what inclusion looks like in the United States looks different in India, particularly at Shishur Sevay—and it should, because of cultural differences. Revisiting Fig. 1, the continuum of inclusion, it is apparent that Miriam, the girls, and the staff have developed a vision of an inclusive home with full inclusion of individuals with and without disabilities in all aspects of living, community, employment, education, recreation/sport and society and they are working together to embrace inclusion as the norm and as the catalyst for social growth. Today, they have partially achieved this, as evidenced by this study. They appear to be in the middle of this proposed continuum in practice, but with a clear and definitive vision of the endpoint of the continuum. They are well on their way and have successfully challenged many social norms and have imparted an inclusive mindset on many. They have shifted cultural views on disability for all whom connect to the Shishur Sevay network. Homes such as Shishur Sevay simply do not exist in India. There are places that call themselves "children's homes" that operate as smaller institutions and are often over crowded. While some basic needs may be met in such a setting, for girls with disabilities, the living conditions are often abysmal (Csaky, 2009). On the contrary, Shishur Sevay is a model inclusive non-institutional care for orphan girls previously housed in a government institution and rejected for adoption. At the heart of this home is having a stable mother, Miriam, and each other. Through this relationship and as operating as a true home, bonds of genuine love are created allowing the children to thrive.

The dedication of the staff at Shishur Sevay is a compelling story in and of itself. Not all the staff initially start with an understanding of true inclusion, but they quickly learn what inclusion means and what it looks like. This exemplifies a culture change of perspectives of inclusion and of disability that also leads to a committed staff. Some staff members have over a 2-h commute just to get to Shishur Sevay, but they continue to do so because they believe in the mission and in providing the best care and opportunities for the girls to thrive. In 2004, the National Commission for Women in India issued a report outlining the challenges that women with disabilities face in the country. Among their recommendations was creating awareness about the plight of women with disabilities and to improve homes for girls with disabilities (Rao, 2004). While women and girls with disabilities do face multiple disadvantages and exclusion from political, social, economic and health opportunities, they have also been absent from conversations and a part of decision-making. To break this pattern of ignoring and further isolating women and girls with disabilities, allyship with staff working with this population is vital. Therefore, even though there are staffing challenges at Shishur Sevay, the staff become ambassadors for the home and for the girls. Rather than attempting curricular inclusion first, this fundamental approach of endorsing inclusive living first helped to get the entire Shishur Sevay family thinking and acting inclusively. The teachers are now able to build off of this framework to work on academic inclusion.

There are, however, some recommended areas for improvement for Shishur Sevay as well as internal challenges that were illuminated through this study. There is a need for more space, staff, equipment for activities, community-based activities and a sustainable funding source. At the time of data collection, the students did go out on field trips occasionally in the community such as to the park or for dance exhibitions. These types of excursions take a lot of planning, and time, and resources, these types of outings and events do a lot too in relation to expanding the notion of inclusion and inclusive living. First, it gives the students non-isolated leisure opportunities, meaning a chance to interact with peers outside of Shishur Sevay. It gives them exposure to the outside world, to do what kids typically do. Second, it enables them to interact with members of the community and to challenge traditional notions of what people with disabilities can and cannot do. Steps were being taken, at the time of data collection, to develop a comprehensive strategic plan to allow for growth of space and staff as well as exploring sustainable funding options.

Limitations and Future Research

The primary goal of this research was to demonstrate the benefits inclusive living has for individuals with disabilities at Shishur Sevay, a non-institutionalized inclusive group home model of care for orphans with disabilities. This paper showed that while inclusive living in this context has been understudied, there is significant promise for individuals with disabilities, particularly orphans, in non-Western contexts. The themes presented by the authors raised additional questions about inclusive living that could inform future areas of research. Critical themes contributing to Shishur Sevay's success were identified, but it is unclear if these themes exist in other inclusive living contexts throughout the rest of India due to the focus, by design, of this specific site.

This research also acknowledged the specific characteristics and idiosyncrasies of Shishur Sevay but did not explore how Shishur Sevay navigates the macro socio-political environment of eastern India. Ongoing research focused on studying Shishur Sevay within this larger socio-political

environment may provide additional insight into how the organization challenged traditional narratives about the capabilities of persons with disabilities and their place within society. Another limitation of this research relates to the defining of disability. At Shishur Sevay, there is a belief that education and this home is being provided for girls with and without disabilities in Kolkata. However, based on the backgrounds of the girls, by Western standards, it is likely that all girls would be labeled as having some sort of disability. However, culturally, there is a perception of distinction between those who can walk versus those who cannot as being paramount in one's 'disability' status. In some ways, when reflecting back on the continuum of inclusion from Fig. 1, it does not matter, as this school is providing an inclusive living option that includes staff and teachers mostly without disabilities alongside girls with various physical, emotional, academic and social needs. As it relates to inclusive education, this study presented evidence that the creation of a family like environment and awareness of discrimination faced by other community members were important parts of ensuring an interdependent learning community at Shishur Sevay. Further research could explore whether these factors are also present in other inclusive schools in other cultural contexts, and how they show up in other types of institutions that are less focused on being homes. Finally, this research indicated how important education professionals (e.g. teachers, administrators, etc.) are to creating effective inclusive living environments. By being exposed to true inclusion, many of the teachers and staff now cannot imagine anything different, this became their new normal. Longitudinal research to explore the experiences of these educators and outcomes of these students could be beneficial.

Implications for Policy and Practice

As discussed previously, the end goal of efforts for inclusive education is true inclusion, where people with disabilities are fully included in all aspects of their community and associated domains such as education, employment and living. Shishur Sevay presents an example of a community that approaches inclusive living and inclusive education differently than other institutions in Kolkata, India. Shishur Sevay is an example of a replicable model for other organizations that hope to practice inclusive education. Our study suggests that even beyond the school, Shishur Sevay has had an influence on how people in the community see disability, which possibly encourages new norms. Other inclusive education spaces could consider the ways that this model promotes interdependence through peer supports and the creation of home, as well as through students having an awareness of discrimination. Other spaces could improve on the model by increasing staffing, but with careful balance so that staff do not become the only providers of care, but rather the community cares for and helps each other.

Given the marginalized position of orphans with disabilities in India, this work has policy implications in that it shows that there are possibilities for interdependent communities of care at least on a small scale. Policies could be put in place to support small homes that subscribe to the ideals of interdependence and family, such as government subsidies. The case of Shishur Sevay also shows a possible model for combatting the strongly held norms about disability, which hinders people from indicating they have disabilities and thus hinders proper supports. The Shishur Sevay focus on family could be further explored on a policy level in thinking about how to combat the greater social norms of fear and misunderstanding of disability. For example, social programs could be developed for all schools to promote the ideals of family and mutual support, specifically mentioning how this is beneficial to students with and without disabilities. This model of non-institutionalized care provides a glimpse of what is possible and highlights the importance of policies existing to support unique models of care such as this that centers inclusive living alongside care and education. Policy solutions could also be explored for teacher training, thinking about how some of the values from Shishur Sevay might be implemented on a wider scale in teacher training.

This case study of Shishur Sevay opens us to new questions about how to approach inclusive living and inclusive education through the creation of interdependent communities. Supporting these interdependent communities and recognizing where they already exist could be a helpful tool for both practitioners and policy makers.

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