



**Improving Educational, Developmental, Economic and Emotional Outcomes for 70 Children with Disabilities, 70 Primary Carers and up to 70 Sibling Carers in Bangalore, India**

A partnership between Shristi Special Academy and Carers Worldwide and funded by the Educational Opportunity Foundation

Evaluation completed and report written by Joyatri Ray

## Acknowledgements

As the evaluator and report writer, I would like to thank all those who made themselves available for interviews, in particular the Teaching staff members, Siblings, Psycho-social counsellors and the Senior staff members.

A special thanks to all Primary Carers (Mothers) who have shared their views, opinions, thoughts with me. Without this group of carers this evaluation would have been incomplete.

I would also like to acknowledge the support extended by the Carers Worldwide Team for smooth functioning during the evaluation period and thereafter.

Joyatri Ray

## Contents

Acknowledgements.....	1
Project Information.....	3
Project Impact, Outcomes and outputs.....	3
Scope of the Evaluation .....	4
The Evaluation Process .....	4
The Evaluation .....	5
Organisational preparedness .....	5
Relevance .....	7
Additionality .....	7
Effectiveness.....	8
Achievements in a nutshell .....	10
Challenges.....	11
Dependency on Shristi among primary carers.....	11
Economic stability/independence for primary carers.....	11
Recommendations.....	12

## Project Information

<b>Project Title</b>	Improving educational, developmental, economic, and emotional outcomes for 70 children with disabilities, 70 primary carers and up to 70 sibling carers in Bangalore, India
<b>Project Summary</b>	The aim of this project was to support the learning and development of 70 disabled children and to promote the emotional and financial wellbeing of their carers through programmes of education, peer support, information and advice, mental health support and income generation initiatives, alongside capacity strengthening of SSA staff.
<b>Funder:</b>	Educational Opportunity Foundation (formerly the British and Foreign Schools Society BFSS)
<b>Grant holder:</b>	Carers Worldwide
<b>Implementing Partner:</b>	Shristi Special Academy (SSA)
<b>Country:</b>	India
<b>Project duration:</b>	December 2021 – November 2023

## Project Impact, Outcomes and Outputs

The lasting impact of the project will be a cohort of up to 70 children with disabilities aged 6 – 16 who will have received an education that ensures they reach their potential, enabling them the best chance of living as independently as possible. Sibling carers will be able to focus on their own education, increasing the options available to them once they become adults and alleviating some of the worries about what their own futures will look like. Primary carers will be able to pursue livelihood activities, securing an increased regular income for the family, thus lifting them out of poverty. Carers groups will provide ongoing peer support for primary carers and improve emotional wellbeing, in turn improving the quality of care they are able to provide to their disabled children. Coping mechanisms that carers learn through counselling sessions will be able to support their emotional wellbeing beyond the life of the project.

## Scope of the Evaluation

The outcome/purpose of this evaluation should be focused on the changes in the children's learning experiences and development; the changes in the emotional and economic wellbeing of their primary carers; and the changes in their siblings' educational experiences and emotional wellbeing.

The project outcomes are expected to have been achieved by the end of the funding period. Baseline information and the project log-frame should be examined and can be referenced as part of the evaluation.

By the end of the project, results may not be exactly as planned. However, there will still be impact and change, both intended and unintended, positive and possibly in some cases negative. This information needs to be recorded in the final evaluation. Through an honest examination of what actually happened against the planned results, important lessons for future projects can be learned. The main objectives of the evaluation are:

- To assess the extent to which the goal, outcome and outputs of the project were achieved
- To identify the impact of the project and the degree to which this impact is likely to be sustained
- To identify the key achievements, challenges and lessons learnt from the project
- To make recommendations for future projects involving Carers Worldwide, SSA, other Carers Worldwide partners and other organisations

## The Evaluation Process

### **Purpose of the final evaluation**

The final evaluation will be used to inform the future practice of Carers Worldwide and SSA and to produce recommendations which can be applied in future projects across India and elsewhere. The results and recommendations will be shared with the donor and will assist their understanding of the grantee's performance at the project level. The report's recommendations and findings will also be disseminated across the networks of Carers Worldwide and SSA.

### **Evaluation methods**

The methodology adopted and used was based on a continuum approach that started by assessing the organisational strength to deliver such a programme. It then delved into collecting evidence and data through various modes of enquiry such as case study approach and timeline approach to confirm the achievements, cull out learnings, challenges and opportunities that would help in deriving recommendations for long-term integration with overall organisational strategies and the approach of Carers Worldwide.

The following individual/groups were interacted with as part of the evaluation process:

- SSA senior and teaching staff
- Children
- Primary carers directly involved in the project activities
- Sibling carers involved in the project

- Fathers/other family members

The evaluator in collaboration with SSA selected a representative sample of primary carers and sibling carers to interview, ensuring a cross section of participants were included as follows:

- Type of disability they are caring for
- Severity of disability they are caring for
- Socio-economic status – age, their own disability or health condition
- Level of engagement with the project

## The Evaluation

### Organisational preparedness

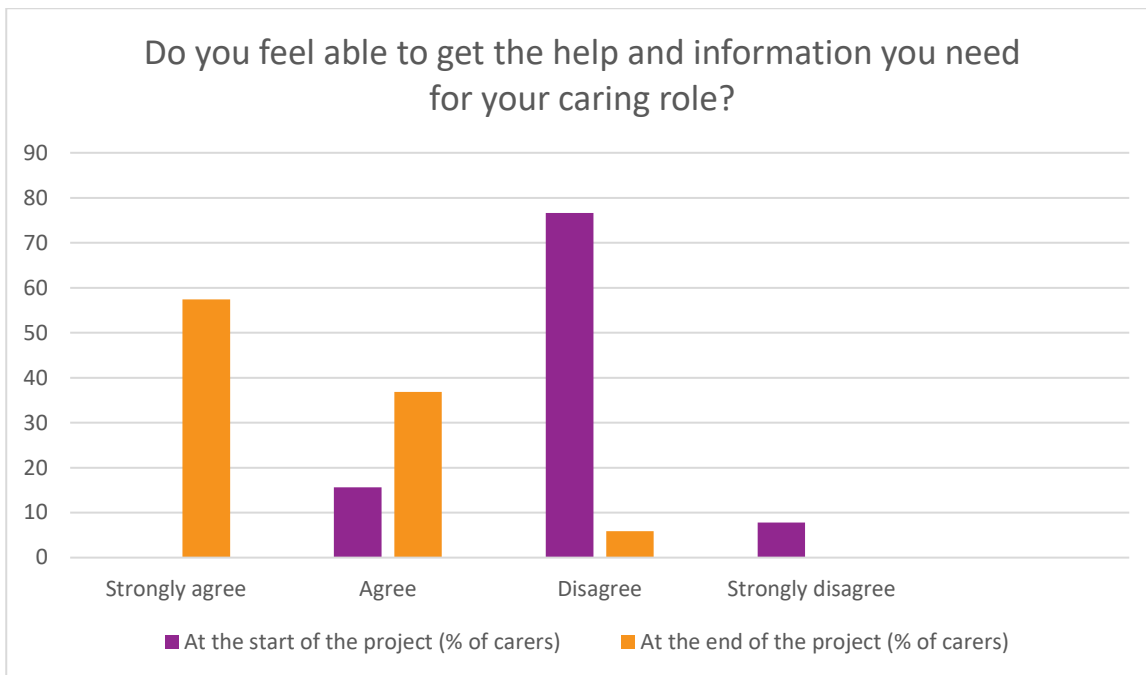
*“Empowering carers to face social challenges through awareness programmes, being sensitive to their feelings/emotions, increasing their moral responsibility, and organising health camps- thereby improving the responsibilities of carers in all areas.”*

Quote from group work with mothers as primary carers

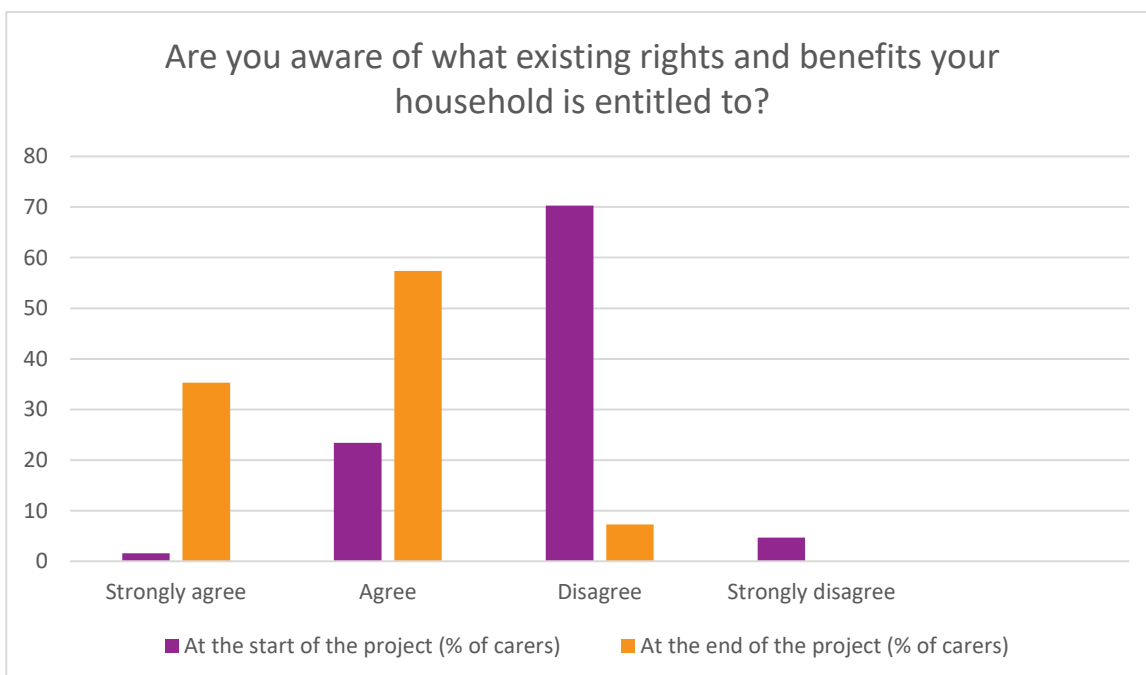
SSA is well positioned to improve the quality of life of the persons with disabilities, protect their rights, provide equal opportunities and ensure full participation and acceptance in the society. The organisation has well-equipped, trained human resource who can deliver quality services. The uniqueness of SSA lies with its intense engagement with each child to customise their service to align with the needs of each child/ person with disability. The organisation invests in training their team members with learning exercises from their daily

interaction with children. The organisation is also very strong in documentation, tracking progress, identifying challenges and opportunities for each disabled child who is under their care services.

Recognising that these children require as much care and support at home for their sustained development as possible, given the severity of their disability, primary carers, often mothers form an integral part of SSA’s work and engagement. Through this project with Carers Worldwide, the organisation has formed carers groups for peer learning and sharing. SSA trains primary carers with techniques and methods of supporting their child with disability. 64 out of the 68 carers surveyed at the end of the project reported their child had learned new skills such as feeding or dressing themselves, meaning they were now less dependent on their carer. As part of the project, carers had access to counselling and all but one of them found this helpful. Other results achieved during this project can be seen in the table below. The organisation is well poised to continue with this much-needed service for children living with disability.



At the start of the project, 84.4% of carers felt unable to get the help and information they needed for their caring role. By the end, that number had dramatically reduced to only 5.8%, with 94.2% expressing confidence in finding help and information.



At the start of the project, 75% of carers were not aware of their and their household's rights and entitlements such as government benefits. By the end of the project, the information sharing and peer support provided meant that this figure had reduced to 7.3% with 92.7% of carers aware and confident to access the benefits which are their family's right.

## Relevance

*“SSA is not an organization limited to working for the development of people with disabilities. It has succeeded in upholding human values. Our heartfelt thanks and gratitude to SSA for that.”*

Quote from group work with mothers as primary carers

The joint work of SSA and Carers Worldwide is highly relevant. The project is a part of SSA’s initiative to ensure children with disabilities become empowered individuals to achieve their maximum potential through therapeutic interventions and special education.

The interventions with primary carers were focused on stabilising their emotional well-being that in turn resulted in quality care for their disabled children. Engaging with carers, understanding their mental health and treating them as individuals with their own identity is unique in itself. Recognising that primary carers have their own aspirations, perspectives, ambitions and identities, SSA’s effort is focused on helping primary carers to realise their reality of taking care of a child with a disability. Through the capacity building inputs of Carers Worldwide, the resulting dual strategy of helping primary carers with coping mechanisms on one hand and on the other teaching/training them on techniques and methods to help/support the disabled child to become independent, have made SSA a unique institution. The relevance of such an institution in the overall disability sector is high.

*“SSA has become so much a part of our life that we feel we don’t exist without SSA.”*

Quote from group work with mothers as primary carers

## Additionality

*“Carers who are affected emotionally and economically are helped in getting the government benefits. SSA’s role in empowering carers emotionally and economically is commendable.”*

Quote from group work with mothers as primary carers

In this context of relevance, the method of additionality was used to understand the opportunity loss in case this project was not implemented. SSA has always focused on primary carers to ensure that children living with disability are cared for at home adequately and appropriately. SSA believes that without the active engagement of primary carers, the disabled child will not be able to progress as the approach/treatment requires structured well-disciplined intervention at home and at SSA. Hence, SSA already had this

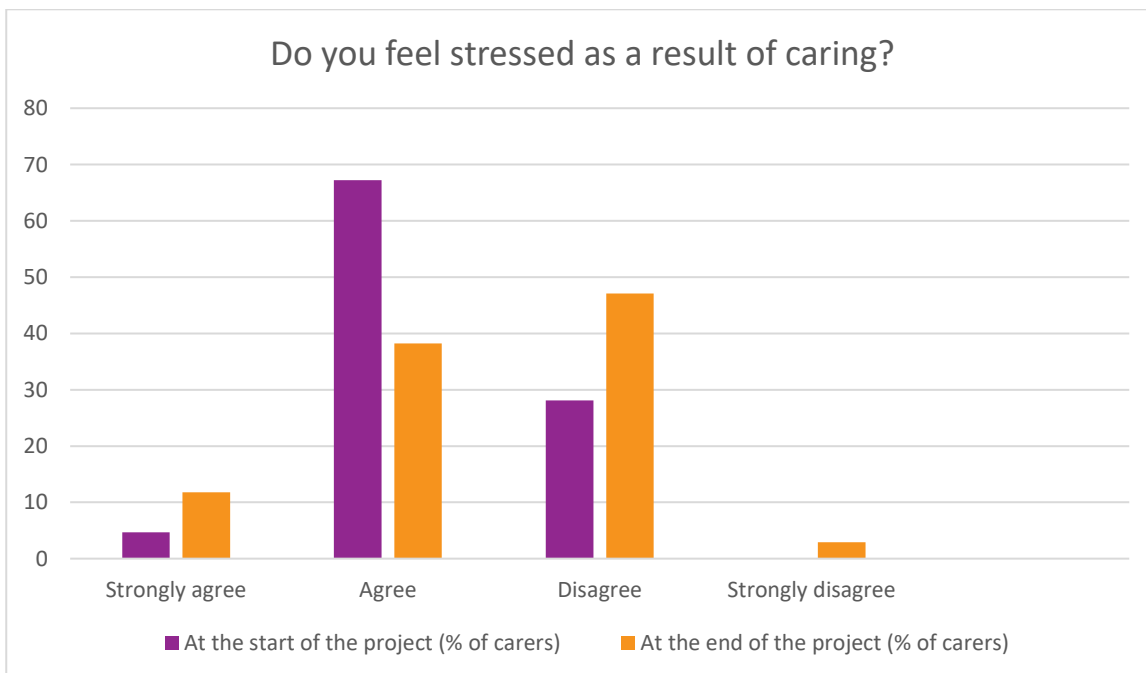
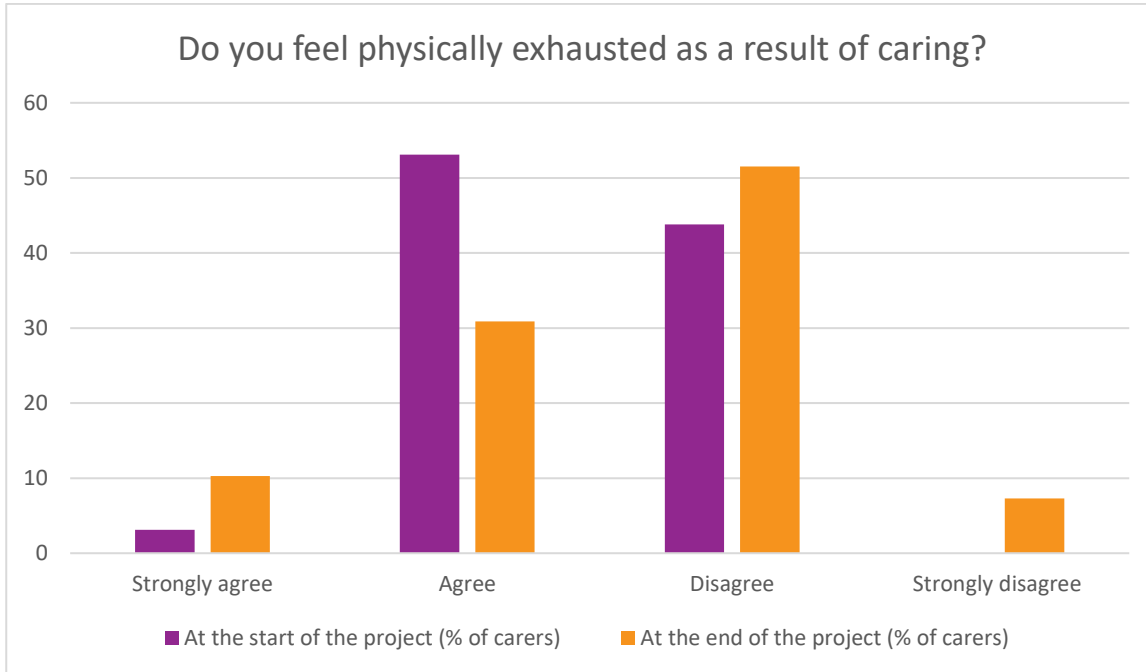
focus on primary carers who are often mothers. But with the unique support offered by Carers Worldwide and shifting the focus onto the impact of caring and the needs of the carers themselves, this project has given an impetus to enhance existing interventions with primary carers by focusing on the well-being of primary carers – attention to their mental health and requirements. This project has brought in much-needed attention for the primary carers. It upholds the well-being of primary carers as an integral part of quality services for children living with disability.

## Effectiveness

*“Mutual understanding and bonding helps carers in one platform.”*

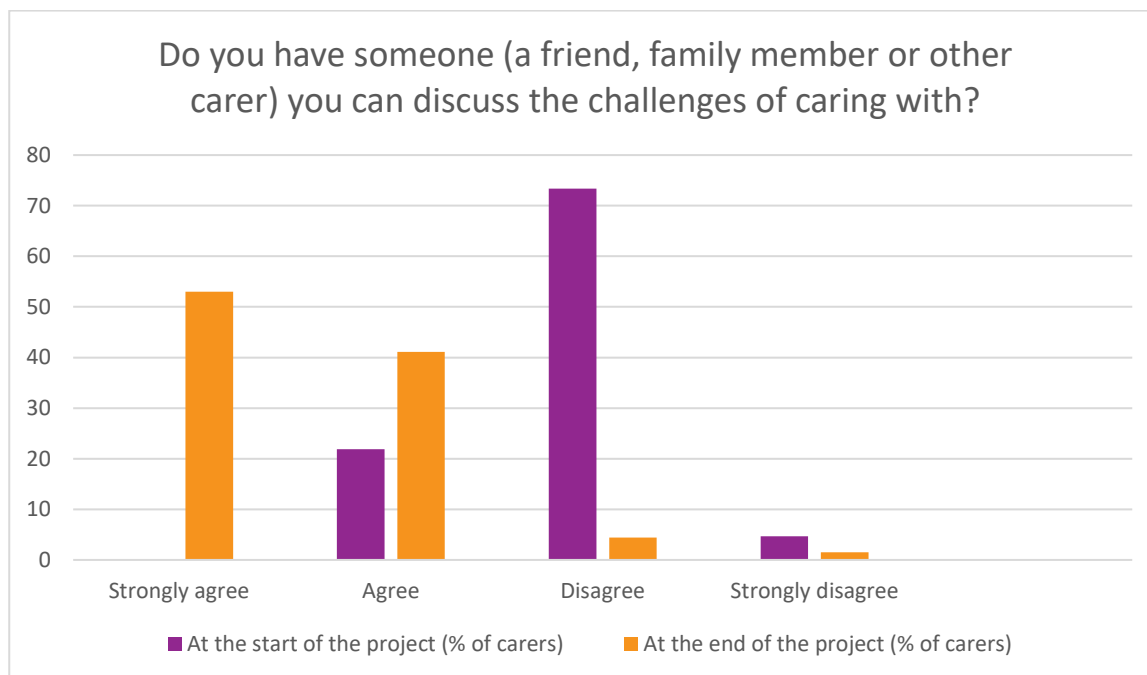
Quote from group work with mothers as primary carers

The project has achieved its stated results as described in the log-frame. The interactions with the stakeholders highlight that there has been considerable progress in terms of developing a base/ foundation to consciously work with primary carers.



Exhaustion and stress levels can vary depending on a variety of factors in the carer’s life, how their child is at any one point in time and the current state of family and other dynamics. These can not expect to be influenced by project interventions alone but the trend for most carers involved in the

project has been towards improved physical and mental wellbeing. It is important to work with those carers for whom this is not the case on an individual basis to explore personalised support that will benefit them.



The benefit of the peer support groups initiated by the project is clear here. At the start of the project, 78.1% of carers did not have anyone that they could discuss the challenges of caring with. This figure had reduced to 5.9% at the end of the project with carers forming strong support networks both within the structure of the groups and informally.

While the project was very effective to ensure improvement in education, development and emotional outcomes of 70 children living with disabilities, and the empowerment and wellbeing of their carers, the economic component of this project lacks data to establish any clear findings.

Other factor to highlight here is the need to focus on secondary carers. Secondary carers are most often fathers, siblings or grandparents. It was noticed that fathers as secondary carers, often have the attitude of acting as provider and of “allowing” the mother (primary carer) to take the child to SSA to access care and services. Interestingly, they seem less interested to invest in the well-being of the primary carer or in the disabled child. For example: During the COVID pandemic, SSA reduced their fees considerably, whereas the private schools maintained the fees. Parents would pay to the private school for their non-disabled children but were unwilling to pay the highly discounted fees to SSA for their disabled child.

Involvement of fathers is quite low for multiple reasons a) job roles b) work shifts c) pressure to earn and d) unwillingness.

On another account, initiatives to support education of siblings of the children living with disability was less effective than anticipated as most of the families were able to provide economic support to their non-disabled children to continue with their education. However, it was noticed that providing tablets during the COVID period had a positive impact on continuing education, keeping contact with the family and the disabled child for helping them with treatments and also well-being of the family

*"We are proud to help/support our disabled sibling. We do not feel shy to take them along with us when we go to family gatherings like marriages."*

Quote from group work with siblings

in general. It also enhanced the relationship between the sibling and the disabled child. Now that the children are back in SSA daily, the tablets need to continue to be used productively.

Siblings play a big role in the well-being of the disabled child at home. They are often secondary carers. Their engagement and interaction with the disabled child is

an important component to focus on. Having intensive engagement with siblings during the project has enabled SSA to receive authentic information on behavioural patterns of children with disability at home and also to identify the reason/root of such behavioural pattern. For example: One sibling shared that the disabled child in the family used bad words when they got angry. She shared that this is because her mother uses these words while scolding her children. This information is absolutely important to note for the psycho-social counsellors so that they can speak to the respective mother on the impact of such behaviour on the child with disability.

During the interaction with siblings, it was found that primary carers (mothers) do not always share complete information with the teachers and counsellors on the behaviour of disabled children at home. One way to address this matter, would be to have a sibling interaction circle at least once in every month for a) sibling well-being – a space to share, a space to learn and b) to assist in understanding the family dynamics

*"I love my sibling very much. But sometimes he is very aggressive and uses bad words. I don't know what to do then. But I love him."*

Quote from group work with siblings

Overall, the project has been effective in highlighting the need for focused, structured programmes for primary carers and sibling carers.

## Achievements in a nutshell

- All 70 children have shown progress during this project period.
- Primary carers (mothers) have attended carers group meetings regularly. They are interested to visit SSA as per the requirements.
- Primary carers have shown distinctive positive change in their perspective on taking care of disabled children.
- Primary carers have established a bond among themselves, are better supported and better informed as a result of the carers support groups providing opportunities to share, learn and support each other.
- Siblings are more engaged and have played an active role in taking care of their disabled siblings.
- There is a sense of belonging among the sibling carers. They support each other and they feel proud to take care of their disabled siblings.

## Challenges

The major challenges identified are two-fold a) Dependency on SSA among primary carers and b) Economic stability/independence for primary carers

### Dependency on SSA among primary carers

From the group discussions and interviews with counsellors, teachers and senior management team, the evaluator felt a sense of over dependence on SSA among the primary carers. This is not unusual when the empathetic support structure is found in an institution rather than in their families with the diverse opinions of family members.

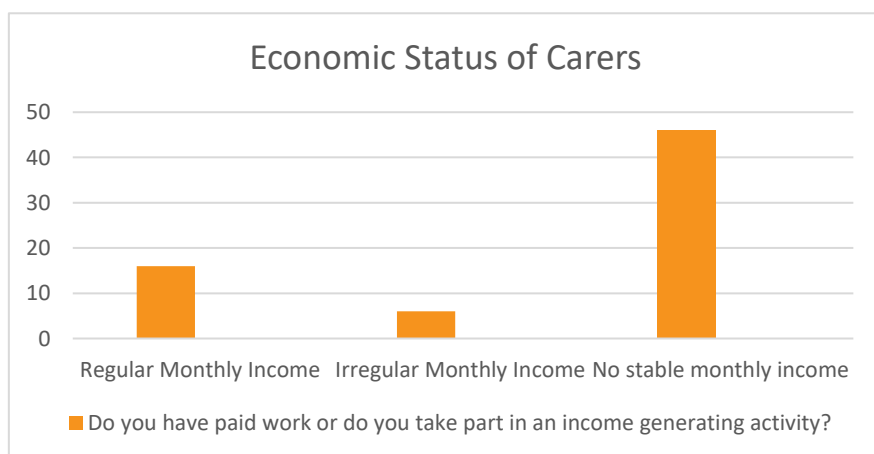
There is evidence that primary carers have done well during the COVID period in terms of maintaining the discipline and routine of their disabled child as advised by SSA counsellors, teachers and senior management, and facilitated by the provision of the tablets. As soon as children returned to schools, it is observed that primary carers found solace in SSA. This shows that primary carers may not have an enabling environment at home that supports them to continue taking care of their disabled child.

Other important factor to note here is that primary carers are confident that SSA will take care of these children, come what may. Home visits by counsellors/teachers have reinstated this belief.

From the counsellor/teacher's perspective, home visits help a great deal for two reasons a) counsellors/ teachers understand the home context and b) families of children with disability feel supported and develop a sense of belonging along with demonstrating to their families and neighbours that they are not alone, SSA is with them This trust and belief and has resulted in a high dependence on SSA by the primary carers.

### Economic stability/independence for primary carers

This is an area that requires deeper assessment and understanding. Primary carers (mothers primarily) are very keen to learn a skill for income generation. They know that if they start earning, they will be able to support the child and themselves better. But still, there is some reluctance to go through systematic training prior to an income generation programme.



Most of them are interested in tailoring as they believe this can be done from their homes. Around 10 women are presently engaged in tailoring after receiving training from SSA through the project. Others have undertaken computer training and oil production training at SSA's new unit. But broadly speaking, the economic empowerment of primary carers remains a grey area.

From the group work conducted as part of this evaluation, certain reasons were highlighted by the primary carers:

- a) It is extremely difficult to balance household chores, caring for the disabled child and learning/practicing a trade.
- b) No time to relax – whatever little time they get in between their daily routine, they prefer that time to rest or relax. This is a very prudent point to note as primary carers may not have adequate time or energy to invest in learning/practicing a trade.
- c) After long years of taking care of the disabled child at home, the fatigue that sets in among the primary carers, results in apathy to take up/learn anything new.
- d) There is a sense of getting a quick return from learning/ practicing a trade which is not the reality. Investment of time and patience to learn a trade and then to access income opportunities is a difficult proposition for these mothers.

To mitigate this challenge, following support from Carers Worldwide, SSA set up facilities for skill training in the centre itself but still the interest is quite low. Hence a separate in-depth assessment needs to be carried out to understand the challenges that is faced by these parents and the strategies needed to address those.

## Recommendations

SSA is a 'one of its kind' institution in the field of disability. The vision and the belief of everyone at SSA in "unconditional acceptance, positivity and an unwavering belief that there can be improvement in every person with disability, irrespective of the nature and severity of disability" makes this organisation unique. It strives to ensure the persons with disabilities become contributory members of society through education, skills development and vocational training leading to employability. Similarly, Carers Worldwide is a unique organisation working strategically to achieve its vision of "a world in which every carer is valued and their needs are met." Together in this project SSA and Carers Worldwide have and will continue to create an enabling environment of empathy, care and services for people living with disability and their families. Carers be it primary or secondary become the backbone of such an initiative. With this understanding, the following recommendations are made:

### **Expand the reach of care to all carers in the family (primary, secondary, tertiary)**

- Assess the need of primary, secondary and tertiary carers in the family for each child and customise the care to address their need for social and emotional well-being.
- Categorise the carers based on the condition of the child (severity of the disability) to engage more effectively on their well-being.
- Initiatives/interventions to be customised for primary carers based on the child's condition and care needs of the child. For example: The skills training for primary carer for income opportunities could be different for primary carers with children who have severe disabilities, moderate disabilities and mild disabilities as the dependence on the primary carer will differ.
- Explore engagement with fathers/male family members to facilitate enabling the family environment by designing programmes/initiatives that help fathers/male members of the family to engage with the disabled child.
- Continue with regular counselling for primary carers.

- Document stories of change from the carers perspective as an acknowledgement of their efforts in taking care of their children. This is an act of empathy and not a reward recognition.

### **Enhance engagement of siblings**

- Engage siblings to form an ongoing peer network for sharing and supporting each other.
- Enhance knowledge and skills of siblings as secondary carers to support primary carers.
- Facilitate joint activities with disabled children and their siblings at regular intervals. For example: Develop a project that the siblings of the family would take part in together and have a recognition programme for best coordinated project (painting, making a creative piece or any other as per the ability of the disabled child).
- Provide linkages for accessing scholarships, government schemes, skill trainings rather than supporting their education financially.

### **Economic independence of primary carers**

- Conduct an assessment on the interest and time availability of the primary carers with details on the challenges faced by them to invest time and effort to learn/practice income generating activities.
- Ensure that the offered trainings are aligned with the time that primary carers can invest (taking into account that they may have free time but they may like to keep that time to relax rather than engage in another activity).
- Develop a plan for introducing incentive schemes for primary carers that would make them interested to learn a skill for income generation.

### **Institutional knowledge building**

- Digitise data, documentation and tracking.
- Prepare a dashboard for registering, tracking and monitoring details of children with disability and carers.
- Introduce app-based data entry mechanisms for easy access and for building institutional knowledge.