

**REPORT ON THE CASE STUDY OF  
SHISHUR SEVAY AND THE ICHCHE DANA  
LEARNING CENTER**

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The following feedback has been collected through interviews with teachers, students, staff members and administrators. Institutional Review Board (IRB) approval was obtained, and all participants signed a consent form if they were old enough or parental/guardian consent was obtained and students were read an assent statement and gave verbal permission to participate in this study. All names throughout this document are pseudonyms. An overall summary of interesting points is provided on page 3.

This document provides direct quotes from these stakeholders on the following categories:

- 1. What makes Shishur Sevay special as compared to other institutions? (p. 4-7)**
- 2. How does inclusion benefit students? (p. 8-10)**
- 3. Voices of the students (general student feedback) (p. 11-13)**
- 4. What improvements need to be made, and what are some internal challenges being faced? (p. 14- 16)**
- 5. What challenges with the community have been faced or are still being faced? (p. 17-18)**

Each section begins with a short summary, and the rest of the section is composed of representative quotes to support the points of the summary.

## OVERALL SUMMARY

### WHAT MAKES SHISHUR SEVAY SPECIAL? (TEACHERS AND STAFF)

1. *Staff report that students with disabilities are treated better at Shishur Sevay than at peer institutions*
2. *The importance of supporting students' progress in multiple aspects of life*
3. *Teachers and staff feel supported at Shishur Sevay*
4. *Voices of staff on community, family, and disability*

### HOW DOES INCLUSION BENEFIT STUDENTS?

*Inclusion benefits students by:*

1. *Providing peer supports*
2. *Supporting individual learning needs*
3. *Providing other resources (e.g. technology)*

### VOICES OF THE CHILDREN OF SHISHUR SEVAY

*The students spoke about:*

1. *The relationship of big girls to little ones, and to little ones facing discrimination*
2. *Their experiences at other homes/schools*
3. *Their aspirations*
4. *Improvements they want (also repeated under the Improvements section of the report)*
5. *Places and things they want to see and/or do on vacation*

### IMPROVEMENTS AND INTERNAL CHALLENGES

*There is a need for:*

1. *More space*
2. *More staff*
3. *More equipment for activities*
4. *More activities in general*
5. *A sustainable funding source*

### CHALLENGES WITH THE COMMUNITY

*In summary, the community and the center often have different goals. The Shishur Sevay administration is concerned about the inflexibility of some community systems.*

## REPRESENTATIVE QUOTES BY SECTION

### WHAT MAKES SHISHUR SEVAY SPECIAL? (TEACHERS AND STAFF)

1. *Staff report that students with disabilities are treated better at Shishur Sevay than at peer institutions*
2. *The importance of supporting students' progress in multiple aspects of life*
3. *Teachers and staff feel supported at Shishur Sevay*
4. *Voices of staff on community, family, and disability*

### **1. Caretakers and some students report that students with disabilities are treated better at Shishur Sevay than at other homes that massis have worked at, or that students have attended.**

“Shishur Sevay is an ashram for orphan children, where handicapped children are given more recognition and respect. The abled kids are also given importance but it's more for the children with disabilities.” (Kalyani, Massi/Staff)

“They [the kids] are taken care of all the time. They don't leave the kids alone in the potty room. The kids are very well taken care of. I am very happy. I have seen other homes. Very dirty very dirty.” (Sharda, Staff/BOD)

“Everything is clean. The kid's bathing, changing clothes, if they pee in their pants they are changed within one minute, after that, food. Everything about here is the best... we can't afford this for even our own kids, these kids get. Everything is very good.” (Sharda, Staff/BOD)

“I'm telling you about the home. You know what they don't take proper care there. You know this Mother Teresa's home I go there also, I have seen also. I have also done duty in one of them, then I saw, even for the big girls the line is not good. They do whatever they feel like, not taken care of. Went to XXX didi's home the kids are not cared for. Here the kids are really well taken care of. There is no home like this one in Calcutta and I have seen a lot of homes!” (Sharda, Staff/BOD )

“There was also a home right next door, now it isn't there anymore. It was mother Teresa but there for eating they had very thick rice, the kids can't eat. Dalia (a kind of cracked wheat), dirty clothes and one some big person would visit, oh my god! They'll put good clothes on them! They'll give good food. I went to place for three months, that boy is now in America, I don't know the address, He was a Marwari, handicapped...I did his duty. He got cured and went. His legs had become better. Poor thing, he was in the home and what food they used to give! I would have tears in my eyes looking at that. I used to say “Bunty (real name) should I bring food for you from home?” “Hmm (yes)”. Oh my god! I saw other kids also. They had given me one kid but I saw other kids also, they did not give good food, you know. Here they give very good food and neat and clean!” (Sharda, Staff/BOD )

“What I can say is our Shishur Sevay is better than any other Shishur Sevay. I have seen so many places because my line (of work) is like that we bring patient, we take patients. Patients come to

us I go there that let me go around and see. My Shishur Sevay is better than any other place.” (Sharda, Staff/BOD)

“Someone else will take a lot of money and will not work like this. Won’t think of them as their own kids and do it. They’ll look at the clock and work. I don’t do that.” (Sharda, Staff/BOD )

## **2.The importance of supporting students’ progress in multiple aspects of life**

“I do ask “Hey are you full?” “Bodhi, you didn’t eat properly?” Bodhi would say “yes” “no, you are lying, you have eaten” you have to say various things. If you don’t how will they understand? No one talks to them like that. I only talk a lot. “Hey do you want water?” “hmm-yes” then you have to give water. If you don’t ask them they wouldn’t be able to say anything, if you put it in front of them only then will they drink it. They can’t speak clearly, they can understand they can’t really talk much. If I am on duty I keep talking to them. This habit you have to teach them...but if I don’t talk with them how will they understand? But no one does that. Physiotherapists don’t talk. I myself have read...the Buddhists have taught us that if you want to show pity (compassion) to the handicapped you have to teach them to talk so that’s what I am teaching.” (Sharda, Staff/BOD)

“And I just wanted to say I don't care what your answer is, but teach them the consistency, this is how you do it. When they first came, within the first month I started them in dance class, they'd never been without dance, probably at least 2 times a week, sometimes 3. And it wasn't for dance, it was the whole concept of lining up, of everybody turn to the same direction at the same time, or the other raises their arms, I mean it was just a whole concept of body and controlling your body and all of that.” (Miriam, Administrator)

“And I showed them. I was just jumping up and down, I said I knew you could do it! You thought you couldn't! I proved I was right, look at that you did them all! I mean, and the thing is, what I wanted them to feel was the excitement of a real achievement.” (Miriam, Administrator)

“It's a wonderful thing when you can really, for me it's all about connection. Making connections. Bridging the gaps. And to really being able to relate to them and you know, to identify their strengths and their weaknesses. So since the day I joined this place I have always tried to understand the areas where they, where I found positivity in them. And my-my I had always tried to work on them first, and then go to the negative aspects. To build some confidence in them and move onto their weak areas and work on them. There are times where I think maybe it wouldn't work and I had to shift to a different strategy.” (Gorma, Teacher)

## **3. Teachers and staff feel supported at Shishur Sevay**

“In other places, like if I am working in a house...Alone...Will work, will stay quiet, that I don’t like. Here I am working with everybody, talking to everybody even if I have some family problem it wouldn’t be on my mind. While working with them, everybody together I don’t keep any headaches. If I am working in a house alone maybe there’ll be family worries (in my head) but here with the kids...specially I have two sons I have left them (with family) and come to

work if I look at these kids then at least I am ok. Looking at them smiling and playing, I'm ok." (Purnanava, Massi )

"I think there was an ad in the newspaper, and I came here, I met Michelle, I liked her idea very much, and I felt it is a place that I'm free to do whatever I want, means I can put my ideas into practice. That ran free. And nobody is telling me you do this you do this you do this. So my creativity, my thinking, I mean I'm just free to do anything. And obviously this feel, I feel it's all trial and error. Working with children. And children who have intellectual disabilities. It's all trial and error. You cannot say that what works for 1 child will work for another child. So you always have to be all the time very innovative and thinking and for that I think you need an environment where you're completely free to do whatever you want, and most of the times, you don't get success. And you learn from those failures. That you are trying something, it doesn't work, ok let's try something else. So here you have that flexibility." (Aesha, Special Educator )

"Whatever I want, it is provided here. And I'm sure whatever I, if it's not here and I want it, it will be provided to me." (Aesha, Special Educator)

"Resource here is that you feel that you are a part of it. Nobody here-you feel that you are a part of Shishur Sevay. There's always somebody to guide you, to show you the way. And to help you to enrich yourself. And give you proper guidance, what needs to be done and everything...And that helps you to better your teaching." (Sudesh, Teacher)

#### **4. Voices of staff on community, family and disability:**

"And for me that's the biggest problem in disability is the loneliness of it. Especially when you can't communicate." (Miriam, Administrator)

INTERVIEWER: Is there any other place (where you work) which is inclusive where children with and without disabilities dance together? Like you have worked only with children with disabilities...have you taught anywhere where they mix together? SAMIR: No (Samir, Teacher)

"In Bangalore there was a school this child was in a wheelchair, muscular dystrophy. He wanted to take an admission to some school, so the principal said "No this child cannot." So the parents said 'Why not?' And he said 'Because he's going in class 6 and the class is upstairs, and we don't have lifts or anything and this child is in wheelchair, so every day who will carry this child and who will bring the child back because for the playtime and all that they have to come down.' So then the parents said 'why can't you shift the class on the ground floor?' And the principal was very sad he never thought about that. But I'm very happy that he agreed to it, and he did that. I'm just saying these are very simple measures we have to take and nobody thinks about it. Is it the responsibility of the people with disability and only their families? And I think it comes from them because I am also passionate about this maybe because I have 2 brothers in my family, I have my own brothers and maybe 1 or 2 cousins that is why I am passionate, I really don't know. (Aesha, Special Educator)

"Let me speak from another angle. Nowadays family. Earlier we were 'bonedi' family (bonedi pronounced bonay-di means something like affluent but I think he meant joint family here)

together (phone rings) so earlier we were bonedi family - together paternal grandma, maternal grandma we would grow up together. In our childhood right after waking up in the morning playing with grandma. Grandfather, cousins all in the same house, it was all together. There was sharing. Eating. That was there. There was no jealousy between the children, we would share with everybody, go on trips together. What has happened now, now meaning for a long time now, small family - one child parents, in a flat, separate... what has happened is that there is a communication gap everybody doesn't have that in them the kid also knows my parents if someone tries to give... if you teach from the very childhood that you should share and parents are so busy nowadays they are leaving the kids in the creches or leaving them with nannies how much will nannies teach that's why it's very less in the children. I think wherever there is work being done together the children get involved, that is very good. So many boys and girls come to my class I know not everybody will be a big dancer but he/she is coming and learning it's doing so good. There's girl in my dance class who doesn't talk to anybody she'll become a patient slowly, silent, but in my class she is frolicking around, the parents had tears in their eyes one day. There are some parents who are like 'my daughter doesn't feel hungry.' If they give food she'll eat otherwise not. When she goes back from my dance class she feels hungry. All this makes me very... I'll teach dance and take money for that that's different this makes me very happy." (Samir, Teacher)

"Now I see, now I so-call disabled people. I don't feel that they are disabled at all. Disability is only in the mind. And I'm also disabled in so many ways. I'm not very good with directions, I am disabled that way. But otherwise they are absolutely fine. And I don't think anybody has a right to think that they are disabled. Because they are not doing anything for that person. So I think we should remove this word disability, because they have abilities, why do, why are we focusing on disabilities. I don't understand this. And as far as inclusion is concerned, first of all I will talk about the schools, from there it starts." (Aesha, Special Educator)

"And then having all those people around is also good for the big girls. Because they're really aunties. Like today we were just cleaning out that cabinet with toys and things that we're not using anymore and we give them to the massis, but some of the pressure for that was coming from the girls. Look we're not using these things, and the massis could use them. And then one of the girls was, we took pages out of little notebooks that we needed to put in their files, and the rest of the notebook one of the girls said "Can we give these to the massis?" And I said "yeah", and she said, "for instance Monica's grandchild can use this for writing letters." So they're involved in the lives of the massis. And I think that's another part of our strength in terms of being a community living together. When we did our inclusive dance we really needed more mobile people, and I brought the massis in. And they were on the stage, and they walked gracefully, I put them in really lovely matching saris and blue saris and gold blouses and they had dignity, and I kept thinking, who's the artist I forgot, Seurat, the Afternoon in the Park." (Miriam, Administrator)

### **HOW DOES INCLUSION BENEFIT STUDENTS?**

*Inclusion benefits students by:*

1. *Providing peer supports*
2. *Supporting individual learning needs*
3. *Providing other resources (e.g. technology)*



**1. Peer Supports: Often the older girls who do not have visible physical disability (called “the big girls”) support the girls with visible physical disabilities in their daily activities.**

“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. Mani 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/BOD)

“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, Massi)

“Our big girls are also very good, they take care of the little ones. Sometimes if the staff isn’t paying attention also they do and their education is timely.” (Sharda, Staff Member/BOD)

“I see a lot of things maybe I can’t recall everything right now. Like they’ll be going out, all the big girls are selecting their dress. Ganga is asking them to select something for her quickly. She is saying we can get that but sometimes we aren’t able to understand her well but if we watch her well she can explain and say that give my dress, which dress she’ll choose, now we’ll go out. The shoe....Gitka, Bodhi they can convey very well. And of course Rugu. If someone is going out, she’ll go out with her.” (Kamana, Massi)

“Whatever little I’m taking her out, the places I am taking her are all familiar places not going anywhere outside. Yes, but we take her on a trip every year. There we get a lot of help. Someone is helping to get her off the train. If I am not able to do it someone is helping take the wheelchair down quickly. Wait wait ‘boudi’ (sister-in-law) hold her hand and pulling her on to the train or exchanging berths.” (Kamana, Massi)

“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)

**2. Individual Learning Needs**

“So I started with teaching her letters, and I know she has dyslexia, it was like after several months she was starting to get it in, but the improvement was not a major improvement. So Miriam advised me to stop working with letters, and instead do Widget. And she did better. So she did better, she was able to read the pictures, she already had prior knowledge of some words so she just visualized them.” (Gorma, Teacher)

“You have to adjust to the situation. Be flexible, and have the patience. You have to reach them, understand them. Understand their weaknesses and their strengths.” (Sudesh, Teacher)

“I’ve taken a different approach, because my whole thing with these kids is how do we break the isolation, how do we let them know there’s another human being here who’s trying to make contact?” (Miriam, Administrator)

“So we had done switches, see the board after a while with things that were possible, um, I had tried the, what is it, Smart Box or something like that, and that equipment is extremely delicate, and I bought one in the U.S. and brought it back here. It was \$2000. And one of the teachers did something to it and it never worked after that. So those things I didn't pursue. Also many of the switch things, many of the boxes, her fingers weren't strong enough. I mean, even when we put, I mean I tried the splints that you use, the foam ones that you twist if you have a broken finger? I tried those, I mean, I tried many different things and she just had no strength... So, and that hasn't changed, at all. Her fingers are still, in spite of a lot of work, they're still very weak. So we had tried that. Then we went to Head Pointer. Oh, she also met someone, I took her to meet him, who uses his toes. And she loved that because she loves using her feet, but her toes, her toes came in the wrong direction, and I tried many things. I mean we tried taping things on, and she couldn't do it. So then we went to Head Pointer. And I couldn't get one here, I ended up ordering one from the US and somebody brought it over, I think it was about \$300, and it turned out to be missing a part, and she had to take it back with her. I mean it took another 6 months to get it back, and a lot more money.” (Miriam, Administrator)

“Like if you are teaching somebody, suppose you are teaching a subject like Geography, and you are talking about, say, India, no you are telling everything orally to the children, and you are showing maps and all those, so how to include that child, so the child is nonverbal, so then you should have some flash cards, some pictures, with, somehow where the child will nod, or the child will read, and then you have options, so there is lot of work which the teacher has to do.” (Aesha, Special Educator)

“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)

### **3. Providing other resources (e.g. technology)**

“And that's more important than what we teach them, and that's the whole thing that is a conflict for me in how it's done. I'm more interested in knowing how this child expresses themselves, how we let them know we hear them, than whether they can identify a hat or a pen.” (Miriam, Administrator)

*Shishur Sevay also provides resources such as technology relevant to the needs of specific girls:*  
 “We have a Tobii eye tracker which is the most advanced technology in communication at this school...I had been following the technology because I really believed what would ultimately help (Gitka) the most, since she was...desperate to communicate. (Miriam, Administrator)

*Dance classes and field trips are also an important part of the Shishur Sevay model of inclusive education:*

“Mummy wanted it to be like an inclusive dance he [the teacher] always keeps thinking of how to involve everybody and so that because it gives the kids happiness so he is constantly thinking of how to do that and choreograph or how to do the dance so that everybody can be involved.”  
(Samir, Dance Teacher)

## VOICES OF THE CHILDREN OF SHISHUR SEVAY

*The students spoke about:*

1. *The relationship of big girls to little ones, and to little ones facing discrimination*
2. *Their experiences at other homes/schools*
3. *Their aspirations*
4. *Improvements they want (also repeated under the Improvements section of the report)*
5. *Places and things they want to see and/or do (the vacation question)*

### **1. The relationships of big girls and little ones:**

*Some big girls express sadness at the discrimination faced by the little ones outside of the home. Others express wanting to spend more time with the little ones, and others discuss methods of teaching their sisters.*

“...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)

PADMA TO A: So, she was saying that because the little ones actually can't go, they don't always go out sometime Bodhi, Sabeena they don't always go with us so she doesn't like that. I mean she is saying she would like to be able to go out with them more often. (Selma, Student)

“Yes aunty, she does. I feel very bad. no one listens...I'm ok I can talk but Gitka can't talk.” (Selma, Student)

“Gitka is 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)

“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)

### **2. Their experiences at other homes/schools**

[At another home] “They didn't like us and we didn't like them.” (Priyal, Student)

“I was in one, before this home I was (at) another home, XXX, 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)

“Good at school but all the friends ask do you have mother? That upset us sometime and now also did, when nobody ask here but still reminding past.” (Komali, Student)

### **3. Their aspirations**

“I want to be an artist only.” (Priyal, Student)

“[I want to be a] special educator...I like to teach student” (Maya, Student)

“I want to teach. I want to teach small babies.” (Premila, Student)

“ [I want to be an] Aunty.” (Selma, Student)

PADMA TO S: Aunty meaning teacher/teaching aunty?

\*Selma nods\*

### **4. Improvements they want (also repeated under the Improvements section of the report)**

“They don’t have much to do, they also get bored...” (Priyal, Student)

“The kids and us if we could go out more.” (Priyal, Student)

“The house will be bigger, there’ll be a garden and pond.....not pond, [pool].” (Premila, Student)

“We need many special teachers for the kids and make the place bigger.” (Komali, Student)

“There are more children, who are behind us, like [name of other home] there are many children like Gitka and Bodhi and there no one looking (after) them. Somebody left them there...they are also crying, I don’t know...more people need to help.” (Komali, Student)

“And the first expansion would be the school, where we also bring in children from the community.” (Miriam, Administrator)

[On bringing in other students] “There are more children, who are behind us, like [name of other home] there are many children like Gitka and Bodhi and there no one looking (after) them. Somebody left them there...they are also crying, I don’t know.” (Komali, Student)

ANJALI: So do you wish that you had more girls coming in?

KOMALI: Then more people need to help.

### **5.Places and things they want to see and/or do:**

PADMA TO A: She wants to go to Vizag again. (Maya, Student)

“Nicco park” (Premila, Student)

“Outside India.” (Premila, Student)

“I really want to go only to the forest and see animals...there’s nothing else but animals, plants...I really want to see.” (Priyal, Student)

“To the big park!” (Kanaka, Student)

PADMA TO K: So do you like beaches?.....Do you like going to the beach, next to the ocean....

KANAKA: probably nods her head.

“ I want to go to the hills!” (Komali, Student)

## IMPROVEMENTS AND INTERNAL CHALLENGES

*There is a need for:*

1. *More space*
2. *More staff*
3. *More equipment for activities*
4. *More activities in general*
5. *A sustainable funding source*

### 1. More space

*A few teachers and staff members suggested that more space and more staff would allow Shishur Seva to better serve its students. Some participants spoke about space for free time activities:*

“The house will be bigger, there’ll be a garden and pond.....not pond.” (Premila, Student)

“To do better, if there is more space kids can run around and play and I would like it even more. I’ll be happier.” (laughs) (Champa, Massi)

*In addition, some of the current spaces are not accessible and so accessibility needs to be improved:*

“So that’s the problem. And eventually, I mean our next building, has to be accessible.” (Miriam, Administrator)

INTERVIEWER: I think both would be the ideal but I also agree that having to rely, I mean that’s one of the reasons I was telling you why I only live on ground floor apartments is that I don’t like to rely on lifts, because they break and you’re stranded.

### 2. More staff

*More staff is needed if the school is to expand, but participants expressed that more staff now would also be helpful:*

“Obviously more (wo)manpower/people...when I had come mummy had said that give them more time. I keep very busy in my work, dance is my work, it’s my love. It’s my work also and my love also. I loved it is why this turned into my job. Dance is like worship to me and I am blessed to able to help them dance, I mean staying with them and not everybody gets this opportunity that’s a big blessing for me so off course more (wo)manpower. The girls here have a lot of patience that they do it with them. Such patient girls and boys are really needed, otherwise it’s very difficult to do with them. The kids are growing bigger with age so doing it with them. Recently we have had some problems in doing it with them. 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)

“We need many special teachers for the kids and make the place bigger.” (Komali, Student)

“There are more children, who are behind us, like [name of other home] there are many children like Gitka and Bodhi and there no one looking (after) them. Somebody left them there...they are also crying, I don't know...more people need to help.” (Komali, Student)

### **3. More equipment for activities**

“And then we're going to get smaller trunks like we have for sewing, because we can put those up nicely with just a label that says arts and crafts or costumes or whatever, and I want to have several small trunks then.” (Miriam, Administrator)

“The wheels get stuck sometimes, they are not very smooth, so in terms of dance that becomes so like if those could be improved and a little more around the chair that makes it easier to move, more graceful to move the chairs around, and he also had said that the girls actually do have a lot of patience and he feels honored to work here and be able to do this and sometimes the little ones do.” (Samir, Teacher [as spoken by PADMA])

“So tomorrow is going to be spent cleaning out lockers, maybe going through books and getting rid of extra textbooks. We're gonna keep one to two copies of everything, and there are a lot of books we'll never use. Obviously if we expand we're gonna get new books, and figure out which books then.” (Miriam, Administrator)

“Yes the harness I think when the harness is made, not everyone makes harnesses I think there are some particular people who do it, we have got it made. We have to think about the harness...Like near the shoulders when they carry them it hurts them if this (the shoulder strap) could be thicker or wider and as the kids are growing we'll have to think about the harness also. We'll have to get a bigger one, keep extra cloth so we can open it later (to make it bigger).” (Samir, Teacher)

“I saw there is a chair (with wheels) so let's use this in some way, harness is there let's do something with the harness, I have thought that way so in the future as the girls are carrying them and they will be carrying them if it's a little convenient for them. Maybe I will talk to mummy or you all can talk to mummy, like some chairs have wheels but not all of the have wheels (I think he meant the wheelchairs have wheels and the other chairs the ones with the castor wheels are harder to push around) so if all the chairs had that then it will be easier for the girls to handle it, it'll be less hard work for the girls, for dance. The chairs (he has been using the term for vehicle but he means the chairs with wheels) have wheels but not all chairs have it, if they are there for dance.” (Samir, Teacher)

“A little smooth [wheels] and for dance there are many barricades if we could open those and make them round then the dance movements would be easier.” (Samir, Teacher)

### **4. More activities in general**

“They don't have much to do, they also get bored...” (Priyal, Student)

“The kids and us if we could go out more.” (Priyal, Student)



## 5. A sustainable funding source

“We'll check that out. We're totally nonprofit. We don't have a profit to sell. Okay, they must have a printed list of requirements. So that's what we have to find out. Maybe you can find that out online?” (Miriam, Administrator)

“To take on running other centers is a nightmare. And it can eat you up. So I would hope to get other NGOs, I would really hope to get the government involved. And there is a place for , I talked with Ian, for foster group homes. That's the category we fall into. And we'll also be applying to, looking at UNICEF. They're all looking for innovative examples of group homes and particularly of inclusive group homes. So we're already there. And we can truly describe ourselves as having a living center, a school, and a learning center with research and teaching. And what he said is, and there are two ways to do this.” (Miriam, Administrator)

OTHER TEACHER: “One more point, because Priyal is painting so well, why not make an exhibition? And we can sell those pictures”

“If we can get a big publisher who wants it they can buy it from us. This is what I did in the US. I couldn't find a publisher, I did it myself, and then Random House bought it from me. After that we can talk about an exhibition of her work. In fact we could sell the books, we could talk about- -I mean the question of sales is always complicated, I mean you don't want to sell your originals not until they're worth a lot of money. I want to know more about it before we try to do it. I also want to protect her and her privacy at this point. I want her education to go on, I don't want pressure on her, and I never want to use our girls to make money.” (Miriam, Administrator)

## CHALLENGES WITH THE COMMUNITY

*In summary, the community and the center often have different goals. The Shishur Sevay administration is concerned about the inflexibility of some community systems.*

“The community only cares about the immediately local. I mean I had somebody working for me who worked on the other side of the road. And that's a different district. So that didn't consider local. It's also very political. And both the parties that were in power here demanded that basically they place a person on the payroll. And I refused. Because I just said I don't hire people unless I can fire them, and I can't fire a government, you know a political appointment. So those were ongoing battles that over the years I mean there were many death threats, there were riots here, they wouldn't let the police in, and we rode it out. I rode it out. I just said ‘You're not getting anything, I'd like our kids in the house with the staff, and go out front and say get out of here’. I mean, I became an immovable object.” (Miriam, Admin)

“Yeah, forget about inclusion even, teachers here, oh let me give you one more example of the rigidity of the system here, let me go back to IICP. Just recently we had, a year ago, we had a group of occupational therapists and other people come from Australia as part of an equal health volunteer program they have. They've been here before. And this time they said your chairs are too small, you need more chairs, and you know bigger chairs and all that. And I said fine. I mean and so we arranged for the carpenter to be here so that they could do drawings and measure and they even got one of the part of the chairs built in the 4 days that they were here, the carpenter was able to produce something. And it was all measured to what these experts from Curtin University and other places in Australia felt were right in terms of the arm rest heights and all of that. So then what we found is that the carpenter hadn't understood about not having any rough corners and so GITKA was kicking and they were scratching themselves and so we needed to put molding on the side. And BIMAL and I went to the lumber mill because by then our carpenter was giving us a hard time, he didn't want to do it. I mean it wasn't about money, it's, we couldn't conceive of there being a problem, so we just went to the lumber yard, and when we went there we discovered there's a whole group there working on chairs clearly for children with disabilities. And they looked like the same chairs that were produced for IICP. And so we said ‘Hey great maybe you guys can help us?’ And we have a number of chairs that we need some changes to, and stuff like that. So the guy came back here with us, we brought him back in the car to look. And he walked in and he saw the chairs, these two, these new ones especially which look like royal thrones, and he started saying ‘No no no no I have to totally rebuild these these are wrong, the arm should be here, the arm should be here’, I mean he was just Ah, he was very upset that we were using these chairs. And he said ‘I've been doing this for 25 years for IICP, and this is how it has to be measured’, and so I tried to explain, and I had somebody translating, that these people were occupational therapists from Australia, nothing, I mean we had to take them back and not have them do anything for us, but that's IICP hasn't changed in 25 years. I mean, that's the um, and all these ideas that I have, the technology, they don't have any of the technology, they're set in their ways, um and they don't want new ideas. They really don't. Neither did REACH. They're, and any of the teachers I hire from them, I mean I don't even hire them anymore because they only know how to do one on one, they don't know how to do any kind of group activity, and no matter, they don't know how to assess, they come out of training not knowing how to write assessment or report or anything or even notes and what you write, and they all they don't assess they just every time you hire a new special educator they start with

first the child has to learn to bathe the doll. And I remember one teacher was having the hardest time I've watched her struggling with Gitka, and a month later finally she said 'you know I'm having a really hard time with Gitka', they were still fixed on washing the doll because Gitka hadn't passed that yet, and I finally, she said 'first of all, all she wants to do is talk to me first. She won't do anything until I talk to her.' And I said 'Well that's okay.' And she said 'and I can't get her to help me wash the doll.' And I said, 'Gitka doesn't like dolls. I mean she has no interest in dolls. She has no interest in bathing dolls. She has no interest in feeding the dolls. Gitka doesn't like dolls at all.' And it just, it took forever to for this person to, it never occurred to her that Gitka doesn't like dolls, and then get a new teacher and they're back to bathing the dolls. I mean we would laugh about this but you couldn't get them off track. It's like they knew the protocol and you couldn't pull them off that track." (Miriam, Admin)