A Study on
Evaluation of the Scheme
'Budgetary Support to National Trust'

Submitted to
Department of Empowerment of Persons with Disabilities
Ministry of Social Justice & Empowerment
Government of India

National Institute of Labour Economics Research and Development

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(Dr. Pitam Singh)
Project Leader

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Executive Summary

People with disabilities (PwDs) encounter many disadvantages in society and are often subjected to stigma and discrimination. Marginalised and disproportionately poorer, PwDs are particularly vulnerable to crisis. Furthermore, these people remain largely excluded from political and civil processes and voiceless on crucial issues that affect them and their society.

The Constitution of India ensures equality, freedom, justice, and dignity to all its citizens in order to promote the establishment of an egalitarian and inclusive society, as is reflected in Article(s) 39 and 41. For empowering PwDs, numerous momentous developments have been made in the global disability rights movement, culminating in the adoption of the United Nations (UN) Convention on the Rights and Dignity of Persons with Disabilities on 13 December 2006. It touches on almost the whole gamut of issues such as equal access to employment, education, healthcare, voting rights, equal participation, right to privacy, respect for choices of marriage and reproduction, availability of mobility aids, and independent living.

The longevity of people with intellectual disabilities is increasing in developing nations. However, developing nations lack a proper system of care for persons with intellectual disabilities. Until now, the care has been provided by parents and relatives in the home environment in developing countries, but this scenario is also changing. Therefore, a plan of care for this population needs to be explored, which is also feasible and replicable. The National Trust is a statutory body of the Ministry of Social Justice and Empowerment (M/O SJE), Government of India that has developed a comprehensive plan of care for people with intellectual disabilities. Various types of day care, and residential and health insurance schemes have been implemented under *t*he National Trust for the welfare of persons with autism, cerebral palsy, mental retardation, and multiple disabilities. It extends to the whole of India, except the state of Jammu and Kashmir. However, a pertinent question arises here that do these schemes have really helped PwDs and even the parents/relatives to have a better life after availing these schemes?

In this context, the Department of Empowerment of Persons with Disability (DEPwD) has entrusted NILERD to conduct an evaluation study to assess the scheme 'Budgetary support to National Trust'. Based on the suggestions made by the Trust, the present study focused on analysing the impact only in the case of day care, residential care, and health insurance schemes.

For the analysis of various study objectives, the present study used both secondary and primary information. Secondary information on fund allocation and the list of beneficiaries under different ongoing schemes was collected from the Trust. Primary information was collected through structured questionnaires designed for both the implementing agencies and beneficiaries. Besides, focus group discussions (FGDs) of the implementing agencies of various schemes were conducted to understand the issues and impact. A 360° evaluation approach was followed covering various stakeholders associated with the schemes. The stakeholders included under the scheme were the beneficiaries,

implementing agencies such as the DEPwD, M/O SJE, registered organisations (ROs), and State-level Nodal Agency Centres (SNACs), state-level coordination committees(SLCCs), and local-level committees(LLCs) at the district level.

The findings of the study from FGDs suggest that the schemes have been quite effective in empowering and instilling hope in the life of special children who otherwise would face a life full of darkness. This was possible only due to the financial support extended by the Trust to the ROs. The financial support provided by the Trust has enabled the ROs to not only maintain quality infrastructure in the centre in terms of building a medical room, activity room, recreation room, and other facilities to motivate and encourage the children but also helped them in hiring special educators, physiotherapists, counsellors, caregivers, Ayas, and trainers to keep the children physically fit and improve their learning skill and mental ability. Although funding has never been sufficient to meet the huge market demand, nonetheless support given by the Trust has been a great source of help to fulfill the dreams of millions. The success story of the little girl Afrin Khatununder the Disha scheme from West Bengal, Ms. Sandhya under the Samarth-cum-Gharaunda scheme from Tamil Nadu, and Mr. Rajesh under the Disha-cum-Vikaas scheme from Gujarat are heart touching examples of nothing is impossible for them if we look after their childhood and groom them with proper care.

The key findings of the study on various schemes are highlighted below.

A. Niramaya (Health Insurance Scheme)

Regional Distribution of Beneficiaries

- Majority of the beneficiaries (70.6%) belong to the rural area and the rest of the beneficiaries (29.4%) belong to the urban area.
- More than three-fourths of the beneficiaries (78.9%) belong to the southern region and the rest of them belong to all other regions. Within the southern region, Kerala alone represents 84% of the beneficiaries.
- The distribution of beneficiaries under the Niramaya scheme into two income groups indicates that more than 80% of them belong to non-below poverty line (BPL) income groups in northern, western, and northeastern regions.

Basic Profile of Beneficiaries

- Of the sampled beneficiaries, around 66% are male members and the rest are female members.
- Maximum of them (43.2%) are in the age group of 18–30 years, followed by 36.9% in the age group of less than 18 years and 15.7% between 30 and 45 years.
- More than 50% of the beneficiaries belong to the other backward castes (OBC) group, followed by 19.3% to the schedule caste (SC) group and 16.7% to the schedule tribe (ST) group. Only 1.6% belongs to the orphan group.
- Maximum beneficiaries have an educational qualification of upper primary (32.3%),

followed by those who are illiterate (23.9%), and those who have higher secondary (15%), upto primary (14.1%), and secondary (13%) education. Only 1.2% of them have an educational qualification of graduation and above.

- Around 67% of the beneficiaries under the Niramaya scheme belong to the BPL group. Across the regions, while maximum BPL beneficiaries are from the eastern region (76.8%), the lowest percentage of BPL beneficiaries is from the western region (33.4%).

Implementation Process of the Scheme

- Majority of the beneficiaries took the help of ROs to fill the form online. Around 88% of the beneficiaries took the help of ROs, whereas 12% of the beneficiaries filled the form themselves or their parents or relatives filled the form.
- A whopping 95.8% of the beneficiaries reported that the ROs were very cooperative during the application process. Only 4.2% of the beneficiaries were not happy with the service of the ROs.
- Majority of the beneficiaries (57.1%) reported that they received the health card within 15–30 days. Another 20.8% beneficiaries reported that they received the health card within 45–60 days.
- It takes an average of 29 days for renewing the health card. Across the region, while it takes 19 days in the northern region, it takes 30 days in the southern region. At the all-India level, majority of the beneficiaries (59.2%) reported that it takes less than 15 days to renew the health card.
- Timely reimbursement of medical expenses is very important to encourage and attract people to join the scheme. Majority of the beneficiaries (78.4%) reported that their medical expenses are reimbursed in1–2 months.
- Regarding the enrolment process and re-imbursement procedures, majority of beneficiaries gave the rating 'very good' in both the cases. Around 25%–34% gave the rating 'excellent' and 20%–27% gave the rating 'good'.

Quality of Services

- Around 76% of the beneficiaries are fully satisfied with the overall benefits of the scheme. Around 22% of them reported that they are satisfied to 'some extent' in terms of the overall benefits of the scheme.
- In case of services rendered by the insurance company, majority of the beneficiaries (62%) reported that they are 'fully satisfied' with the services. Further, around 34% of the beneficiaries indicated that they are satisfied to 'some extent' with the services.
- Around 32% of the beneficiaries indicated they are 'fully satisfied' with the treatment offered under the scheme, while 65.6% reported that they are satisfied to 'some extent'.

- The quality of grievance service offered to the beneficiaries is strongly supported by the beneficiaries as 54.8% of them are 'fully satisfied' with the grievance services, while 43.7% of them are satisfied to 'some extent'.

Impact of the Scheme

- Majority of the beneficiaries (59.8%) indicated that they are 'fully satisfied' with the scheme as far as their health improvement is concerned after the subscription of the scheme. Around 39% reported that they are satisfied to 'some extent'.
- In case of learning ability, maximum beneficiaries (53%) opined that they are 'fully satisfied' with the scheme, followed by 43.8% who said they are satisfied to some extent.
- Maximum beneficiaries (57.9%) reported that they are 'fully satisfied' with the scheme as far as its impact on their speaking ability is concerned. Around 39% of them also indicated that they are satisfied to 'some extent'.
- About 58.5% of the beneficiaries viewed that the scheme has 'some extent' of impact on interpersonal skills, whereas 37.8% reported they are 'fully satisfied' with the scheme with respect to improvement in interpersonal skills.
- The scheme has a significant impact on the physical strength of the beneficiaries as 61.1% of them reported that they are 'fully satisfied' and 28.3% reported satisfied to 'some extent'.
- An overwhelming 91.9% of the beneficiaries agreed that the scheme has been an important source of financial support for medical treatment. Importantly, more than 90% beneficiaries in all the regions reported in favour of the scheme.
- A whopping 95.4% of the beneficiaries viewed that they are better off than those who have not been able to enrol under the scheme. Across the regions, all sampled beneficiaries in eastern and northern regions reported that they are better off than the others.
- Only 0.2% said the scheme has not reduced their health expenditure burden, whereas an overwhelming 85.6% reported that it has partially reduced the burden and 13.8% reported it has completely reduced the health expenditure burden.

B. Disha (Day Care Scheme)

Regional Distribution of Beneficiaries

- The regional distribution of beneficiaries under the Disha scheme shows that majority of them (41.5%) belong to the central region of the country, followed by the eastern region (16.8%) and southern region (15.6%). The lowest percentage of beneficiaries (6.9%) belongs to the northeastern region.
- In case of four types of PwDs, while on one hand the highest percentage of autism

cases (26.7%) is from the northeastern region. On the other hand, the highest percentages of cerebral palsy (33.3%) and mental retardation cases (44.1%) are from the eastern and central regions, respectively. The central region also reported the highest percentage of multiple disabilities cases (57.9%) under the scheme.

- Except the eastern region, in all other regions, the percentage of beneficiaries of mental retardation is the highest, which falls within the range of 50%–70%. In case of the eastern region, the percentage of beneficiaries (56.4%) of cerebral palsy is the highest, followed by those of mental retardation (35.3%) and multiple disabilities (7.3%).
- In total, 80.5% beneficiaries belong to the BPL income group of families and the rest belong to the non-BPL income group of families. Under the BPL category, the highest percentage of beneficiaries belongs to the southern region (94.1%), followed by those belonging to the eastern region (91.7%) and central region (89.1%).

Basic Profile of Beneficiaries

- Location-wise, more than 80% of the beneficiaries under the Disha scheme are from the rural area.
- By gender, the results show that the ratio between male and female beneficiaries is 3:1.
- Majority of the beneficiaries are from the OBC group (43.5%), followed by the ST (33.9%) and SC (19.4%) groups. Only 1.6% beneficiaries are each from the orphan and other castes groups.

Implementation Process of the Scheme

- More than 90% ROs reported that the enrolment portal of the ministry was user friendly and more than 83% of them said they did not face any difficulties while paying the enrolment fee online.
- More than 91% said that the application process was not tedious, 100% reported officers from the Ministry were cooperative during the application process, and more than 83% opined that they did not face any difficulties while trying to reach out to the concerned officer in the Ministry.
- More than 72% ROs reported that the SNAC visits their centre once every year. Around 18% ROs reported that the SNAC visits their office 1–2 times in a year.

Quality of Services

- A whopping 69.4% beneficiaries/parents reported that they are satisfied to 'some extent' with the services of the special educator, which suggests that the services rendered by the special educator is not fully upto the mark.
- The situation is even worse in the case of a physiotherapist, wherein a significant

percentage of beneficiaries/parents (30.6%) are not satisfied with the services. In this case, around 55% beneficiaries/parents reported that they are satisfied to 'some extent'.

Quality of Infrastructure

- Maximum beneficiaries/parents (66.1%) rated the conditions of the medical room as 'good', whereas the facilities available in the medical room were rated as 'average' by a majority of the beneficiaries/parents (62.9%). A similar result was also noted in case of the activity room, whereas in case of the recreation room, majority of the beneficiaries reported that they are satisfied to 'some extent'.

Funding Pattern and Issues

- More than 90% ROs expressed that they had claimed funds in time and all of them had received the funds in time in case of sustenance cost.
- Around 44% ROs complained that they did not receive funds in time in case of recurring cost, particularly from the financial year 2018–19 and onwards.
- Majority of them (75%) stated that the present fund amount on different heads should increase to more than 5% and the rest of the ROs pointed out that the Ministry should increase the fund amount by at least 5%.

Impact of the Scheme

- A total of 95.2% parents pointed out that they are sending their child to the centre for his/her betterment.
- In total, 4.8% parents reported they have been able to attend to office/business work after sending their child to the Disha centre.
- Around 89% parents said that the scheme has helped them get extra time. The extra time has also helped the parents complete productive tasks and generate more revenue as 98.2% parents are in favour of the scheme.
- Majority parents (more than 80%) reported that the learning, speaking, eye contact, and day-to-day activities of their child have improved to 'some extent'.
- A whopping 82.3% parents reported that their child is better off than other children who have been left out from the scheme.

C. Vikaas (Day Care Scheme)

Regional Distribution of Beneficiaries

- Beneficiaries under the Vikaas scheme are distributed unequally across the regions as the highest percentages of beneficiaries belong to the central region (54.5%), and the lowest percentage of beneficiaries belongs to the northeastern region (0.2%).
- A common factor found in case of all types of disabilities is that more than 50% beneficiaries belong to the central region and the rest of the beneficiaries are distributed among all other regions.
- In terms types of disabilities, maximum beneficiaries have mental retardation. Its range varies from 54% in the eastern region to 93% in the western region.
- The second highest percentage of beneficiaries belongs to cerebral palsy category, and its range varies from 6.1% in the western region to 36.4% in the eastern region.
- Maximum beneficiaries belong to the BPL group in all regions other than the western region. The percentage of beneficiaries in this category of income group varies from 46.5% in the western region to 87.5% in the eastern region.

Basic Profile of Beneficiaries

- By gender, the data shows that the male percentage is around 75% and the female percentage is 25%.
- In terms of social group, majority of the beneficiaries are from the ST group (55.8%), followed by the OBC group (30.4%) and the SC group (10.9%).
- Main occupation of the head of the household of the beneficiaries points to the fact that majority of them are self-employed (43.5%), followed by those involved in agriculture (21.7%) and services (18.8%).

Implementation Process of the Scheme

- Mode of transportation by children from their home to Vikaas centres indicates that majority of the children (41%) travel by their own or parent's vehicle.
- Other modes of transportation used by children are public transportation (25%) and Vikaas centre transportation (16%).
- Parents of around 33% beneficiaries reported that the centre is located between 10 and 15 km from their home. Another 32% pointed out that the centre is located between 5 and 10 km from their home.
- Maximum beneficiaries (35.4%) came to know about the scheme from newspaper advertisements, followed by 33.6% from hospital doctors.
- Majority of the ROs also indicated that they did not find any difficulties while paying

the enrolment fee online and the application process was tedious. The timeline given for the enrolment process was adequate for 92.9% ROs.

- About 93% ROs reported that they did not face any difficulties in reaching out to the Ministry for any clarification during the enrolment process.
- Around 80% ROs reported that the frequency of visit by the SNAC is 'once in a year' and another 15% said that the frequency of visit is'1–2 times in a year'.

Quality of Services

- A substantial number of beneficiaries/parents (25%–35%) reported they are not satisfied with the services of the physiotherapist, counsellor, speech therapist, and caregivers, and Ayas, which is a matter of concern as far as the quality of the service is concerned.

Quality of Infrastructure

- Maximum beneficiaries (97.8%) rated the conditions of the medical room as 'good', whereas the facilities available in the medical room were rated as 'average' by majority of the beneficiaries/parents (87%).
- Similar results were also reported in terms of conditions and facilities available in the activity and recreation rooms.

Funding Pattern and Issues

- About 90% of ROs reported that they had claimed fund in time and all of them had received fund in time in case of setup cost.
- In case of sustenance cost, a whopping 87.5% of the ROs said that they had received the fund. However, in case of recurring cost, a substantial number of ROs (44.4%) reported that they did not receive the funds under the same head.
- Majority of them (75%) stated that the present fund amount on different heads should increase to more than 5% and the rest of the ROs pointed out that the Ministry should increase the fund by 5%.

Impact of the Scheme

- Around 39% parents/relatives of beneficiaries reported they are availing the service for the betterment of their child, 34.8% reported that they can attend to household work after sending their child to the centre, and 14.5% reported that they need the service to attend to office/business work.
- Around 40% parents pointed out that they have been able to save and invest extra time in household or office work due to relief from child care, whereas the rest 60.1% of them did not agree to it.

- Unlike the Disha scheme in which majority of the parents reported a positive impact of the scheme on their child, the Vikaas scheme relatively failed to deliver such a significant impact.

D. Samarth (Residential Scheme)

Regional Distribution of Beneficiaries

- The Samarth scheme witnessed a significant variation in the distribution of beneficiaries among the regions. While the highest percentage of beneficiaries belongs to the central region, the lowest percentage belongs to the western region.
- In each case of types of disability, while the maximum percentage of autism cases are found in the northern region (66.7%), the maximum cases of cerebral palsy, mental retardation and multiple disabilities are found in the central region.
- The number of mental retardation cases is the highest among the beneficiaries in all the regions, and the cases vary from 66.7% in the northeastern region to 85% in the southern region.
- The second highest category of disability is cerebral palsy, and its range varies from 5.6% in the western region to 21.3% in the northeastern region.
- The Samarth scheme belongs to the BPL income group (79.2%), and the distribution of the said group of beneficiaries across the region shows that the highest percentage of them belongs to the eastern region (96.7%) and the lowest percentage to the northeastern region (46.7%).

Basic Profile of Beneficiaries

- In total, 80% of the beneficiaries are from the rural area and the remaining 20% are from the urban area, which suggests that the scheme has focused mostly on the rural population.
- By gender, the data shows that the percentage of male members is nearly 96%. This in turn indicates that the scheme has not been able to cover more female PwDs.
- Majority of the beneficiaries are from the SC group (58.3%), followed by the ST (25%) and OBC (16.7%) groups.
- Main occupation of the head of the household is agriculture and self-employment.

Implementation Process of the Scheme

- The average distance of the Samarth centre from the beneficiaries' home is 24 Km. In some cases, the actual distance is more than 40 km, which is quite a long distance and a huddle for the families to travel and regularly meet their relatives at the Samarth centre.

- Around 29.2% of the beneficiaries' parents reported that the centre is located within 5 km of their house. A high percentage of respondents (41.7%) reported that the Samarth centre is located more than 15 km away.
- Maximum beneficiaries (60%) got to know about the scheme from the ROs.
- In total, 87.5% ROs reported that the enrolment portal of the Ministry was user friendly. About 75% of the ROs reported that they did not face any difficulties while paying the enrolment fee online, and 62.5% of them reported that the application process was not tedious.
- About 84% ROs reported that the frequency of visit by the SNAC is once in a year and another 14% said that the frequency of visit by SNAC is '1–2 times in a year'.

Quality of Services

- Significant percentages of beneficiaries (91.7%) reported that they are 'fully satisfied' with the services rendered by the special educator/vocational trainer.
- A total of 83.3% beneficiaries reported that the services rendered by cook are 'fully satisfactory'. In case of services offered by the physiotherapist/occupational therapist, around 83% beneficiaries reported that they are satisfied to 'some extent', while 79.2% reported that they are satisfied to some extent with the services of caregivers and Ayas.
- A large percentage of beneficiaries (91.7%) reported that they are fully satisfied with the vocational training being offered to them at the Samarth centre.

Quality of Infrastructure

- Maximum beneficiaries (66.7%) rated the conditions of the medical room as 'good', where as a high percentage of beneficiaries (75%) also rated the facilities available in the medical room as 'good'.
- A high percentage of beneficiaries (79.2%) rated the condition of the activity room as 'good', and 62.5% of the beneficiaries rated the facilities available in the activity room as good.

Impact of the Scheme

- Maximum (66.7%) parents/relatives of beneficiaries reported that they are availing the service for the betterment of their child.
- Another significant proportion of beneficiaries (29.2%) reported that they are availing the scheme to attend to household work.
- In case of the impact of the Samarth scheme on time, work, and income of the parents, the scheme helped a substantial percentage of parents (83.3%) save and invest extra time in household or office work due to relief from the responsibility of the child.

- Further, majority of the parents (88%) agreed that their child is better off than other children who have been left out from the scheme.
- Majority of the parents (83.3%) reported full improvement in the day-to-day activities of beneficiaries. In case of eye contact and body balance and improvement in speaking ability, majority of the parents viewed that the condition of beneficiaries improved to 'some extent'.

E. Gharaunda (Residential Scheme)

Regional Distribution of Beneficiaries

- Across the regions, the highest percentage of Gharaunda beneficiaries is from the central region (56.6%), followed by 18.7% from the eastern region, 12.5% from the southern region, and 3.2% from the northeastern region.
- Maximum beneficiaries belong to the central region, and this range varies from 50% in case of autism to 63.6% in case of multiple disabilities.
- Around 71.8%–91.6% beneficiaries belong to the mental retardation category of disability, and 4.1%–22.5% beneficiaries belong to the cerebral palsy category of disability.
- Across the region, the percentage of beneficiaries from the BPL income group varies from 50% in the northeastern region to 95.6% in the central region. A maximum percentage of beneficiaries belong to the mental retardation category in all the regions .

Basic Profile of Beneficiaries

- Majority of the beneficiaries under the Gharaunda scheme are from urban areas. The percentage of male members is nearly 3times of that of female members at the Gharaunda centre.
- Half of the beneficiaries belong to the OBC social group, followed by 25% who belong to the SC group and 18.8% who belong to the ST social group.
- The general and orphan groups represent 4.2% and 2.1% of the beneficiaries, respectively.
- Nearly 18% of the beneficiaries are from the age group of18–30 years, followed by 25% from the age group of40–50 years and 12.5% from the age group of 30–40 years.
- Educational qualification of the beneficiaries suggests that maximum beneficiaries are illiterate (45.8%). Beneficiaries with primary-level and upper primary-level education, respectively, represent 29.2% and 16.7% of the sample.

Implementation Process of the Scheme

- More than 56% of the beneficiaries reported that the centre is located between 10 and15 km from their home. Around 29% beneficiaries reported that the centre is located between 5 and10 km from their home.
- Majority of the beneficiaries (58%) stated that they came to know about the scheme from the ROs.
- The second important source of information was awareness programmes, where 10% beneficiaries had received the information. The percentage of beneficiaries who had received information from hospital doctors and relatives is 5% and 3.3%, respectively.

Quality of Services

- A significant percentage of beneficiaries (75%) reported that they are fully satisfied with the services rendered by the special educator/vocational trainer.
- About 50% beneficiaries reported that they are also fully satisfied with the services of caregivers/Ayas.
- In case of services offered by the physiotherapists, around 71% beneficiaries reported that they are satisfied to some extent, while 18.8% said that they are fully satisfied with the service.
- In total, 45.8% beneficiaries reported that they are fully satisfied with the vocational activities carried out at the centre, and an equal number of beneficiaries are satisfied with these activities to some extent.

Quality of Infrastructure

- Maximum beneficiaries (85.4%) rated the conditions of the medical room as 'good', whereas an equal percentage of beneficiaries reported the facilities available in the medical room as 'good'.
- A higher percentage of beneficiaries (60%–75%) rated the condition and facilities in the activity and recreation rooms as 'good'.
- In total, 91.7% beneficiaries reported that safe drinking water is available at the centre.
- A total of 89.6% beneficiaries expressed that hygienic toilets and bathrooms are available, and 93.8% of them reported continuous supply of electricity to the centre.
- In total, 87.5% beneficiaries stated that adequate infrastructure is available at the centre.

Impact of the Scheme

- ❖ Maximum parents/relatives (47.9%) of beneficiaries reported that they are availing the service to attend to household work.
- ❖ A significant proportion of beneficiaries also said that they are availing the scheme for the betterment of their child.
- ❖ As far as the impact of the Gharaunda scheme on time, work, and income of the parents is concerned, the scheme helped 45.8% parents to save and invest extra time in household or office work due to relief from the responsibility of the child.
- ❖ In total, 86% parents/relatives reported that they have used the extra time in productive work, and as a result, their income has increased by 5%.
- ❖ Majority of the parents (77.1%) agreed that their child is better off than other children who have been left out from the scheme.
- ❖ Majority of the parents also reported that the learning ability of their child has improved to 'some extent'.
- ❖ A total of 30%–50% of the beneficiaries also rated their condition as fully improved with respect to learning ability, eye contact, and performing day-to-day activities.

F. Policy suggestions

On Awareness:

- ✓ Ministry should allocate more funds for promoting different schemes of the National Trust through non-governmental organisations (NGOs) working in the field of intellectual disability.
- ✓ For awareness, the state government can also play a major role in faster spreading of information on different schemes of the National Trust.
- ✓ Advertisement through television, social media, workshops, and seminar will be more beneficial in terms of achievement of more coverage of all the schemes of the National Trust.
- ✓ Some mechanism should be implemented at the village level to spread awareness about the scheme and the process to get the benefits under the scheme.
- ✓ More advertisement brochures printed in Hindi/English and local languages should be given to the ROs for distribution among PWDs and their parents.
- ✓ For effective awareness generation, the State Department of Social Welfare needs to be involved.
- ✓ Awareness should be created in the Social defense department, physiotherapists and pediatricians' clinics, as well as schools and village panchayats.

- ✓ The *Badhte Kadam* scheme should be sanctioned to all ROs for awareness generation.

On Implementation:

- ✓ The claim settlement process should be faster in the Niramaya scheme. For this, a cashless card may be issued in place of reimbursement.
- ✓ Special online treatment should be provided to students with intellectual disability, especially those are not able to come to the centre.
- ✓ The place where the disability certificate is issued such as CDMO etc., should have some information or address of the nearest RO where enrolment can be done.
- ✓ The scheme should be a cashless voucher of Rs. 10,000 as maximum beneficiaries are from the BPL category and do not have the capacity to pay the bills of treatment in advance.
- ✓ In the absence of NGO's support, PWDs from villages find it difficult to avail the scheme. For example, while filling the claim form with proper bills and required documents such as medical certificate, ration card, bank passbook, and Niramaya health card. In such cases, NGO's role is very important.
- ✓ Enrolment charges may be waived off. There should be no restriction on the type of diseases. All types of medical problems should be considered under the scheme.
- ✓ The rule to submit claims within 30 days may be relaxed to 3 months so that the claim for OPD medicines and therapy charges can be claimed quarterly. The insurance agency contract should be renewed every 3years so that better service can be ensured.
- ✓ The insurance company should respond to the queries and reimbursement process on time. Also, the documentation process should be user friendly. The process of cancel cheque should be banned in reimbursement of medicines.
- ✓ The state government has the entire data of PwDs. The scheme will be more efficiently implemented under the government. The scheme will be implemented through ROs, but the process should be recorded and fostered under the PwD department of each state government.
- ✓ The district's Social Welfare Department should be involved in the enrolment of PwDs under the Niramaya scheme in whichever district the ROs are unavailable. Thus, one can avail the scheme at their district level itself rather than approaching other district officials.
- ✓ The hospitals involved in the process of issuing a disability certificate should also be given an authority to enrol PwDs into the Niramaya scheme. This will also help parents to avail the scheme at their nearest landmark.

- ✓ Registration application needs to be done at the beginning of the month of the year and the insurance card should be issued immediately.

On Funding:

- ✓ In Niramaya, the enrolment fee of Rs. 40 is not sufficient and should be increased to Rs. 200 for the ROs, and this amount should be provided on time.
- ✓ The sum amount of the insurance should be increased to Rs. 4 lakhs under the Niramaya scheme, and the bifurcation of the amount on different heads should be removed.
- ✓ Eye problems and women's reproductive problems are currently not covered under the Niramaya scheme. However, they should be included.
- ✓ The reimbursement should be within 15–20 days, or cashless insurance can be introduced.
- ✓ Coverage therapy charges should be increased. The PWDs need more amount for OPD as some of the PwDs have serious health problems.
- ✓ There should be an instant reimbursement process (at least on a quarterly basis).
- ✓ General treatment under this scheme must be extended.
- ✓ For OPD, the limit may be extended from Rs. 15,000 to 20,000 under the Niramaya scheme.
- ✓ The amount Rs. 8,000 for medication under Niramaya is not sufficient since a lot of PwDs are on treatment involving neurological drugs. It should be at least minimum Rs. 50,000/- yearly.
- ✓ Now-a-days, all pedagogy is on smart class and through e-learning. The National Trust should provide systems such as smart board, laptop, projectors, and tablets under the Vikaas scheme.
- ✓ The funding pattern of the Gharaunda scheme should be can be modified. It will pay for the same number of LIG (including BPL) PwDs as above LIG enrolled beneficiaries in the scheme. This funding pattern of the Gharaunda Scheme wherein the RO has to maintain a ratio of 1:1 for LIG (including BPL) and above LIG PwDs makes it difficult to enrol PwDs who are in actual need of the scheme, that is, BPL and LIG. Those who can pay are able to find other support. If the cap on the ratio can be removed, the National Trust and the required Gharaunda scheme holder would be able to help a larger number of PwDs.
- ✓ Under the Disha-cum-Vikaas scheme, the APL beneficiaries should also get some financial benefits.

On Application Process:

- ✓ The ROs feel that the online application process can be made more simple and easily accessible for them.
- ✓ The health ID of every beneficiary should be issued at the earliest so that they can get the benefits of the policy.
- ✓ To follow-up the process of application at the National Trust, there should be a designated help desk.
- ✓ Premium charges for all beneficiaries under Niramaya should be waived off.
- ✓ The beneficiaries are to be renewed every year. Duration of renewal can be extended.
- ✓ The applicant should get an intimation as soon as his/her application gets processed under Niramaya.
- ✓ The Ministry may send circular to all the banks to allow all PwDs to open their account with zero balance to get the benefits under Niramaya.
- ✓ It would be easier to cover all categories of PwDs for claiming the benefit. It should be covered by a health card, allowing the beneficiaries access to free treatment and medication.
- ✓ Offline/manual enrolment of Niramaya may be permitted directly other than through the ROs.

Overall, it is important to recognise the voice of the disabled, and strong encouragement and assistance needs to be given to people with mental disability and their representatives. Information regarding disability needs to be disseminated far and wide across the country. The attitude of the professionals working for PwDs needs to be changed, and organised monitoring of disability services and benefits disbursed is also needed. Lacunae in mental health laws should be periodically reviewed, and amendments should be planned or new legislation should be implemented from time to time. Additional research on factors associated with disability and psychiatric disorders and the quality of services required by such people is warranted.

Chapter 1

The National Trust–Vision, Mission, and the Flagship Welfare Schemes

1. Introduction

The National Trust (henceforth Trust) is a statutory body of the Ministry of Social Justice and Empowerment (M/O SJE), Government of India, set up under the 'National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities' Act (Act 44 of 1999).It has been serving the nation since 1999 in terms of delivering some path-breaking social welfare schemes for persons with disability (PwDs).

The vision of the Trust is to work for an inclusive society that values human diversity and enables and empowers full participation of PwDs to live independently with dignity, equal rights, and opportunities. The Trust's vision statement reflects a very changed India for all Indians and is based on the human rights, that is, UNCRPD, approach. The vision statement presents the National Trust as being a leader in the disability sector in India. As laws focusing on PwDs are changing, focused leadership needs to be established. Working through local and regional registered organisations (ROs) and local-level committees (LLCs), the Trust must make its vision and focus clear throughout the country.

The mission of the Trust is to work towards providing opportunities for capacity development of PwDs and their families, fulfilling their rights, and facilitating and promoting the creation of an enabling environment and an inclusive society. The Trust's mission, or fundamental purpose, is to create an enabling environment that is, providing opportunities for PwDs through comprehensive support systems, which can also be done by collaborating with other ministries, etc., thereby leading towards the development of an inclusive society. To fulfill its goals, the Trust has constantly worked towards achieving the following key objects:

- To enable and empower PwDs to live as independently and as fully as possible within and as close to their community as possible;
- To facilitate the realisation of equal opportunities, protection of rights, and full participation of PwDs;
- To extend support to its ROs to provide need-based services; and
- To evolve procedures for appointments of guardians and trustees for PwDs.

To achieve the key objective of inclusive social welfare of PwDs, the Trust had launched several flagship schemes. These are Disha (Early Intervention andSchool Readiness Scheme), Vikaas (Day Care), Samarth (Respite Care), Gharaunda (Group Home for Adults), Sahyogi (Caregiver Training Programme), Niramaya (Health Insurance Scheme), Badhte

Kadam (Awareness, Community Interaction, and Innovative Project), Prerna (Marketing Assistance), and Sambhav (Aids and Assisted Devices). The schemes are illustrated in the following chart.

Flagship Schemes of the National Trust

1.2 A Brief about the Schemes

This section presents a brief introduction of each scheme. The details of each scheme are discussed in the next chapter of the study.

1.2.1 DISHA (Early Intervention and School Readiness Scheme)

The scheme aims at setting up Disha centres for early intervention for PwDs of 0–10 years who are covered under the National Trust Act, through therapies, trainings, and support to family members. ROs were asked to provide certain minimum facilities in their Disha centres. The ROs should provide day care facilities to PwDs for at least 4 hours in a day. The batch size of the centre is 20 PwDs and the ROs should maintain a ratio of 1:1 for the lower income group (LIG (including BPL)) and above LIG PwDs. The scheme is available in the entire country except Jammu and Kashmir.

1.2.2VIKAAS (Day Care)

This is a day care scheme, primarily to expand the range of opportunities available to a child with disability who is attaining the age of 10 years for enhancing interpersonal and vocational skills as they are on a transition to higher age groups. The centre also offers care giving support to PwDs when they are in the Vikaas centre. In addition, it also helps in supporting family members of PwDs with disabilities covered under the National Trust Act to get some time during the day to fulfill other responsibilities. The ROs should provide daycare facilities to PwDs for at least 6 hours a day (between 8 am to 6 pm) and arrange age-specific activities. Day care should be open for at least 21 days in a month. The expected batch size of a Vikaas centre is 30 PwDs.

1.2.3SAMARTH (Respite Care)

The Samarth scheme provides respite home for orphans or abandoned PwDs, families in crisis, and PwDs from BPL and LIG families including destitute with atleast one of the four disabilities covered under the National Trust Act. It also aims at creating opportunities for family members to get respite time in order to fulfill other responsibilities. It would be the responsibility of the ROs to bring in PwDs who are either non-LIGs or who are not covered in the abovementioned category to ensure sustainability. The ROs should provide group home facility for all age groups with adequate and quality care services and acceptable living standards including basic medical care from professional doctors. The capacity of a Samarth centre is 30 including non-LIGs and non-BPL PwDs.

1.2.4. GHARAUNDA (Group Home for Adults)

The Gharaunda scheme is to provide an assured home and minimum quality of care services throughout the life of the person with autism, cerebral palsy, mental retardation, and multiple disabilities and ensure the following for them:

- Facilitate establishment of requisite infrastructure for the assured care system throughout the country.
- Encourage assisted living with independence and dignity.
- Provide care services on a sustainable basis.

The ROs should provide lifelong group home facility for all adult PwDs covered under the National Trust Act with adequate and quality care services and acceptable living standards including basic medical care from professional doctors. The batch size of a Gharaunda centre is 20 PwDs, with a maximum 30% additional PwDs of the batch size being allowed, that is, 26, for the Gharaunda centres.

1.2.5. SAHYOGI (Caregiver Training Scheme)

This scheme provides caregiver training and creates a skilled workforce to support high need persons with autism, cerebral palsy, mental retardation, and multiple disabilities; their families; and institutions(hospitals, schools, NGOs, etc.).This scheme aims at setting

up caregiver cells to provide training and create a skilled workforce of caregivers to provide adequate and nurturing care for PwDs and their families who require this support. It also seeks to provide parents an opportunity to get trained in care giving if they so desire. This scheme provides a choice of training through two levels of courses to allow the creation of caregivers suited to work both with families of PwDs and other institutions catering to the needs of PwDs (NGOs, work centres, etc.). Primary training involves a 3-month course expected to train candidates in basic caregiver skills.

1.2.6. NIRAMAYA (Health Insurance Scheme)

This scheme provides an affordable health insurance policy to PwDs. The health insurance covers up to Rs.1.0 lakh. Facility for OPD treatment including medicines, pathology, and diagnostic tests; regular medical checkup for non-ailing disabled; preventive dentistry; surgery to prevent further aggravation of disability; non-surgical techniques/ hospitalisation; corrective surgeries for existing disability including congenital disability, ongoing therapies to reduce the impact of disability and disability-related complications; and alternative medicine. It also covers the transportation costs of the treatment. No pre-insurance medical tests are required. The treatment can be availed from any hospital. The scheme is available in the entire country except Jammu and Kashmir.

1.2.7. BADHTE KADAM (Awareness and Community Interaction)

Badhte Kadam aims at community awareness, sensitisation, social integration, and mainstreaming of PwDs. It has below mentioned objectives:

1. Raise awareness in the public, regarding PwDs covered under the National Trust Act, and encourage their inclusion in the society, social integration, and participation of PwDs in all aspects of life.
2. Disseminate information on preventive strategies for the disabilities under the National Trust Act, 1999
3. Sensitise community stakeholders
4. Publicise and maximise the benefits of the National Trust schemes for the ROs, PwDs, and families of PwDs.
5. Increase representation in remote areas and in areas where the National Trust is under-represented
6. Spread awareness about myths and misconceptions about disability, disability etiquette, etc.

This scheme shall support ROs of the National Trust to perform activities that focus on increasing the awareness about disability schemes of the Trust.

1.2.8. PRERNA (Marketing Assistance)

'Prerna' is the marketing scheme of the National Trust with an objective to create viable and widespread channels for the sale of products and services produced by PwDs covered under the National Trust Act. This scheme aims at providing funds to participate in events such as exhibitions, melas, and fairs to sell the products made by PwDs. The scheme also provides an incentive to the ROs based on the sales turnover of the products made by the PwDs. The National Trust fund the participation of ROs in national-, regional-, state-, and district-level events such as fairs, exhibitions, and melas for marketing and selling products prepared and services rendered by the PwDs. However, at least 51% of the employees of these work centres should be PwDs having disabilities covered under the National Trust Act. The ROs have to submit the proposal for each event in which they would want to participate as per the guidelines of the scheme. This scheme would not include any permanent stalls allotted to the National Trust. The National Trust can also fund (up to Rs.10,000 in a year) ROs if they have prepared and distributed brochures in any event.

1.2.9. SAMBHAV (Aids and Assistive Devices)

This is a scheme to setup additional resource centres, one each in each city of the country (apart from Delhi, which currently has a Sambhav centre) with a population of greater than 5 million (as per the 2011 Census) to collate and collect aids, software, and other forms of assistive devices developed with a provision of display and demonstration of the devices. The scheme also includes maintaining information pertaining to aids and assistive devices present at the Sambhav centre on the National Trust website. These centres aim to provide information and easy access to devices, appliances, aids, software, etc. for betterment and empowerment of PwDs of the National Trust disabilities. A display and demonstration of the devices is also provided to the concerned stakeholders. The centre should construct a bedroom, kitchen, and bathroom setup that is disabled friendly and employs assistive devices that are useful and improve the quality of life of the people.

1.3 Implementation of the Scheme

The Trust has been implementing all its schemes with the help of over 650 ROs covering most of the states/UTs in the country. For smooth and efficient functioning of these schemes, the Government of India had granted Rs. 100 crores to the Trust in 1999. The 12th Five-Year Plan had envisaged augmentation of corpus fund of National Trust by Rs. 200 crores. However, the Ministry of Finance (Expenditure) has turned down the proposal, instead it has suggested for annual budgetary support to some of the flagship schemes of the Trust. As reported by the Trust, due to paucity of fund, the performance of the Trust was not effective in the past few years relating to running of several flagship schemes. The data reported by the National Trust shows that it had no shortfall of revenue with respect to expenditure during 2017–18 and 2018–19. In 2019–20, it has however reported 60% shortfall of revenue compared to the expenditure.

To achieve better performance in various schemes within limited resources, with effect from 1 April 2018, the Trust has decided to merge a couple of schemes as under:

1. Disha (Early Intervention and School Readiness Scheme) and Vikaas (Day Care) have been merged and renamed as the Disha-cum-Vikaas Scheme.

2. Samarth (Respite Care) and Gharaunda (Group Home for Adults) have been merged and renamed as the Samarth-cum-Gharaunda Scheme.

Further, the Trust has discontinued the Gyan Prabha scheme since 1 April 2018 because a similar scheme is being run by the Department of Empowerment of Persons with Disability (DEPwD), M/O SJE. The Trust has also proposed to revise two of its flagship schemes such as Sambhav (Aids and Assisted Devices) and Prerna (Marketing Assistance), and hence, it has not allocated any fund to these schemes since 2016–17.

Other Stakeholders

There are other stakeholders appointed/constituted by the Trust to look after the legal guardian issue, conduct meetings and organise workshops/seminars, and monitor the functions of the various schemes. These stakeholders are as follows:

(i) *LLC:* As per the Section 13(2) of the Trust, there will be an LLC under the Chairmanship of District Magistrate/District Commissioner or Officer of the Civil service of the Union/ State Government not the below the rank of a District Magistrate and constituting members representative from RO, a PwD, and other co-opted additional members such as District Social Justice Officer/District Welfare Officer/District Rehabilitation Officer, Civil Surgeon or Chief Medical Officer, a Psychiatrist of the District Hospital, a Reputed Lawyer in the district, and any other government officer or disability experts to assist the LLC in various activities. The committee looks after the legal issue of appointing a legal guardian with the consent of the parent or relative of a PwD and monitor the services of the legal guardian from time to time. The Trust allocates funds on an yearly basis for the smooth functioning of the LLC.

(ii) *State-level Nodal Agency Centre (SNAC)*: The Trust has appointed a SNAC in every state, and23 SNACs have been appointed till date. The role of the SNAC is to create awareness in the state with government functionaries about the Trust and its activities, maintain a regular database, facilitate LLCs, mentor small NGOs, conduct professional training, and inspect NGOs. The Trust makes monthly and half-year funding to the SNAC for conducting various activities.

1.4 Study Objectives

To continue the flagship schemes in coming years, it is imperative to understand the functioning and effectiveness of each scheme in achieving its basic objectives and goals and the effective utilisation of funds under each scheme. Further, due to shortage of funding, the Trust seeks to redesign some of the schemes in order to achieve maximum benefits with limited resources. Thus, in this regard, the DEPwD has entrusted NILERD to conduct an evaluation study on 'Evaluation of the Scheme Budgetary Support to National Trust, M/O SJE, Government of India'. Based on the suggestions made by the Trust, the present study focused on analysing the impact of only day and residential schemes (Disha, Vikaas, Disha-cum-Vikaas, Samarth, Gharaunda, and Samarth-cum-Gharaunda) and the health insurance scheme (Niramaya).

The general objective of the evaluation study isa comprehensive and in-depth impact

assessment of the various schemes implemented by the Trust and assessment of budgetary support to the Trust. The specific study objectives are outlined below.

i. To assess the coverage of the scheme in all states/union territories (UTs) covering rural, urban, and remote areas of the country.

ii. To examine the implementation process including availability, adequacy and timeliness of funds earmarked for Budgetary Support Scheme.

iii. To examine the linkage of the scheme of the scheme with educational and economic empowerment schemes for disabled and suggest strengthening of the linkage

iv. To examine the system to prevent duplication of beneficiaries and suggest suitable measures, including IT-based solutions, for preventing such duplication

v. To examine the present system of monitoring the implementation of the scheme and suggest suitable improvement

vi. To suggest ways and means for spreading awareness about the scheme

vii. To find out the bottlenecks of the scheme, if any and to suggest remedial measures for improvement

1.5 Report Outline

Chapter 2 presents the review of literature and a detailed overview of various schemes under the Trust. The scope and methodology of the study are presented in chapter 3. Chapter 4 discusses the data analysis and key findings of the study, followed by success stories of beneficiaries under various schemes in chapter 5 and conclusions and policy suggestions in chapter 6.

Chapter 2

The Review of Literature, Scope, Implementation, and Financing of Schemes

This chapter discusses the review literature on disabilities, and the scope, objectives, implementation process, and funding pattern of each scheme in detail.

2.1 Review of Literature

'Taare Zameen Par' (2007) (titled 'Like Stars on Earth' internationally) is a movie directed by Aamir Khan that tells about an 8-year-old boy named Ishaan Awasthi as the main cast. At first, he is a cheerful creative little boy who loves painting and playing puzzle. He can make creative paintings by using a beautiful combination of colour and concept. Yet, his difficulty in reading has led him into depression. Teachers consider him as a 'lazy and shameless boy', and his classmates mock him and treat him as a class clown because of his mispronunciation. This movie portrays a child suffering from dyslexia, a learning disability, which affects the brain's ability to receive, process, analyse, or store information. These problems can make it difficult for a student to learn as quickly as someone who is not affected by learning disabilities (Begum, 2008: 26).[1]

With the above backdrop, the following section reviews some of the important studies and their findings, implication for future research, and practices adopted for the improvement of PwDs. This review highlights the urgency for a seamless and co-ordinated approach to service delivery for people with intellectual disability and mental illness. There is emerging evidence of the high prevalence of mental illness in persons with intellectual disability. The notion that people with intellectual disability can have mental illness has only been recently acknowledged. Furthermore, people with intellectual disability experience a wide range of psychiatric disorders often seen in the general population. Despite recent developments in treatment options for these people, many of them continue to experience barriers in accessing mental health services.

In 2007, India signed and ratified the Convention on the Rights of Persons with Disability (CRPD), absent of the Optional Protocol (which provides an internationally recognised mechanism to ensure that rights are realised through systematic reporting and evaluation of countries by established international committees). Although it was enacted in 2008, comprehensive reforms are yet to take place (Manecksha, 2010).[2] Given the large discrepancies between the approach of the Indian government and CRPD, there are debates about whether the previous disability legislation should be reformed or a new act should be created.

1 Begum, S. (2008). Understanding Disability Psycho-Social perspective. USA: Global Books Organisation
2 Manecksha F. Implement the UNCRPD, say activists. In: India Together. New Delhi: India Together; 2010. http://indiatogether.org/uncrpd-health.

Although the legislation focused attention on disability, there has been a noted lag in the implementation of services and programming for the PwDs (Seeley, 2001).[3] This is especially true in rural areas because the relatively few public rehabilitation services are mostly located in urban centres (UN, 2006)[4] As governmental and non-governmental agencies begin to address this gap, it remains unclear what factors contribute the most to PwD employment, and whether their employment experiences differ geographically across India.

Considering labour market supply, PwD experience barriers in terms of accessibility to and ability at the workplace. Productivity is largely dependent on the characteristics of the type of disability and the requirements of the job. For example, a person with hearing impairment may find it difficult to do telecommunication work but may excel in mathematically based accounting work. Overall, according to labour market theory, a higher reservation wage and a lower market wage make a PwD less likely to be employed than a person without disability (Mitra and Sambamoorthi, 2006).[5]

In the past three decades, the concept of disability has shifted from individual impairment to a more social phenomenon. Thus, disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives. In this view, PwDs are seen as being restricted in performing daily activities because of a complex set of interrelating factors, some pertaining to the person and some pertaining to the person's environment and social/political arrangements. The social concept of disability introduces the notion that society has erected barriers, physical or attitudinal, which affect a PwDs. Consequently, government programmes and policies have evolved to include fixing the environment (e.g., making buildings barrier-free) and providing income assistance or work-related support to help PwDs participate more fully in the community and workplace. Even the World Health Organization (WHO) goes beyond a medical approach to take a much broader view of disability. It also recognises the role environment plays in either facilitating functioning or raising barriers (Singh, A. 2009).[6]

It is a well-accepted fact that mental illnesses are also associated with a significant disability. Nearly 31% of the world's disability is accounted by mental disorders. Globally, 5 of the 10 leading causes of disability are in the category of mental illnesses: major depression, alcohol dependence, schizophrenia, bipolar affective disorder, and obsessive-compulsive disorder (OCD) (Mohan, I. *etAl.*, 2005).[7] The World Health Report 2001 by the WHO assessed the leading causes of disability by using disability adjusted life years (DALY). Mental illnesses accounted for 25% of total disability and 16% of total burden (WHO, 2001).[8]

Psychiatric disorders, by virtue of their very nature, display different patterns of disabilities when compared to that of physical ailments. Social- and work-related

3 Seeley J. Recognizing Disability: Disability and Rural Livelihoods Approaches in India. In: National Resources Perspective. London: The Overseas Development Institute; 2001. p. 4.
4 ESCAP. Disability at a Glance: A profile of 28 countries and areas in Asia and the Pacific. In: Pacific EaSCfAat, editor. Bangkok: United Nations; 2006. p. 87.
5 Mitra S, Sambamoorthi U. Disability and the Rural Labor Market in India: Evidence for Males in Tamil Nadu. In: York New, editor. New York Fordham University; 2006. p. 3.
6 Singh A, Nizamie SH. Disability: The concept and related Indian legislations. Mental HealthReviews. 2009.
7 Mohan I, Tandon R, Kalra H, Trivedi JK. Disability assessment in mental illnesses using Indian disability evaluation assessment scale (IDEAS) Indian J Med Res. 2005;121:759–63.
8 Mental health: New understanding, New hope. Geneva: World Health Organization; 2001. World Health Report 2001.

functioning is more important in those with mental illnesses. We also need to remember that mental disability in the form of apathy, a motivation, poor self-care, communication difficulties and poor interpersonal skills are not visible unlike other disabilities, such as blindness or locomotor disability. There are instances when disability benefits such as bus passes were denied because they look physically strong. It is compounded by stigma and discrimination. Therefore, measures of psychiatric disability have been designed.

Research initiatives in the area of psychiatric disability in India have focused more on schizophrenia. Attention has been given to two important issues: development or modification of scales for assessments and disability evaluation in persons with chronic psychiatric illnesses. Disability has been assessed in psychiatric patients in different settings such as in hospitals, community, and follow-up studies. As early as in 1979, Wig*et al*. constructed a scale to measure the disability of Indian psychiatric patients. They found that psychotics (ICD-8) obtained significantly higher scores than neurotics, and persons with greater personal disability accepted treatment more often than those with less personal disability scores.[9]

A decade later, Thara *et al*. (1988) modified the Disability Assessment Schedule (WHO DAS-II) by deleting certain items and regrouping the rest into four main areas of personal, social, occupational, and global disability because DAS-II was not entirely culture-free. This modified instrument was developed, validated, and called the Schedule for Assessment of Psychiatric Disability (SAPD). They also administered this instrument to 30 patients, each from the three groups of psychoses, neurotics, and diabetics. The SAPD effectively discriminated the psychotic group from the other two groups. The authors recommended this instrument for the measurement of disability in an outpatient psychiatric population.[10]

Further, Thara and Rajkumar (1993) followed up 68 schizophrenia patients prospectively for 6 years using standardised instruments. Disability was assessed using the SAPD at the end of 4, 5, and 6years of follow-up. They found that the 3-year course of disability tended to be stable without any fluctuations and that the highest disability was in the area of occupational functioning. Moreover, the disability was not related to the number of relapses. The authors noted that this could be due to the following factors: (1) The cohort was closely followed up and well treated, and (2) all patients were started on treatment early in the course of their illness.[11]

Shankar *et al*. (1995) reported gender differences in disability among married patients with schizophrenia. The study sample included 30 married patients of both sexes. Disability was evaluated using the modified version of the Disability Assessment Schedule. Results indicated that women were more disabled than men, in contrast to the findings from the literature elsewhere. Negative symptoms predominated among the factors associated with global disability in both sexes.[12]

Srinivasa *et al*. (2005) assessed the costs and effects of a community outreach programme for untreated schizophrenia patients in a rural community. Hundred patients were recruited and provided appropriate psychotropic medication and psychosocial support. Over one and a half years, they also assessed symptomatology, disability, family burden,

9 Wig NN, Murthy RS, Pershad D. Relationship of disability with psychiatric diagnosis and treatment acceptance patterns. Indian J Psychiatry. 1979; 21:355–8.
10 Thara R, Rajkumar S, Valecha V. The schedule for assessment of psychiatric disability - A modification of the DAS-II. Indian J Psychiatry. 1988; 30:47–55.
11 Thara R, Rajkumar S. Nature and course of disability in schizophrenia. Indian J Psychiatry. 1993; 35:33–5.
12 Shankar R, Kamath S, Joseph AA. Gender differences in disability: A comparison of married patients with schizophrenia. Schizophr Res. 1995;16:17–23.

resource use, and costs every 3 months. Results showed that the summary scores of disability along with psychotic symptoms and family burden all reduced over the follow-up period. These were also accompanied by reductions in the costs of informal-care sector visits and family care giving time.[13]

Mohan *et al*. conducted a tertiary hospital-based study to assess and compare disability using the Indian Disability Evaluation and Assessment Scale (IDEAS) in patients with schizophrenia and OCD. They included patients with only mild severity illness. Majority of the schizophrenia patients were from rural areas, whereas most of the OCD patients were from an urban background. Patients in both groups had considerable global disability. Understandably, schizophrenia patients had significantly greater disability across all domains of the IDEAS. Duration of illness had no effect on disability scores in schizophrenia patients, but it had a negative impact in OCD patients.

Choudhry *et al*. (2006) assessed some aspects of disability associated with seven psychiatric disorders: schizophrenia, bipolar affective disorder, anxiety disorder, depression, OCD, dementia, and mental and behavioural disorders due to the use of alcohol. Their aimed to evaluate the nature and quantity of disabilities in the study groups, compare the degree of disability with the severity of the disorder, compare disability among various disorders, and study the longitudinal stability of disability in the disorder groups. They assessed a total of 228 patients attending the outpatient department of Assam Medical College, Dibrugarh, India, between July 2003 and June 2004. Patients were initially diagnosed using the ICD-10 criteria. Further, for those who consented to participate in the study, interviewers administered the Schedule for Clinical Assessment for Neuropsychiatry. Severity of the disorders was assessed by applying commonly used rating scales for each specific disorder. Disability was assessed using the IDEAS. Patients were followed up at 6and 12 months. Results showed that all the seven disorders studied were associated with significant disability, with schizophrenia being maximally disabling. The domains of disability varied across the various disorders studied. The disability tended to correlate with the severity of the disorders. Disability associated with alcohol use disorder and anxiety was comparable to disability due to OCD. Although the follow-up rates were low, analysis of the available data showed that the disability across most disorders reduced at the end of the 6-month follow-up and then tended to even out after that period.[14]

Kumar *et al*. (2008) assessed the prevalence and pattern of mental disability in a rural taluk of Karnataka district. In this community-based cross-sectional study, 1,000subjects were randomly selected from four villages and the IDEAS was administered. Overall, the prevalence of mental disability was 2.3%. Among the disabled, majority of the subjects had mild disability, followed by those with severe disability, moderate disability, and disability of profound severity. All disabled subjects were previously diagnosed with one or the other mental disorder such as affective disorders, mental retardation, epilepsy, neurosis, schizophrenia, and alcohol addiction.[15]

13 Srinivasa Murthy R, Kishore Kumar KV, Chisholm D, Thomas T, Sekar K, Chandrashekari CR. Community outreach form untreated schizophrenia in rural India: A follow-up study of symptoms, disability, family burden and costs. Psychol Med. 2005;35:341–51.

14 Choudhry PK, Deka K, Chetia D. Disability associated with mental disorders. Indian J Psychiatry. 2006; 48:95–101.

15 Kumar SG, Das A, Bhandary PV, Soans SJ, Kumar HN, Kotian MS. Prevalence and pattern of mental disability using Indian disability evaluation assessment scale in a rural community of Karnataka. Indian J Psychiatry. 2008; 50:21–3.

Krishnadas *et al*. (2007) measured cognitive dysfunction in 25 remitted schizophrenia patients attending a psychiatry unit of a general hospital. Remission was confirmed using the Brief Psychiatric Rating Scale and the Scale for the Assessment of Negative Symptoms. The following neuro cognitive measures were used: PGI Memory Scale, trail making tests A and B, Rey–Osterrieth complex figure test, and frontal assessment battery. Disability was assessed using the IDEAS. Results showed that patients had considerable cognitive dysfunction across all measures. Moreover, the authors found no statistically significant relationship between cognitive dysfunction and disability scores.[16]

Gururaj *et al*. (2008) assessed disability along with family burden and quality of life of moderately ill OCD patients and compared those with that of schizophrenia patients of comparable severity. Disability was assessed using the WHO-DAS. Results showed that both groups were similar across most domains of disability.[17] The authors concluded that OCD is associated with significant disability often comparable to schizophrenia. Thirthalli *et al*. assessed disability in 182 community-dwelling schizophrenia patients in Thirthalli taluk of Shimoga district, Karnataka using the IDEAS. Their aim was to compare disability of schizophrenia patients receiving continuous antipsychotic treatment with that of those who were not taking antipsychotics or taking irregular treatment. Results showed that patients on antipsychotics had significantly less disability across all domains and as indicated through total IDEAS scores. Treatment status predicted disability scores even after controlling for the effects of controlling factors such as age, sex, education, socioeconomic status, and duration of illness and alcohol dependence/harmful use. Different levels of exposure to antipsychotics were associated with different levels of disability. Although no randomisation was used, this study was conducted with a naturalistic design. The two groups did not differ in any of the clinical or socio demographic variables. The authors concluded that treatment with antipsychotics is associated with significantly less disability.[18]

Thirthalli *et al*. (2009) compared the course of disability in schizophrenia patients receiving antipsychotics and those remaining untreated in a rural community. Of the 215 patients identified, 58% were not receiving antipsychotics. Trained raters assessed the disability using the IDEAS in 190 of them at baseline and after 1 year. The course of disability in those who remained untreated was compared with that in those who received antipsychotics. Results showed that in patients who remained untreated, the mean disability scores remained unchanged, but in those who continued to receive treatment and in those who were started on antipsychotics, the scores showed a significant decline (indicating decrement in disability). The proportion of patients classified as 'disabled' declined significantly in the treated group, but it remained the same in the untreated group. The authors concluded that treatment with antipsychotics in the community results in a considerable reduction in disability.[19]

16 Krishnadas R, Moore BP, Nayak A, Patel RR. Relationship of cognitive function in patients with schizophrenia in remission to disability: A cross-sectional study in an Indian sample. Ann Gen Psychiatry. 2007;30:6–19.

17 Gururaj GP, Math SB, Reddy JY, Chandrashekar CR. Family burden, quality of life and disability in obsessive compulsive disorder: An Indian perspective. J Postgrad Med. 2008;54:91–7.

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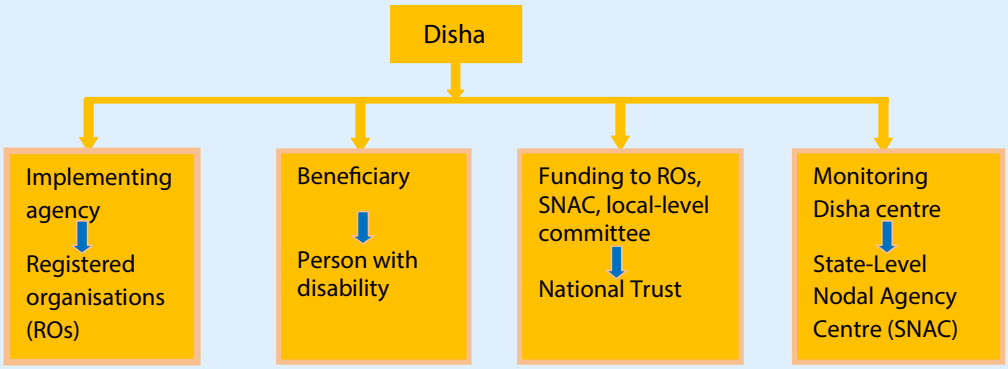
2.2 DISHA (Early Intervention and School Readiness Scheme)

2.2.1 About the Scheme

This is an early intervention and school readiness scheme for children in the age group of 0–10 years with the four disabilities covered under the National Trust Act and aims at providing training (specifically school readiness) and counselling to both children and parents.

2.2.2 Structure of the Scheme

Several stakeholders are involved in the running and monitoring of the Disha scheme. The scheme is being implemented at the ground level by ROs under the guidance and budgetary support of the Trust. The scheme is monitored by the Trust with the help of the SNAC. Moreover, an LLC looks after the legal guardianship of PwDs. The below chart illustrates the structure of the scheme.



2.2.3 Implementation of the Scheme

The scheme is being implemented by ROs. Before applying for opening a Disha centre, an RO must be registered with the National Trust and under the PwD Act. The eligibility criteria for a PwD to enrol in a Disha centre are as follows: he or she should be in the age group of 0–10 years; should have one of the disabilities covered under the National Trust Act, 1999, which are autism, cerebral palsy, mental retardation, and multiple disabilities; and should not be registered under the Samarth scheme.

The ROs should provide daycare facilities to PwDs for at least 4 hours in a day (between 8 am to 6 pm) along with age-specific activities. Day care should be open for at least 21 days in a month. The minimum attendance required for a PwD in the Disha centre is 15 days per month for the National Trust to fund the PwD. The batch size of a Disha centre is 20 PwDs, with amaximum 30% additional PwDs of the batch size being allowed, that is, 26, for the Disha centres. On reaching the maximum limit of 26 PwDs, a Disha centre does not allow anymore PwDs to enrol in the centre. ROs are encouraged to apply again if they have sufficient number of PwDs for anew Disha centre.

ROs should maintain a ratio of 1:1 for LIG (including BPL) and above LIG PwDs (which are paid seats for ROs). Payment for the above LIG seats could be received by the ROs from parents, guardians, family members, ROs, or any other institute/individual directly as per mutually agreed terms and conditions between the ROs and other party involved (parents, guardians, family members, ROs, or any other institute/individual) The ROs should also contact paediatricians or experts in the similar field to seek help in getting more PwDs enrolled in the Disha centre.

Staffing

There should be a provision of a special educator or early intervention therapist, physiotherapist or occupational therapist, and counsellor for PwDs along with a caregiver and Ayas in the centre. Availability of a physical trainer and speech therapist in these centres is also desirable.

Infrastructure Facilities

The Disha centre must have one medical/assessment room (with therapeutical aids and appliances), one activity room, and one recreation room (all rooms to be of reasonable size) for PwDs. The centre should also have provision for a personal computer, scanner, and net connection for the office purpose and for sending fund request, submitting reports, etc. to the National Trust.

Assessment and Evaluation

PwDs should be assessed and evaluated by experts in the related field on a regular basis to understand their individual needs and to monitor the progress of the PwDs. The Disha centre should maintain a record of the growth and development charts of the PwDs on a regular basis (with the help of experts).

Counselling

Counselling and guidance especially for activities for daily living (ADL) must be provided to parents or guardians of PwDs with regular follow-ups by the ROs to ensure that parents or guardians attend a minimum number of counselling sessions. The ROs should provide assistance to PwDs for further admissions in mainstream schools.

Transport Facilities

ROs can also provide transportation facilities to PwDs in case it is mutually suitable for both. The National Trust provides additional but limited transport allowance to ROs only for PwDs who are availing transport facilities provided by the ROs.

2.2.4 Funding Pattern

The National Trust provides funding to the Disha centre under the following three heads:

(i) Setup Cost

This is a non-recurring one-time cost that would be provided to ROs initially to set up a Disha centre. In addition to the grant from the National Trust, the ROs are free to arrange grant from other sources for improving the infrastructure. It shall be the prerogative of the ROs to buy the necessary products and items for the setup from the places of their choice.

(ii) Sustenance Cost

Sustenance cost is provided by the National Trust to the Disha centre for a maximum of 3 months after the setup period. This has been provisioned considering the fact that the RO would find it difficult to enrol 20 PwDs in the first month. The sustenance cost is given in order to ensure that all staff and facilities are available and functional from the first day of operation of the centre, irrespective of the number of PwDs enrolled. The advantage of providing sustenance cost is that the RO would be able to run the centre without any difficulty, and because the National Trust believes that the centre would become stable within the sustenance period.

The National Trust provides sustenance cost to the centre only if the minimum number of PwDs in a Disha centre in the initial 3 months is at least 20% of the expected batch size in each month (that is, 4 in this case). The centre can be made operational only when minimum 4 PwDs are enrolled.

The sustenance cost is calculated on a pro-rata basis based on the difference in total expected PwDs and number of actual PwDs in the centre during the 3 months. For example, if an RO has 4 PwDs in the first month of its operation, then the sustenance cost will be paid for 20−4 = 16 PwDs. However, for the 4 PwDs already enrolled, monthly recurring cost shall be paid as per the scheme.

The provision of sustenance cost is conditional upon the timely start of operation of the Disha centre. The centre is expected to start operations within 1 month from the release of setup cost. In case the start of operations exceeds this deadline by more than a month (which means operations have not started even within 2 months from the release of setup cost), the overall period for which sustenance cost is provided would be reduced by the duration of delay. For example, if the Disha centre starts the operation 3months after the setup cost has been provided, then sustenance cost shall only be provided for 2 months. Similarly, if the Disha centre starts the operation 4 months after the setup cost has been provided, then the sustenance cost shall only be provided for 1 month.

In case the Disha centre is closed down within 1year of the start of operations, the sustenance amount that was given to the concerned RO for the Disha centre shall be taken back from the RO by the National Trust.

(iii) Monthly Recurring Cost

The National Trust pays monthly recurring cost for all PwDs at the Disha centre who are eligible to be funded by the National Trust starting from the first month of operations. The National Trust funds the centre only if the minimum number of PwDs in the centre in the months is 30% of the expected batch size (i.e., 6 in this case).

The National Trust funds the PwD as per the following conditions:

a. The National Trust funds PwDs in a Disha centre in a 1:1 ratio provided there are equal number of LIG (including BPL) and above LIG PwDs. LIG is defined as follows:

LIG = BPL limit set by the state + additional 50% of BPL limit of that state

b. If the number of LIG (including BPL) PwDs is higher than that of above LIG PwDs, funds shall be provided for only those LIG PwDs for which a 1:1 ratio is maintained (LIG including BPL: above LIG category). In this scenario, BPLs shall be given preference for funding.

c. If the number of LIG (including BPL) PwDs is lower than that of above LIG PwDs, the National Trust shall fund the total number of LIGs (including BPL).

d. Apart from this, the National Trust funds 100% BPL in a Disha centre as per the scheme irrespective of the ratio, but the same is not true for LIG PwDs.

e. Transport allowance (optional) is given to an RO only in case the PwD has availed transport facility from the RO after the submission of the required document proofs by the parents/guardians of the PwD.

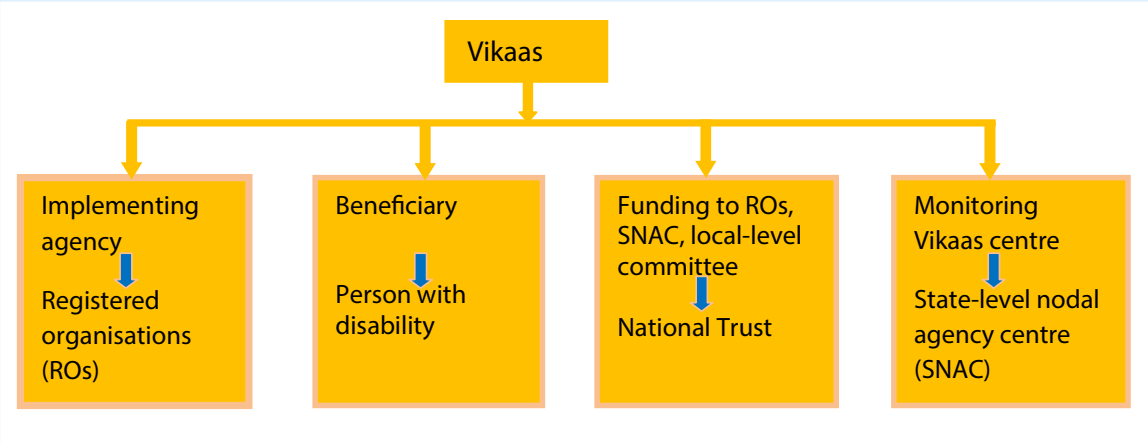
2.3 VIKAAS (Day Care)

2.3.1 About the Scheme

This is a day care scheme, primarily to expand the range of opportunities available to a PwD attaining the age of 10 years for enhancing interpersonal and vocational skills as they are on a transition to higher age groups. The centre will also offer caregiving support to the PwD when the PwD is in the Vikaas centre. In addition it helps in supporting family members of the PwDs having disabilities covered under the National Trust Act to get some time during the day to fulfill other responsibilities.

2.3.2 Structure of the Scheme

Like in Disha, several stakeholders are involved in the running and monitoring of the Vikaas scheme. The scheme is being implemented at the ground level by ROs under the guidance and budgetary support of the Trust. The scheme is monitored by the Trust with the help of the SNAC. Moreover, an LLC looks after the legal guardianship of PwDs. The below chart illustrates the structure of the scheme.



2.3.3 Implementation of the Scheme

ROs are the implementing agencies of the scheme at the ground level and are required to provide the following minimum facilities in their Vikaas centre:

Day Care

ROs should provide daycare facilities to PwDs for at least 6 hours in a day (between 8 am to 6 pm) along with age-specific activities. Day care should be open for at least 21 days in a month. The expected batch size of a Vikaas centre is 30 PwDs. The minimum attendance required for a PwD in the Vikaas centre is 15 days per month for the National Trust to fund the PwD. The batch size of a Vikaas centre is 30 PwDs, with the maximum PwDs allowed being 30% additional of a batch size, that is, 39. On reaching the maximum limit of 39 PwDs, the Vikaas centre does not allow anymore PwDs to enrol in the centre. ROs are encouraged to apply again if they have sufficient number of PwDs for anew Vikaas centre.

ROs should maintain a ratio of 1:1 for LIG (including BPL) and above LIG PwDs (which are paid seats for ROs). Payment for the above LIG seats could be received by the ROs from parents, guardians, family members, ROs, or any other institute/individual directly as per mutually agreed terms and conditions between the ROs and other party involved (parents, guardians, family members, ROs, or any other institute/individual). The ROs should also contact paediatricians or experts in the similar field to seek help in getting more PwDs enrolled in the Vikaas centre

Staffing

There should be a provision of special educators (+vocational trainers), a physiotherapist or occupational therapist, and a counsellor for PwDs along with caregivers and Ayas in the centre. Availability of a physical therapist and speech therapist in these centres is also desirable.

Infrastructure facilities

The Vikaas centre must have one medical or assessment room (with therapeutical aids and appliances), one activity or vocational room, and one recreation room (all rooms to be of reasonable size) for PwDs. Thecentre should also have a provision for a personal computer, scanner, and net connection for office purpose and for sending fund request, submitting reports, etc. to the National Trust. Assistance for setting up work centres (only the setup cost) is provided by the National Trust depending on the viability of the proposal and availability of space.

Assessment and Evaluation

PwDs should be assessed and evaluated by experts in the related field on a regular basis to understand their individual needs and monitor the progress of the PwDs. The Vikaas centre should maintain a record of the growth and development charts of the PwDs on a regular basis (with the help of experts).

Counselling

Counselling and guidance especially for ADL must be provided to parents or guardians of PwDs. The ROs should provide assistance to PwDs for further training, education, and employment.

Transport Facilities (OPTIONAL)

ROs can also provide transportation facilities to PwDs in case they so desire. The National Trust provides additional transport allowance to ROs only for PwDs who are availing transport facilities provided by the ROs.

2.3.4 Funding Pattern

The National Trust provides funding to the Vikaas centre under following three heads:

(i) Setup Cost

This is a non-recurring one-time cost that would be provided to ROs initially to setup a Vikaas centre. In addition to the grant from the National Trust, the ROs are free to arrange grant from other sources for improving the infrastructure. It shall be prerogative of the ROs to buy the quality and quantity of setup from the places of their choice. Infact, it is desirable for the viability of the centre. However, the National Trust does not deduct its setup cost if extra funds are arranged by the ROs.

(ii) Sustenance Cost

Sustenance cost is provided by the National Trust to the Vikaas centre for a maximum of 3 months after the setup period. This has been provisioned considering the fact that the RO would find it difficult to enrol 30 PwDs in the first month. The sustenance cost is given in order to ensure that all staff and facilities are available and functional from the first day

of operation of the centre, irrespective of the number of PwDs enrolled. The advantage of providing sustenance cost is that the RO would be able to run the centre without any difficulty, and because the National Trust believes that the centre would become stable within the sustenance period.

The National Trust provides sustenance cost to the centre only if the minimum number of PwDs in a Vikaas centre in initial 3 months is at least 20% of the expected batch size in each month (that is, 6 in this case). The centre can be made operational only when minimum 6 PwDs are enrolled.

The sustenance cost is calculated on a pro-rata basis based on the difference in total expected PwDs and number of actual PwDs in the centre during the 3 months. For example, if an RO has 6 PwDs in the first month of its operation, then the sustenance cost will be paid for 30−6 = 24 PwDs. However, for the 6 PwDs already enrolled, monthly recurring cost shall be paid as per the scheme.

The provision of sustenance cost is conditional upon the timely start of operation of the Vikaas centre. The centre is expected to start operations within 1 month from the release of setup cost. In case the start of operations exceeds this deadline by more than a month (which means operations have not started even within 2 months from the release of setup cost), the overall period for which sustenance cost is provided would be reduced by the duration of delay. For example, if the Vikaas centre starts the operation 3 months after the setup cost has been provided, then sustenance cost shall only be provided for 2 months. Similarly, if the Vikaas centre starts the operation 4months after the setup cost has been provided, then the sustenance cost shall only be provided for 1 month.

In case the Vikaas centre is closed down within 1 year of the start of operations, the sustenance amount that was given to the concerned RO for the Vikaas centre shall be taken back from that RO by the National Trust.

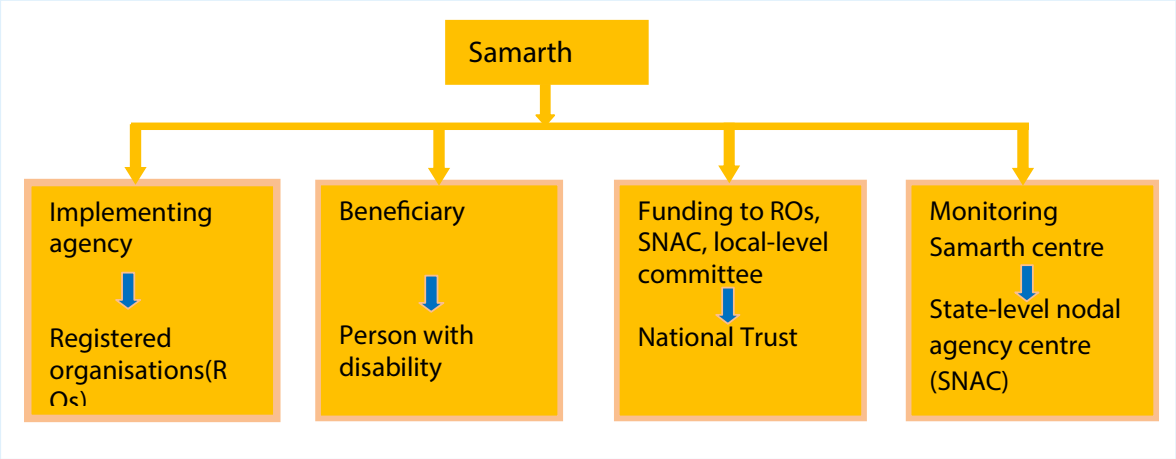
2.4 SAMARTH (Respite Care)

2.4.1 About the Scheme

The scheme aims to provide respite home for orphans or abandoned PwDs, families in crisis, and PwDs from BPL and LIG families including destitutes with at least one of the four disabilities covered under the National Trust Act. It also aims at creating opportunities for family members to get respite time in order to fulfill other responsibilities. It would be the responsibility of the RO to bring in PwDs who are either non-LIGs or who are not covered in the aforementioned category to ensure sustainability.

2.4.2 Structure of the Scheme

Several stakeholders are involved in the running and monitoring of the Samarth scheme. The scheme is being implemented at the ground level by ROs under the guidance and budgetary support of the Trust. The scheme is monitored by the Trust with the help of the SNAC. Moreover, an LLC looks after the legal guardianship of PwDs. The below chart illustrates the structure of the scheme.



2.4.3Implementation of the Scheme

ROs are the implementing agencies and are required to provide the following minimum facilities in their Samarth centres.

Group Home

ROs should provide group home facility for all age groups with adequate and quality care services and acceptable living standards including basic medical care from professional doctors**.** The capacity of a Samarth centre is 30 including non-LIG and non-BPL PwDs. The batch size of a Samarth centre is 30 PwDs, and the maximum number of PwDs allowed is 30% extra of the batch size, that is,39. On reaching the maximum limit of 39 PwDs, the Samarth centre does not allow anymore PwDs to enrol in the centre. ROs are encouraged to apply again if they have sufficient number of PwDs for anew Samarth centre.

ROs should maintain a ratio of 1:1 for LIG (including BPL) and above LIG PwDs (which are paid seats for ROs). Payment for the above LIG seats could be received by the ROs from parents, guardians, family members, ROs, or any other institute/individual directly as per mutually agreed terms and conditions between the ROs and other party involved (parents, guardians, family members, ROs, or any other institute/ individual).

As stated earlier in the document, it is to be noted that ROs should bring in more PwDs to the Samarth centre who are either non-LIGs or who are not covered in the aforementioned category to ensure sustainability.

Vocational Activities

The Samarth centre should provide age-specific vocational activities, pre-vocational activities, and assistance for training or schooling as applicable on case-to-case basis.

Staffing

There should be a provision of at least two special educators (+vocational trainers), one physiotherapist or occupational therapist, three caregivers, two Ayas, and a cook in the

Samarth centre. Provision of a physical trainer and a speech therapist in these centres is also desirable.

Infrastructure facilities

The Samarth centre must have at least one medical or assessment room (with therapeutical aids and appliances), at least one activity or vocational room, at least one recreation room (all rooms to be of reasonable size), hygienic lodging, and other facilities for the PwDs. The centre should also have provision for a kitchen and office supplies including a personal computer for the office purpose and for sending fund request, submitting reports, etc. to the National Trust. Assistance for setting up work centres (only the setup cost)is provided by the National Trust depending on the viability of the proposal.

Assessment and Evaluation

PwDs should be assessed and evaluated by experts in the related field on a regular basis to understand their individual needs and monitor the progress of the PwDs. The Samarth centre should maintain a record in the growth and development charts of the PwDs on a regular basis (with the help of experts).

Linkage with Gharaunda

The Samarth centre should facilitate shifting the PwDs who are above 18 years of age and have spent more than 5 years in the Samarth centre to the Gharaunda centre.

2.4.4 Funding Pattern

National Trust provides funding to the Samarth centre under following three heads:

(i) Setup Cost

This is a non-recurring one-time cost that is provided to the ROs initially to setup the Samarth centre. In addition to the grant from the National Trust, the ROs are free to arrange grant from other sources for improving the infrastructure. It shall be the prerogative of the ROs to buy the necessary products and items for the setup from the places of their choice.

(ii) Sustenance Cost

Sustenance cost is provided by the National Trust to the Samarth centre for a maximum of 3 months after the setup period. This has been provisioned considering the fact that the ROs would find it difficult to enrol 30 PwDs in the first month. The sustenance cost is given in order to ensure that all staff and facilities are available and functional from the first day of operation of the centre, irrespective of the number of PwDs enrolled. The advantage of providing sustenance cost is that the ROs would be able to run the centre without any difficulty and because the National Trust believes that the centre would become stable within the sustenance period.

The National Trust provides sustenance cost to the centre only if the minimum number of PwDs in a Samarth centre in the initial 3 months is at least 20% of the expected batch size in each month (that is, 6 in this case). The centre can be made operational only when minimum 6 PwDs are enrolled.

The sustenance cost is calculated on a pro-rata basis based on the difference in total expected PwDs and number of actual PwDs in the centre during the 3 months.

For example, if an RO has 6 PwDs in the first month of its operation, then the sustenance cost will be paid for 30−6 = 24 PwDs. However, for the 6 PwDs already enrolled, monthly recurring cost shall be paid as per the scheme.

The provision of sustenance cost is conditional upon the timely start of operation of the Samarth centre. The centre is expected to start operations within 1 month from the release of setup cost. In case the start of operations exceeds this deadline by more than a month (which means operations have not started even within 2 months from the release of setup cost), the overall period for which sustenance cost is provided would be reduced by the duration of delay.

For example, if the Samarth centre starts the operation 3 months after the setup cost has been provided, then sustenance cost shall only be provided for 2 months. Similarly, if the Samarth centre starts the operation 4 months after the setup cost has been provided, then the sustenance cost shall only be provided for 1 month.

In case the Samarth centre closes down within 1 year of the start of operations, the sustenance amount that is given to the concerned RO for the Samarth centre shall be taken back from that RO.

2.5 GHARAUNDA (Group Home for Adults)

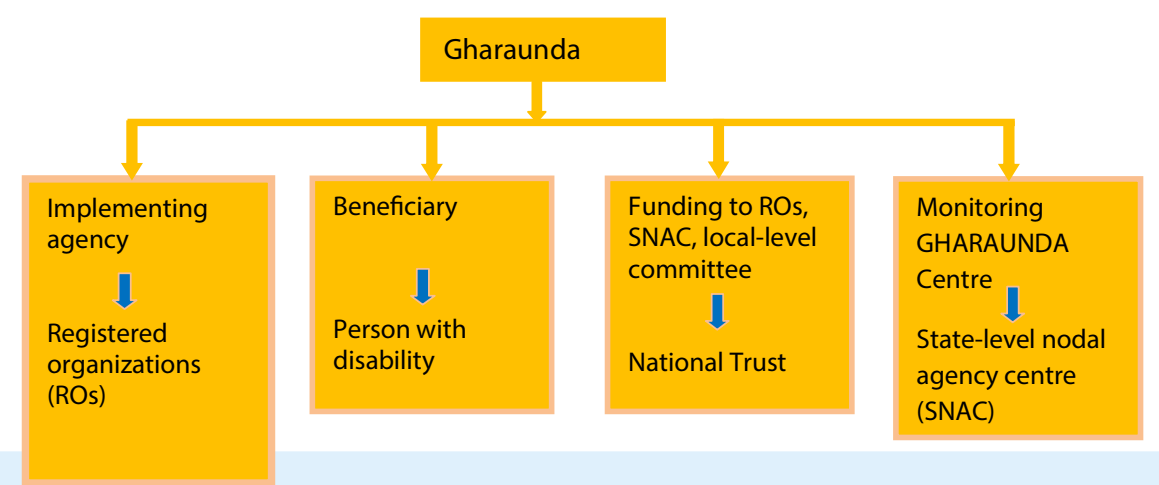
2.5.1 About the Scheme

The scheme aims to provide an assured home and minimum quality of care services throughout the life of persons with autism, cerebral palsy, mental retardation, and multiple disabilities and ensure the following for them:

- Facilitate establishment of requisite infrastructure for the assured care system throughout the country
- Encourage assisted living with independence and dignity
- Provide care services on a sustainable basis

2.5.2 Structure of the Scheme

Several stakeholders are involved in the running and monitoring the Gharaunda scheme. The scheme is being implemented at the ground level by ROs under the guidance and budgetary support of the Trust. The scheme is monitored by the Trust with the help of the SNAC. Moreover, an LLC looks after the legal guardianship of PwDs. The below chart illustrates the structure of the scheme.



2.5.3 Implementation of the Scheme

The scheme is being implemented by ROs. The scheme aims at setting up Gharaunda centres for lifelong shelter and care of PwDs covered under the National Trust Act. The Gharaunda centre should provide a minimum of the following facilities:

Group Home

ROs should provide lifelong group home facility for all adult PwDs covered under the National Trust Act with adequate and quality care services and acceptable living standards including basic medical care from professional doctors.

The batch size of a Gharaunda centre is 20 PwDs, with the maximum PwDs allowed being 30% additional of a batch size, that is, 26, for the Gharaunda centres. On reaching the maximum limit of 26 PwDs, the Gharaunda centre does not allow anymore PwDs to enrol in the centre. ROs are encouraged to apply again if they have sufficient number of PwDs for anew Gharaunda Centre. The ROs should maintain a ratio of 1:1 for LIG (including BPL) and above LIG PwDs (which are paid seats for RO). Payment for the above LIG seats could be received by the ROs from parents, guardians, family members, ROs, or any other institute/individual directly as per mutually agreed terms and conditions between the ROs and other party involved (parents, guardians, family members, ROs, or any other institute/individual)

Vocational Activities

The Gharaunda centre should provide vocational activities, pre-vocational activities, and assistance for further training.

Staffing

There should be a provision of at least two special educators who would also provide vocational training, one physiotherapist or occupational therapist, and three caregivers,

Ayas and cook(s) in the centre. Availability of a physical trainer and speech therapist in these centres is also desirable.

Infrastructure Facilities

The Gharaunda centre must have at least one medical or assessment room (with therapeutical aids and appliances), at least one activity or vocational room, at least one recreation room (all rooms to be of reasonable size), hygienic lodging, and other facilities for the PwDs. In addition, there should be a provision for a kitchen and office supplies including a personal computer for the office purpose and for sending fund request, communicating with the National Trust, and submitting reports and other documents as and when required under the scheme. Assistance for setting up work centres (only the setup cost)is provided by the National Trust depending on the viability of the proposal.

Assessment and Evaluation

PwDs should be assessed and evaluated by experts in the related field on a regular basis to understand their individual needs and monitor the progress of the PwDs. The Gharaunda centre should maintain a record of the growth and development charts of the PwDs on a regular basis (with the help of experts).

Linkage with Samarth

The Gharaunda centre should facilitate intake of a PwD who is above 18 years of age and has spent more than 5 years in the Samarth centre.

2.5.4 Funding Pattern

The National Trust provides funding to the Gharaunda centre under following three heads:

(i) Setup Cost

This is a non-recurring one-time cost that would be provided to the ROs initially to setup the Gharaunda centre. In addition to the grant from the National Trust, the ROs are free to arrange grant from other sources for improving the infrastructure. It shall be the prerogative of the ROs to buy the necessary products for the setup from the places of their choice.

(ii) Monthly Recurring Cost

The National Trust pays monthly recurring cost for all PwDs at the Gharaunda centre who are eligible to be funded by the National Trust starting from the first month of operation. The National Trust funds the centre only if the minimum number of PwDs in a Gharaunda centre in the months is 30% of the expected batch size (i.e.,6 in this case).

The National Trust funds the PwD as per the following conditions:

a. The National Trust funds PwDs in a Gharaunda centre in a 1:1 ratio provided there are

equal number of LIG (including BPL) and above LIG PwDs. LIG is defined as follows: LIG = BPL limit set by the state + additional 50% of BPL limit of that state

b. If the number of LIG (including BPL) PwDs is higher than that of above LIG PwDs, funds shall be provided for only those LIG PwDs for which a 1:1 ratio is maintained (LIG including BPL: Above LIG category). In this scenario, BPLs shall be given preference for funding.

c. If the number of LIG (including BPL) PwDs is lower than that of above LIG PwDs, the National Trust shall fund the total number of LIGs (including BPL).

d. Apart from this, the National Trust funds 100% BPL in a Gharaunda as per the scheme irrespective of the ratio, but the same is not true for LIG PwDs.

(iii) Crisis Fund

The National Trust maintains a crisis fund for each Gharaunda Centre, which may be utilised in case of any emergency. The crisis fund may be utilised by the RO via multiple requests within the total limit set for the crisis fund. Once used, the crisis fund shall not be replenished. At the time of crisis, the RO needs to obtain an approval from the State Government for using the crisis fund. Upon submitting the proof of this approval and/or receiving a directive from the State Government, the National Trust releases the required funds.

(iv) Setup Cost for Work Centre (If Availed by the RO)

The National Trust also considers funding the setup cost for work centres opened by existing ROs after validating the viability of the proposal. Existing ROs should have a minimum of 10 trained PwDs to work in these work centres to avail the setup cost.

In case the work centre is closed down within 1year of the start of operations, the setup cost for the work centre shall be taken back from that RO by the National Trust.

2.6 NIRAMAYA (Health Insurance Scheme)

2.6.1 About the Scheme

The objective of the scheme is to provide affordable health insurance to PwDs with an insurance cover of up to Rs. 1.0 lakh; facility for OPD treatment including medicines, pathology, and diagnostic tests; regular medical checkup for non-ailing disabled; preventive dentistry; surgery to prevent further aggravation of disability; non-surgical techniques/ hospitalisation; corrective surgeries for existing disability including congenital disability; ongoing therapies to reduce the impact of disability and disability-related complications; alternative medicine; and transportation costs. The scheme is available in the entire country except Jammu and Kashmir.

2.6.2 Implementation of the Scheme

The scheme is being implemented by ROs. All ROs registered under the Trust after paying the registration fee of Rs.1000/- could get registration under the Niramaya Health Insurance Scheme and then will be eligible to enrol the PwDs under the National Trust Act. All PwDs who have at least one of the disabilities listed under the National Trust Act, 1999 with a valid disability certificate are eligible to apply for the scheme.

(i) Enrolment Process

Any eligible person can apply for enrolment under the scheme in the prescribed format given on the website and submit it to the nearest organisation registered with the National Trust or to any other agencies specially entrusted in this regard by the National Trust at any time during the year. On successful enrolment and approval, a Health ID No./card is issued to each beneficiary and the Ecard can be printed through the website.

A nominal processing fee will be applicable as determined from time to time, which shall be payable to the National Trust. Fresh enrolment may be done throughout the year through the National Trust ROs. Both fresh enrolment and renewal will be from the enrolment date with the insurance company to the end of the financial year. Any beneficiary enrolled during any month of the financial year will be covered upto 31March. The enrolment/renewal fee will be full, and one will be eligible to claim upto Rs.1 lakh.

(ii) Premium and Other Charges

The insurance company shall be selected and premium shall be decided through a transparent process. The premium amount shall be paid by the National Trust in advance to the selected insurance company.

(iii) Approval Process

The PwD enrolment process defines the steps to be followed while enrolling for Niramaya for the first time. It also details out the required information and documents at each step and timelines for various activities wherever applicable.

Any eligible person can apply for enrolment under the scheme in the prescribed format through the nearest organisation registered with the National Trust or to any other agencies specially entrusted in this regard by the National Trust at any time during the year. The PwD will be responsible for paying the application fee as applicable, and the RO will be entitled to Rs.40 payable by the National Trust per form for processing.

STEP-1: Parents/guardian of the PwD will visit the nearest RO for Niramaya enrolment with required documents (as detailed in Step 2)

STEP-2: The RO will follow the process detailed below for enrolment of the PwD:

- RO to send the online application form/proposal
- RO to fill up the Niramaya application form online and upload the scanned documents as required after verification of originals
- RO to submit the duly filled in form on the National Trust portal

STEP-3: The National Trust receives the application form and documents, which are checked for completion. However, if there is any missing information or wrongly submitted information, and the form needs to be submitted again, the RO is given 15 days' time to submit it again.

STEP-4: On successful enrolment and approval, Health ID No./card is issued to each beneficiary.

Communication to the RO by the National Trust is done within 30 days on receipt of final documents.

STEP-5: Enrolment is completed, and the Health ID card is uploaded online and can be downloaded by the beneficiary online or through the RO.

(iv) Enrolment and Renewal Fee

The enrolment/renewal fee is for 1year, that is, upto 31 March of the next year. This means, every year the policy needs to be renewed online through www.thenationaltrust.gov.in by the beneficiary or NGO, and the fee has to be paid as per the applicable rate (fixed by the National Trust) directly to the bank.

(v) Guidelines for Enrolment

Enrolment is being done online by all ROs. The list of ROs is available on the website.

The applicant is required to submit the duly filled enrolment form to the registered NGO, along with the following documents:

1. Disability certificate issued from the district hospital or appropriate government authority
2. Address proof
3. One passport size photograph of the special need person
4. BPL card, if applicable
5. Income certificate (Latest IT return, or income certificate from Tehsildar)
6. Proof of payment of applicable fee (bank receipt)
7. Bank details for settlement of claims

(vi) Process of Claim Settlement

Claim forms for settlement, through reimbursement basis only, under Niramaya have to be submitted in the prescribed claim form format along with relevant vouchers/bills, etc. within 30 days of treatment or discharge from the hospital. The claim form can be downloaded from the website and sent to the third party administrator, authorised by the insurance company.

Chapter 3

Scope, Coverage, and Methodology

The National Trust has been thrived with the key objectives of addressing two fundamental issues pertaining to PwDs such as legal and welfare. It provides legal support to PwDs through LLCs and welfare through several flagship schemes. Since its inception in 1999, it has taken several path-breaking steps to monitor and evaluate its schemes and their funding patterns and taken concerted efforts to redesign the schemes in order to achieve maximum benefits with minimum funding. Such decisions were not taken unilaterally, rather efforts were being made for wider consultation with different stakeholders such as NGOs, parents, PwDs, and public at a large by conducting several workshops/seminars and awareness programmes. Therefore, continuous evaluation of new schemes has been the guiding principle for the Trust to understand the pros and cons of each scheme. In this context, in order to carry forward the new schemes in the future and to change the existing funding pattern, the Trust has envisaged a third-party evaluation of the performance of various schemes and their funding patterns.

3.1. Scope and Coverage of the Study

3.1.1. Data Coverage

It is a pan-India study covering desirable number of beneficiaries from a wider spectrum of geographical locations to ensure that people from different walks of life including different castes, religions, rural and urban areas, and youth and senior citizens are part of the study. The study analysis is based on both primary and secondary information. Secondary information on fund allocation and the list of beneficiaries under different ongoing schemes were collected from the Trust. The up-to-date data received from the Trust suggests that there are 1,301 beneficiaries enrolled under the Disha scheme in India (**table 3.1**). Similarly, there are 1,982 under Vikaas, 1,415 under Disha-cum-Vikaas, 881 under Samarth, 760 under Gharaunda, 331 under Samarth-cum-Gharaunda, and 76,831 under the Niramaya scheme.

Table 3.1: No. of Beneficiaries under Various Schemes

Schemes	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Total
Disha	30	369	757	145	1,301
Vikaas	8	329	1,455	190	1,982
Disha-cum-Vikaas	8	312	1,001	94	1,415
Samarth	3	142	667	69	881
Gharaunda	4	104	597	55	760
Samarth-cum-Gharaunda	1	47	262	21	331
Niramaya	1,328	11,008	57,094	7,401	76,831

Source: Database of the National Trust, Ministry of Social Justice & Empowerment, Government of India.

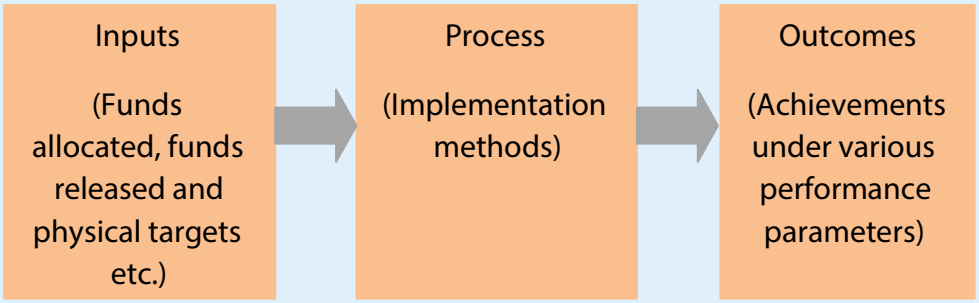
Of the aforementioned beneficiaries, the study selected a list of sample beneficiaries for the primary survey. A detailed discussion on sampling is done in the next section. As far as primary data is concerned, a field-level data collection procedure was followed to collect the information using a structured questionnaire of different stakeholders such as beneficiaries, ROs, and SLCCS.

3.1.2 Target Group

Beneficiaries assisted by implementing agencies from grants-in-aid received under the scheme during the financial years (2016–17, 2017–18, and 2018–19) participated in the study. This comprises beneficiaries of the schemes, namely Disha, Vikaas, Disha-cum-Vikaas, Samarth, Gharaunda, Samarth-cum-Gharaunda, and Niramaya. The other stakeholders covered under the survey were centres of ROs, LLCs for legal guardian support, and the SNAC for onsite visits and monitoring of different centres.

3.2 Methodology and Sample Size

To examine the objectives, the study proposed to use a mix of quantitative and qualitative methodologies. A 360° evaluation approach was followed covering various stakeholders associated with the schemes. The stakeholders included under the schemes are beneficiaries, implementing agencies such as the DEPwD, M/O SJE, beneficiaries of key schemes, ROs, LLCs for legal guardian support, and the SNAC for onsite visits and monitoring of different centres. The study used the following approach to evaluate the performance of each scheme of the National Trust:



3.2.1 Data Collection

The study collected information using the following methods:

i. Through a structured questionnaire for both beneficiaries and ROs

ii. Focus group discussions (FGDs) with the SNAC

iii. Secondary records (office records) and other documents from the ministry.

3.2.2 Data Validation and Analysis

The data validation and analysis process include the following steps:

i. Data coding

ii. Data editing

iii. Data cleaning

iv. Validation of data range

v. Sampling validation

vi. Tabulation plan

vii. Reliability and validity of indicators

For the data analysis, the study used statistical tools such as ratio, proportion, percentage, mean, cross tabulation analysis, bar charts, pie charts, etc. as per case-to-case basis. The purpose of using these techniques was to keep the data analysis as simple as possible and make it useful for the understanding of larger audience.

3.2.3 Sampling Design

As directed by the Ministry, it was decided to cover 8,000 (sample size) beneficiaries across different regions of the country. Because the Trust has been running two major categories of schemes such as health insurance and day and residential care, the study allocated 7,000 as the sample size for the former category of the scheme and 1,000 as the sample size for the latter category of the scheme. A stratified random sampling method was used to distribute the sample size across regions/states and to ensure that sample selection is representative across states/regions, centres/ROs, and beneficiaries from different income groups and regions. There are six geographical regions: northern, central, northeastern, eastern, western and southern. All states and UTs have been distributed under these six regions as illustrated below.

Northern region: Delhi, Haryana, Himachal Pradesh, Punjab, Rajasthan, and the Union Territory of Chandigarh

Northeastern region: Assam, Arunachal Pradesh, Manipur, Meghalaya, Mizoram, Nagaland, Tripura, and Sikkim

Central region: Chhattisgarh, Madhya Pradesh, Uttarakhand, and Uttar Pradesh

Eastern region: Bihar, Jharkhand, Odisha, and West Bengal

Western region: Goa, Gujarat, and the Union Territories of Daman &Diu and Dadra & Nagar Haveli

Southern region: Andhra Pradesh, Karnataka, Kerala, Tamil Nadu, Telangana, and the Union Territory of Puducherry

Table 3.2 illustrates the sample size of the study. The actual sample size of the study was 7,137as against the proposed sample size of 8,000. In case of Niramaya, we were able to cover more than 94.6% of the proposed sample size, which is fair enough for any data analysis. In other cases too such as Vikaas, Disha, and Disha-cum-Vikaas, the actual sample size was more than 50% to 60%, which is reasonably good enough for the analysis. The data collection however was reported low in case of Samarth-cum-Gharaunda and Samarth. There are two reasons for low data collection in case of residential schemes. First, many states had imposed restrictions on visiting to residential centres owing to COVID-19. Second, some centres did not allow the team to interact with the beneficiaries due to the fear of transmission of infection. Besides beneficiaries, the study collected information from a good number of ROs under different schemes and carried out FGDs of implementing agencies.

Table 3.2: Sample Size of Beneficiaries of the Study

Sl. No	Name of Scheme	Proposed Sample Size	Actual Sample Size	Actual Sample (% Share of Proposed Sample)
1	DISHA	144	62	43.1
2	VIKAASz	204	138	67.6
3	DISHA-CUM-VIKAAS	421	230	54.6
4	SAMARTH	58	24	41.4
5	GHARAUNDA	95	48	50.5
6	SAMARTH-CUM-GHARAUNDA	78	14	17.9
7	NIRAMAYA	7000	6621	94.6
	Total	8000	7137	89.2

Source: NILERD

3.3. Target Indicators, Method of Evaluation, and Key Outcomes

A list of target indicators on which primary data was collected through structured questionnaires and different other methods is presented in the below box.

INBOX: Parameters and methods of evaluation		
Scheme Name	Target Indicators	Method of Evaluation
Group A		
Disha (Early Intervention and School Readiness Scheme) Vikaas (Day Care) Samarth (Respite Care) GhAraunda (Group Home for Adults)	Coverage of the scheme in rural/urban/ remote areas Budgetary/sanctioned/actual release of fund Availability/adequacy/timely release of fund. Quality of service delivered by ROs Quality of infrastructure available at the centre Impact of the scheme on parents and children Impact on education and economic empowerment of PwDs Measures to check leakages such asduplication of beneficiaries Effectivenessofthepresentimplementation system and scope for improvement Adequacy of awareness programmes	-Through a structured questionnaire Personal interaction with the staff at ROs HH survey of beneficiaries (PwDs) Personal interaction with the parents of the beneficiaries FGD Personal interaction with the key personnel at the LLC, SNAC, and NGOs Capturing success story
Group B		
Niramaya (*Health Insurance Scheme)*	Coverage of the scheme in rural/urban/ remote areas Benefits of health insurance Adequacy of the service offered under the scheme Duration of claim settlement Effectivenessofthepresentimplementation system and scope for improvement. Impact of the scheme on personal and professional life of PwDs	

Some of the key expected outcomes of the study are illustrated below.

i. Number of PwD beneficiaries covered (in rural and urban areas) gender-wiseand disability-wise

ii. Percent of girls/women/SC/ST benefited from the scheme

iii. Percentage of implementing agencies and beneficiaries satisfied with services offered by the Ministry

iv. Percentage of beneficiaries satisfied with services offered by ROs

v. Percentage of beneficiaries satisfied with the service offered by insurance companies

vi. Percentage of beneficiaries satisfied with the quality of infrastructure available at various centres

vii. Impact of the scheme on learning, speaking, and interpersonal life of PWDs

viii. Impact of the scheme on household income and time

ix. Adequacy of the scheme in terms of medical coverage

x. Adequacy of the scheme in terms of fund available

Chapter 4

Impact, Implementation, and Improvement: An Analysis of Key Objectives of the Study

4.1 Introduction

The United Nations Convention states that PwDs 'must be able to fully enjoy all human rights and fundamental freedoms in conditions of equality with respect to others'[20]. The OECD declares that in various social, economic, and cultural contexts in the world the search for means to stimulate social progress in a more inclusive way is active[21].

System actions need to be implemented through different welfare schemes that lead to the achievement of full inclusion and the construction of a society for all categories of people. This is why some social innovation projects were born based on an idea of community that becomes welcoming and can carry out strategic functions of support. Innovation concerns new ideas to respond to urgent needs and problems that now have no response and, at the same time, create new social relationships or forms of collaboration.

In view of the above, the National Trust works towards providing opportunities for the capacity development of PwDs and their families, thereby fulfilling their rights and facilitating and promoting the creation of an enabling environment and an inclusive society. The National Trust's mission, or fundamental purpose, is to create an enabling environment, that is, providing opportunities for PwDs through comprehensive support systems, which can also be done by collaborating with other ministries, etc., thereby leading towards development of an inclusive society.

The ongoing chapter is based on the analysis of data collected from several beneficiaries under different schemes of the National Trust and the feedback of the ROs running different schemes under the National Trust. We hope that by making visible the challenges of as well as the benefits received by the children and their parents interviewed in our study, we will able to provide researchers and policy practitioners with some valuable insight and practical suggestions for improving the scheme in future.

20 J, Snoddon K, M De, Underwood K. (2018) Intersectional inclusion for deaf learners: moving beyond General Comment no. 4 on Article 24 of the United Nations Convention on the Rights of Persons with Disabilities. International Journal of Inclusive Education 1-15.

21 Boheim R, Leoni T. (2018) Sickness and disability policies: Reform paths. in OECD countries between 1990 and 2014. International Journal of Social Welfare,27(2) 168-185.

4.2 Trends and Patterns of Fund Allocation of the Trust

The balance sheet of the Trust for the period 2016–17 to 2018–19 is illustrated in **table 4.1**. It shows that the Trust had experienced shortage of fund with the tone of Rs.568.18 lakh in 2016–17 due to higher expenditure compared to revenue generation. The deficit further increased to Rs. 587.44 lakh in 2017–18. However, in 2018–19, the Trust had a surplus with the tone of Rs. 396.63 lakh owing to significant reduction in expenditure on various schemes and an increase in revenue. The total expenditure was declined at 21.58% during 2018–19 over 2017–18, whereas the total revenue increased at a reasonable rate of 13.97% during the same period.

Table 4.1: Income and Expenditure of National Trust

Heads	Rs. Lakhs			Growth Rate (%)	
	2016–17	2017–18	2018-19	2017–18	2018–19
(A) Income	2014.51	2411.39	2748.22	19.70	13.97
Income from Sales/Services	0.00	0.00	0.00		
Grants/Subsidies/ Sponsorships	647.83	1346.98	1623.34	107.92	20.52
Fees/Subscriptions	339.80	177.50	225.16	–47.76	26.86
Income from Investments (in RBI Bonds)	853.29	848.00	848.00	–0.62	0.00
Income from Royalty, Publication etc.	0.00	0.00	0.00		
Interest Earned on Bank Deposits	104.93	9.65	20.67	–90.80	114.19
Other Income	68.67	29.27	31.05	–57.38	6.11
Increase/Decrease in Stock of Finished Goods	0.00	0.00	0.00		
(B) Expenditure	2582.69	2998.83	2351.59	16.11	–21.58
Establishment Expenses	234.22	274.92	212.01	17.37	–22.88
Administrative Expenses, etc.	151.06	152.16	134.05	0.73	–11.90
Expenditure on Grants, Subsidies, etc.	2188.01	2565.86	2000.87	17.27	–22.02
Interest, etc.	0.00	0.00	0.00		
Depreciation (Net Total at the Year End Corresponding to Sch.8)	9.40	5.89	4.66	–37.31	–20.97
Deficit (–)/Surplus (+)	–568.18	–587.44	396.63		

Source: Various Annual Reports, National Trust.

Expenditure of the Trust on several schemes for PwDs is reported in **table 4.2**. The data shows that a major portion of the fund (about 73%) was allocated for running two important schemes, namely Disha-cum-Vikaas and Samarth-cum-Gharaunda, during 2016–17. However, the share of these schemes in total expenditure declined in 2017–18 and 2018–19. On the other hand, expenditure on the Niramaya scheme increased over the period. It went up from about 22% in total expenditure in 2016–17 to 41.4% in 2018–19. In case of *Badhte Kadam*, the data shows that the fund allocation to the scheme declined significantly in the recent years.

Table 4.2: Scheme-wise Expenditure

Programmes and Projects	Rs. Lakhs			Growth Rate (%)	
	2016–17	2017–18	2018–19	2017–18	2018–19
Disha-cum-Vikaas (Early Intervention and School Readiness -cum-Day Care)#	939.37	809.09	750.14	–13.87	–7.29
Samarth-cum-Gharaunda (Respite Care-cum-Group Home)#	614.94	708.74	365.52	15.25	–48.43
Sahyogi (Caregiver Training Scheme)	46.82	118.36	14.63	152.79	–87.64
Niramaya (Health Insurance Scheme)	463.31	729.92	803.99	57.54	10.15
Gyan Prabha (Educational Support)*	1.74	4.09	2.90	135.96	–29.22
Sambhav (Aids and Assiste Devices)**	-	-	-	-	-
Prerna (Marketing Assistance)**	-	-	-	-	-
Badhte Kadam (Awareness, Community Interaction, and Innovation)	63.94	11.27	3.67	–82.37	–67.45
Total	**2,130.12**	**2,381.47**	**1,940.84**	**11.80**	**–18.50**

Source: Various Annual Reports, National Trust.

Note: # schemes are merged w.e.f 01-04-2018; * the scheme is being closed w.e.f 01-04.2018; ** the schemes will be revised.

Table 4.3: Expenditure on Awareness and Institutional Arrangements (Rs. Lakhs)

Heads	2016–17	2017–18	2018–19
Awareness and publicity			
(i) Print and electronic media	0.67	15.61	0.22
(ii) Workshops/seminars	20.84	76.73	16.21
Total	**21.52**	**92.34**	**16.43**
Institutional arrangements, meetings, and others			
(i) SNAC/SNAP	21.10	67.37	29.14
(ii) LLCs	4.22	2.13	4.31
(iii) Annual general meeting	1.81	2.26	1.61
(iv) Board meetings	5.80	5.94	5.56
(v) Misc. other meetings	3.43	2.38	2.98
Total	**36.37**	**80.07**	**43.60**

Source: Various Annual Reports, National Trust.

Note: SNAC = State-level Nodal Agency Centre, SNAP = State Nodal Agency Partner, LLCs = Local-Level Committees

Fund allocation for conducting workshops/seminars, organising meetings, advertisements, and running different committees constituted by the Trust are given in **table 4.3**. The data shows that except expenditure in the LLC, in all other cases, the expenditure significantly increased during 2017–18 over 2016–17. However, in 2018–19, baring one or two items such as the LLC and miscellaneous other meetings, in all other cases, the expenditure declined substantially.

In a nutshell, the expenditure pattern of the Trust on social schemes indicates that the expenditure substantially reduced in 2018–19. Except Niramaya, all other schemes witnessed a decline in fund allocation in the same year.

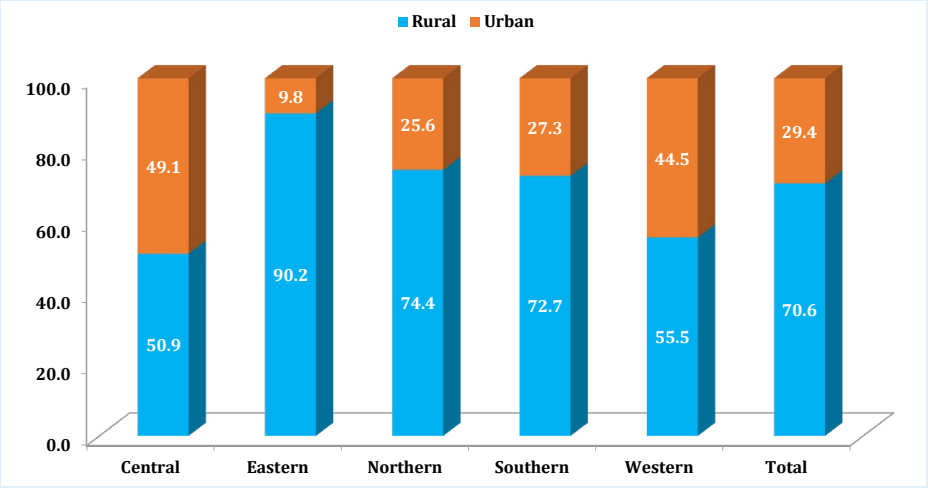
The next section presents the findings of different schemes based on information collected from both primary and secondary sources.

4.3. Niramaya–the Health Insurance Scheme

4.3.1 Regional Distribution of Beneficiaries

The distribution of beneficiaries by rural and urban areas under the Niramaya scheme reported in **figure 4.1** suggests that majority of the beneficiaries (70.6%) belong to the rural area and the rest of the beneficiaries (29.4%) belong to the urban area. Across the regions, the eastern region represents maximum percentage of beneficiaries from the rural area (90.2%) and the lowest percentage of beneficiaries belongs to the rural area in case of the central region.

Figure 4.1: Distribution of Beneficiaries by Rural and Urban areas (%)



Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

Table 4.4 illustrates the distribution of beneficiaries under the Niramaya scheme in different regions. The data shows that more than three-fourths of the beneficiaries (78.9%) belong to southern region and the rest of them belong to all other regions. Within the southern region, Kerala alone represents 84% of the beneficiaries, which is very encouraging as far as outreach of the scheme is concerned. The presence of the scheme in the northeastern region is miniscule, as the said region represents only 0.05% of the total beneficiaries. The representation of the rest of the regions, namely central, eastern, and northern, is also not very encouraging.

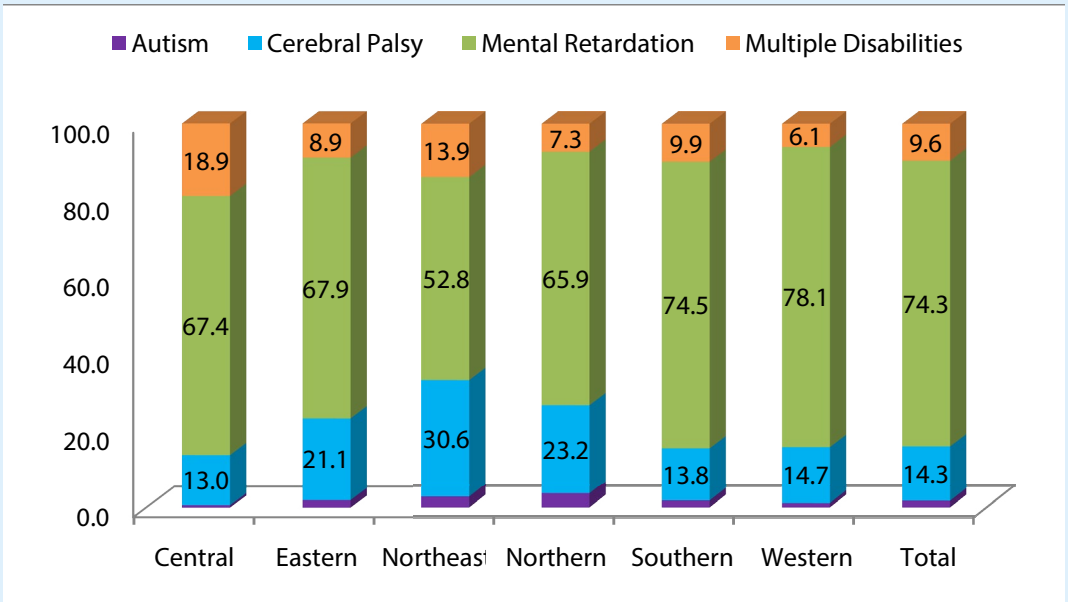
Table 4.4: Between-Region Distribution of Beneficiaries by Types of Disabilities under the Niramaya Scheme (%)

Region	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Total
Central	1.2	2.7	2.7	5.9	3.0
Eastern	5.5	6.7	4.2	4.2	4.6
Northeastern	0.1	0.1	0.0	0.1	0.05
Northern	2.9	2.3	1.3	1.1	1.4
Southern	82.3	75.7	79.1	81.1	78.9
Western	8.0	12.4	12.7	7.6	12.1
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

The coverage of the scheme as far as types of disabilities is very encouraging in case of mental retardation and cerebral palsy. The distribution of beneficiaries under different categories of disabilities is quite balanced across all the regions (**figure 4.2**).

Figure 4.2: Within-Region Distribution of Beneficiaries by Types of Disabilities under the Niramaya Scheme (%)



Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

Unlike other schemes of the Trust, the distribution of beneficiaries of the Niramaya scheme under two income group categories indicates that more than 80% of them belong to the non-BPL income group in the northern, western, and northeastern regions. In the remaining regions, the percentage of beneficiaries belonging to the BPL income group is higher than that of beneficiaries belonging to the non-BPL income group (**table 4.5**).

Table 4.5: Distribution of Types of Disabilities of Beneficiaries by Income Group and Region under the Niramaya Scheme (%)

Regions	BPL					Non-BPL					Grand Total
	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub- Total	Autism	Cerebral Palsy	Mental Retardation	Multiple Dis-abilities	Sub-Total	
Central	0.2	4.2	44.5	13.9	62.8	0.5	8.9	22.9	5.0	37.2	100.0
Eastern	0.4	13.6	42.0	5.8	61.8	1.7	7.5	25.9	3.1	38.2	100.0
Northeastern	0.0	8.3	8.3	2.8	19.4	2.8	22.2	44.4	11.1	80.6	100.0
Northern	0.1	3.4	9.6	1.1	14.2	3.5	19.8	56.3	6.2	85.8	100.0
Southern	0.8	9.6	49.8	6.1	66.3	1.0	4.1	24.7	3.8	33.7	100.0
Western	0.1	2.6	13.4	1.3	17.4	1.1	12.1	64.7	4.8	82.6	100.0
Total	**0.6**	**8.7**	**44.3**	**5.7**	**59.3**	**1.1**	**5.6**	**30.0**	**4.0**	**40.7**	**100.0**

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

4.3.2 Basic Profile of Beneficiaries

This section analyses the basic information of beneficiaries such gender, age, social group, educational qualifications, and income group. The distribution of beneficiaries under the Niramaya scheme by gender is presented in **table 4.6**. The data shows that of the sampled beneficiaries, around 66% are male members and the rest are female members. The percentage variation of male members is not very significant among the regions. While the percentage of male members is maximum in the central region (73.6%), and the percentage is the lowest in the southern region (64.4%).

Table 4.6: Distribution of Beneficiaries by Gender under Niramaya (%)

Region	Male	Female	Total
Central	73.6	26.4	100.0
Eastern	68.8	31.3	100.0
Northern	70.5	29.5	100.0
Southern	64.4	35.6	100.0
Western	71.3	28.7	100.0
Total	**65.5**	**34.5**	**100.0**

Source: Primary Survey, NILERD, 2020

In the age category, the distribution of beneficiaries under the Niramaya scheme demonstrates that maximum percentage of beneficiaries (43.2%) fall in the age group of 18–30 years, followed by 36.9% in the age group of less than 18 years and 15.7% between 30 and 45 years (**table 4.7**). Beneficiaries in the age group of more than 60 years are very less (0.9%).

Table 4.7: Distribution of Beneficiaries by Age Groups under Niramaya (%)

Region	<18 Years	≥18–30 Years	>30–45 Years	>45– 60 Years	>60 Years
Central	51.6	38.4	6.3	2.5	1.3
Eastern	53.6	36.6	8.0	1.8	0.0
Northern	41.0	37.1	21.9	0.0	0.0
Southern	35.1	43.1	17.0	3.8	1.1
Western	44.8	47.1	7.5	0.6	0.0
Total	**36.9**	**43.2**	**15.7**	**3.4**	**0.9**

Source: Primary Survey, NILERD, 2020

Regarding social groups, the study considered five such groups as SC, ST, OBC, orphan, and others which includes general category of beneficiaries. The data given in **table 4.8** shows that more than 50% beneficiaries belong to the OBC group, followed by 19.3% to the SC group and 16.7% to the ST group. Only 1.6% beneficiaries belong to the orphan group.

Table 4.8: Distribution of Beneficiaries by Social Groups under Niramaya (%)

Region	SC	ST	OBC	Orphan	Others	Total
Central	20.8	8.2	21.4	0.0	49.7	100.0
Eastern	13.4	8.9	66.1	0.9	10.7	100.0
Northern	30.5	17.1	49.5	0.0	2.9	100.0
Southern	17.8	17.8	53.4	1.9	9.0	100.0
Western	30.5	11.1	31.0	0.0	27.4	100.0
Total	**19.3**	**16.7**	**50.5**	**1.6**	**11.8**	**100.0**

Source: Primary Survey, NILERD, 2020

The distribution of beneficiaries by education in **table 4.9** indicates that maximum beneficiaries have an educational qualification of upper primary (32.3%), followed by those who are illiterate (23.9%) and those who have higher secondary (15%), primary (14.1%), and secondary (13%) education. Only 1.2% of them have and educational qualification of graduation and above.

Table 4.9: Distribution of Beneficiaries by Educational Qualification (%)

Region	Illiterate	Literate up to Primary	Upper Primary	Secondary	Higher secondary	Graduation and Above	Total
Central	27.7	11.9	6.3	11.9	42.1	0.0	100.0
Eastern	40.2	4.5	35.7	4.5	15.2	0.0	100.0
Northern	11.4	22.9	39.0	1.9	24.8	0.0	100.0
Southern	21.1	15.0	35.5	13.7	12.9	1.5	100.0
Western	45.5	7.5	10.8	11.0	24.9	0.0	100.0
Total	**23.9**	**14.1**	**32.3**	**13.0**	**15.1**	**1.2**	**100.0**

Source: Primary Survey, NILERD, 2020

The primary survey results presented in **table 4.10** shows that the scheme has focused more on extending benefits of the scheme to the poorer and weaker section of the society. Around 67% beneficiaries under the Niramaya scheme belong to the BPL group. Across the regions, while maximum BPL beneficiaries are found in the eastern region (76.8%), the lowest percentage of BPL beneficiaries is found in the western region (33.4%).

Table 4.10: Distribution of Beneficiaries by Income Group(%)

Region	BPL	APL	Total
Central	50.3	49.7	100.0
Eastern	76.8	23.2	100.0
Northern	64.8	35.2	100.0
Southern	71.3	28.7	100.0
Western	33.4	66.6	100.0
Total	**66.8**	**33.2**	**100.0**

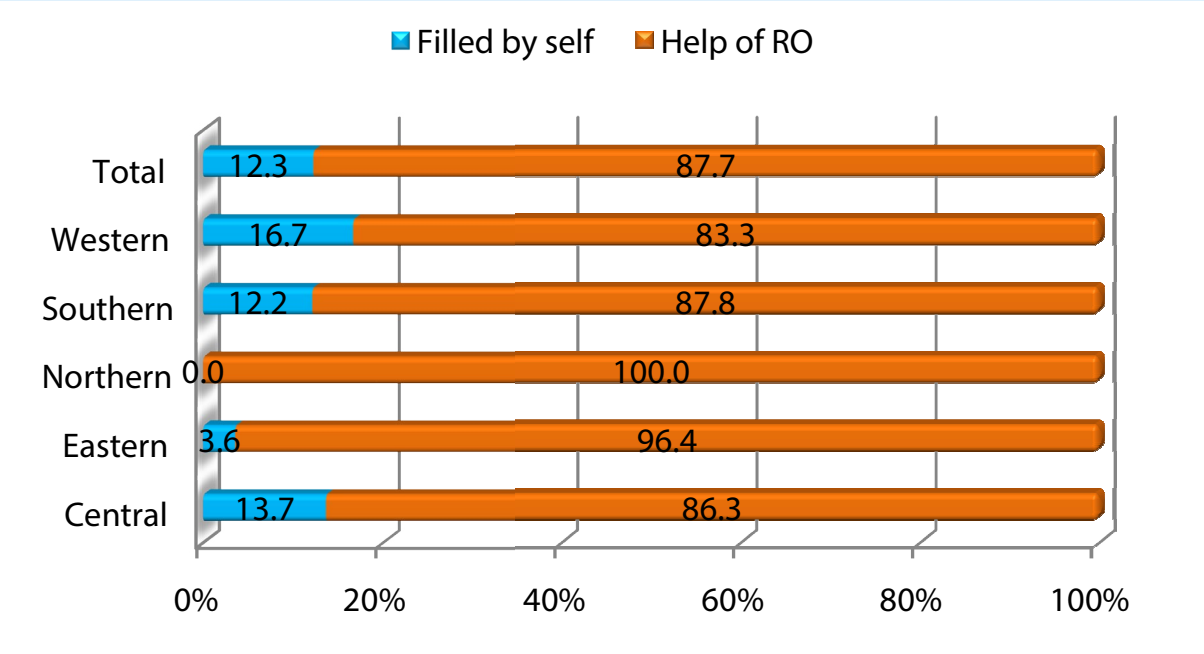
Source: Primary Survey, NILERD, 2020

4.3.3 Implementation Process of the Scheme

An effective implementation of the scheme resulted in the desired level of outcomes. To evaluate the implementation process of the Niramaya scheme, information regarding the perception of beneficiaries on different steps of implementation has been collected. The findings related to implementation of the scheme are discussed below.

The results illustrated in **figure 4.3** show that majority of the beneficiaries took the help of ROs to fill the form online. Around 88% beneficiaries took the help of the ROs, whereas 12% beneficiaries filled the form by themselves or through their parents or relatives. Across the regions, the findings are more or less consistent as far as the role of ROs in filling up the form is concerned.

Figure 4.3: Mode of Application for the Scheme by Beneficiaries



Source: Primary Survey, NILERD, 2020

At the time of applying for the scheme, people take the help of ROs while filling up the application form. In this regard, it is important to understand whether ROs are very cooperative during the application process. A whopping 95.8% beneficiaries reported that the ROs were very cooperative during the application process. Only 4.2% beneficiaries were not happy with the service of the ROs. Across the regions, all beneficiaries from the northern region reported that the ROs were supportive **(table 4.11)**

Table 4.11: Responses of Beneficiaries on Whether the ROs Were Supportive during the Enrolment Process (%)

Region	Yes	No
Central	100.0	0.0
Eastern	96.4	3.6
Northern	99.0	1.0
Southern	95.4	4.6
Western	98.1	1.9
Total	**95.8**	**4.2**

Source: Primary Survey, NILERD, 2020

Regarding the time duration in getting the health card is concerned, the results given in **table 4.12** indicate that majority of the beneficiaries (57.1%) got the health card within 15–30 days. Another 20.8% beneficiaries received the health card within 45–60 days. Across the regions, more than 60% beneficiaries pointed out that they received the health card with 15 days, which is a quite encouraging sign. At the all-India level, the results suggest that the average number of days for getting the health card is 29, while the average number of days is 19 and 30 in the northern and southern regions, respectively.

Table 4.12: Time Taken to Get the Health Card

Region	Frequency/ Number of responses (%)					Average Time Taken (Days)
	≤15 Days	>15 Days–30 Days	>30 Days–45 Days	>45 Days–60 Days	>60 Days–90 Days	
Central	37.1	53.5	1.9	6.9	0.6	23
Eastern	5.8	91.3	1.0	0.0	1.9	24
Northern	60.2	38.6	1.2	0.0	0.0	19
Southern	13.6	54.4	23.9	3.4	4.6	30
Western	10.7	75.6	7.4	2.6	3.6	28
All	**14.5**	**57.1**	**20.8**	**3.3**	**4.3**	**29**

Source: Primary Survey, NILERD, 2020

The efficiency of the implementation process can also be analysed using the indicator of time taken to renew the health card. The results demonstrated in **table 4.13** indicate that it takes on an average 29 days for renewing the health card. Across the region, while it takes 19 days in the northern region, it takes 30 days in the southern region. At the all-India level, majority of the beneficiaries (59.2%) reported that it takes less than 15 days to renew the health card.

Table 4.13: Time Taken to Renew the Health Card

Region	Frequency/ Number of responses (%)					Average Time Taken(Days)
	≤15 Days	>15 Days–30 Days	>30 Days–45 Days	>45 Days–60 Days	>60 Days–90 Days	
Central	46.5	50.3	3.2	0.0	0.0	23
Eastern	67.3	31.7	1.0	0.0	0.0	24
Northern	95.3	4.7	0.0	0.0	0.0	19
Southern	59.1	36.0	4.6	0.1	0.1	30
Western	56.3	40.9	2.8	0.0	0.0	28
All	**59.2**	**36.4**	**4.2**	**0.1**	**0.1**	**29**

Source: Primary Survey, NILERD, 2020

The data on the service provided by the customer care of the insurance company to beneficiaries is illustrated in **table 4.14**. The results indicate that majority of the beneficiaries (77.2%) are only satisfied to some extent with the service. Nearly 22% beneficiaries are fully satisfied with the service. Across the regions, an overwhelming percentage of beneficiaries (more than 96%) are satisfied with the service to some extent. Thus, there is need for further improvement of the service for the betterment of the beneficiaries.

Table 4.14: Satisfaction of Beneficiaries with Customer Care Service

Region	Fully Satisfied	Satisfied to Some Extent	Not Satisfied	Very Dissatisfied
Central	1.3	96.9	1.9	0.0
Eastern	3.6	96.4	0.0	0.0
Northern	21.0	79.0	0.0	0.0
Southern	22.9	76.1	0.6	0.4
Western	20.8	77.9	1.0	0.3
All	**21.8**	**77.2**	**0.6**	**0.4**

Source: Primary Survey, NILERD, 2020

Timely reimbursement of medical expenses is very important to encourage and attract people to join the scheme. Further, it also encourages people to continue the service, else the delay in reimbursement demotivates them and they would be forced to discontinue the service. The survey results reported in **table 4.15** suggest that majority of the beneficiaries (78.4%) feel that it takes 1–2 months for reimbursement of their medical expenses. In the central region, about 9% beneficiaries reported that it takes 2–5 months for reimbursement. Even, 6.3% beneficiaries from the same region feel that it takes more than 5 months. Therefore, it is indeed important to strengthen the system in coordination with the insurance company.

Table 4.15: Time Taken for Reimbursement (in months)

Region	<1m	≥1m–2m	>2m–5m	>5m
Central	12.6	72.3	8.8	6.3
Eastern	4.5	95.5	0.0	0.0
Northern	12.4	85.7	1.0	1.0
Southern	19.7	78.1	1.5	0.7
Western	17.1	78.8	3.2	0.9
All	**18.9**	**78.4**	**1.8**	**0.8**

Source: Primary Survey, NILERD, 2020

Questions were asked to understand the overall experiences of beneficiaries on the enrolment process and reimbursement procedures. Results reported in **tables 4.16 and 4.17** indicate that majority of the beneficiaries gave the rating 'very good' in both the cases. Around 25%–34% gave the rating 'excellent' and 20%–27% gave the rating 'good'. Nearly 2% beneficiaries reported that the reimbursement process is 'bad'. Thus, there is further scope for improving the reimbursement process.

Table 4.16: Overall Experience of Beneficiaries in terms of the Enrolment Process

Region	Excellent	Very good	Good	Fair	Bad
Central	5.7	62.3	31.4	0.6	0.0
Eastern	8.0	56.3	34.8	0.9	0.0
Northern	41.9	31.4	25.7	1.0	0.0
Southern	36.3	43.9	19.4	0.3	0.0
Western	24.3	53.0	22.4	0.3	0.0
All	**33.9**	**45.3**	**20.4**	**0.3**	**0.0**

Source: Primary Survey, NILERD, 2020

Table 4.17: Overall Experience of Beneficiaries in terms of the Disbursement Process of Expenses

Region	Excellent	Very Good	Good	Fair	Bad
Central	7.5	59.7	32.1	0.6	0.0
Eastern	7.1	41.1	50.9	0.9	0.0
Northern	21.9	48.6	28.6	1.0	0.0
Southern	25.7	45.7	25.4	0.5	2.6
Western	23.1	44.9	31.0	0.9	0.0
All	**24.6**	**45.9**	**26.7**	**0.6**	**2.2**

Source: Primary Survey, NILERD, 2020

4.3.4 Quality of Services

It is important evaluate the quality of service offered by the services providers to the beneficiaries under the Niramaya scheme, which will enable us to understand the importance of the scheme in improving the life of the millions. The study selected certain key health-related parameters to collect the information. The findings are outlined below. In **table 4.18**, the data shows that around 76% beneficiaries are fully satisfied with the overall benefits of the scheme. Around 22% of them reported that they are satisfied to some extent with the overall benefits of the scheme. Only a miniscule percentage of beneficiaries (0.02%) reported that they are very dissatisfied with the scheme.

Table 4.18: Level of Satisfaction of Beneficiaries in terms of Overall Benefits of the Scheme (%)

Region	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Central	89.9	8.8	1.3	0.0
Eastern	83.9	15.2	0.0	0.0
Northern	89.5	9.5	1.0	0.0
Southern	75.4	23.0	1.5	0.0
Western	73.2	23.9	2.8	0.0
Total	**75.9**	**22.4**	**1.6**	**0.02**

Source: Primary Survey, NILERD, 2020

Around 95% beneficiaries reported that they are either satisfied to some extent or fully with the services rendered by ROs during the enrolment process and at the time of processing the documents for reimbursement of medical expenses **(table 4.19).**

Table 4.19: Level of Satisfaction of Beneficiaries in terms of the Services Provided by ROs (%)

Region	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Central	38.4	61.6	0.0	0.0
Eastern	17.9	80.4	0.9	0.0
Northern	24.8	56.2	7.6	11.4
Southern	35.3	60.8	0.3	0.1
Western	39.1	60.6	0.0	0.0
Total	**35.3**	**61.0**	**0.4**	**0.2**

Source: Primary Survey, NILERD, 2020

Majority of the beneficiaries (62%) reported that they are fully satisfied with the services rendered by the insurance company. Further, around 34% beneficiaries indicated that they are satisfied to some extent with the services (**table 4.20**). Across the region, the beneficiaries from the northern region however are not quite satisfied with the services of the insurance company. About 20% beneficiaries from this region expressed that they are not satisfied with the services. In all other regions, majority of the beneficiaries that they are either fully satisfied or to some extent with the services.

Table 4.20: Level of Satisfaction of Beneficiaries in terms of the Services Provided by the Insurance Company (%)

Time	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Central	76.7	23.3	0.0	0.00
Eastern	80.4	16.1	2.7	0.00
Northern	39.0	39.0	20.0	0.00
Southern	61.3	34.3	3.1	0.04
Western	65.3	34.3	0.3	0.00
Total	**62.0**	**33.8**	**3.0**	**0.03**

Source: Primary Survey, NILERD, 2020

Distribution of the satisfaction level of beneficiaries in terms of quality of treatment received under the scheme is reported in **table 4.21**. The results show that around 32% beneficiaries indicated that they are fully satisfied with the treatment offered under the scheme, while 65.6% reported that they are satisfied to some extent. Only 0.6% beneficiaries said that they are not at all satisfied with the treatment.

Table 4.21: Level of Satisfaction of Beneficiaries in terms of the Treatment Received under the Scheme (%)

Time	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Central	34.6	64.8	0.6	0.00
Eastern	17.0	79.5	1.8	0.00
Northern	24.8	64.8	7.6	2.86
Southern	32.6	64.9	0.5	0.05
Western	29.6	69.5	0.1	0.00
Total	**31.9**	**65.6**	**0.6**	**0.09**

Source: Primary Survey, NILERD, 2020

Quality of grievance service offered to beneficiaries is strongly supported by the beneficiaries as 54.8% of them reported that they are fully satisfied with grievance services, while 43.7% of them are satisfied to some extent. Across the regions, maximum percentage of beneficiaries from the eastern region (67%) reported that they are fully satisfied with the grievance service (**table 4.22**).

Table 4.22: Level of Satisfaction of Beneficiaries in terms of the Grievance Redressal Mechanism (%)

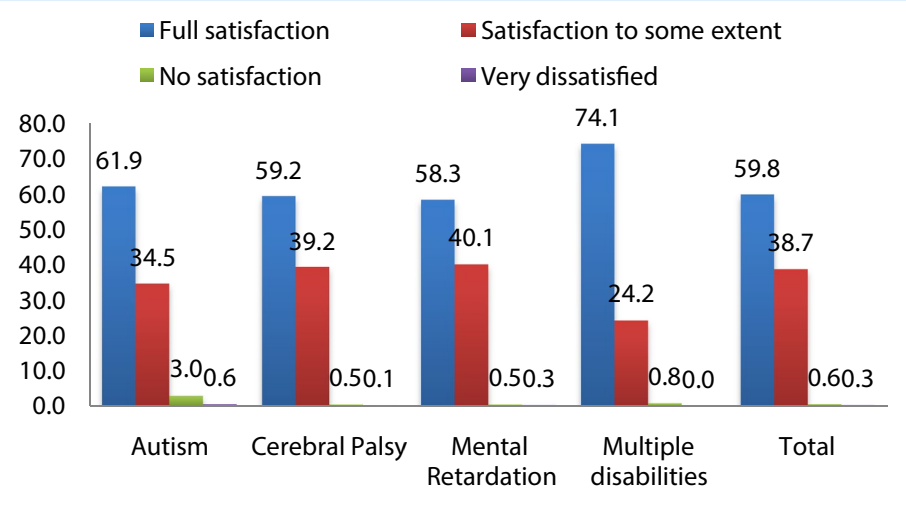
Time	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Central	41.5	56.0	1.9	0.00
Eastern	67.0	27.7	4.5	0.00
Northern	46.7	37.1	8.6	7.62
Southern	55.0	43.8	0.6	0.11
Western	55.8	44.1	0.0	0.00
Total	**54.8**	**43.7**	**0.8**	**0.21**

Source: Primary Survey, NILERD, 2020

4.3.5 Impact of the Scheme

The study attempted to capture the impact of the scheme on the overall benefits of the beneficiaries by investigating some of the key health-related parameters. The findings of the study on these health parameters are given in the below tables and figures. **Figure 4.4** illustrates the impact of the scheme on health improvement of the beneficiaries. Majority of the beneficiaries (59.8%) reported that they are fully satisfied with the scheme as far as their health improvement is concerned after subscription of the scheme. Around 39% reported that they are satisfied to some extent. Only 0.3% said that they are very dissatisfied with the scheme.

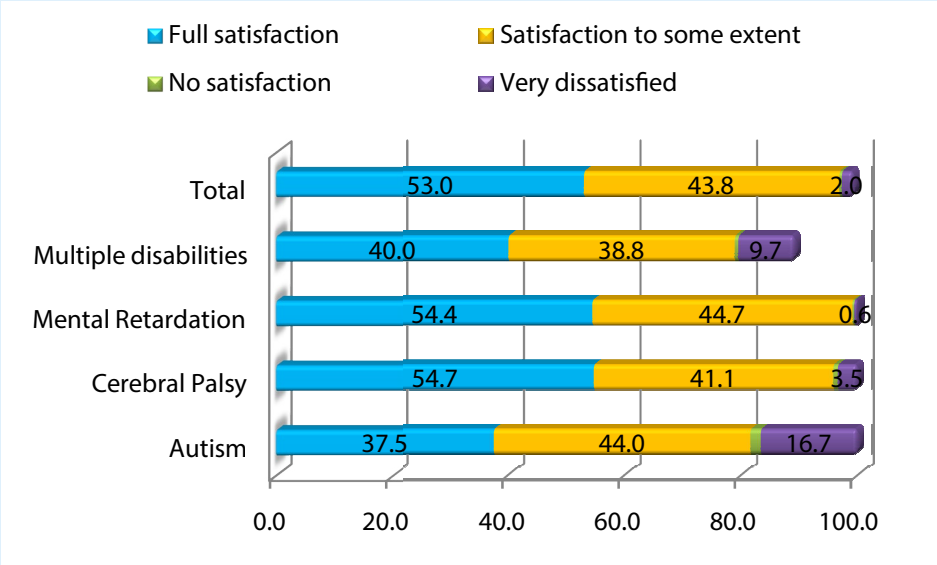
Figure 4.4: Beneficiaries' Perception Regarding Health Improvement after Subscribing the Scheme (%)



Source: Primary Survey, NILERD, 2020

In case of learning ability, majority of the beneficiaries (53%) reported that they are fully satisfied with the scheme, followed by 43.8% who stated that they are satisfied to some extent **(figure 4.5)**. Within the categories of disability, maximum beneficiaries having mental retardation and cerebral palsy reported that they are fully satisfied with the scheme as far as learning ability is concerned.

Figure 4.5: Beneficiaries' Perception Regarding Improvement in Learning Ability after Subscribing the Scheme (%)



Source: Primary Survey, NILERD, 2020

Maximum percentage of the beneficiaries (57.9%) reported that they are fully satisfied with the scheme as far as the impact of the scheme on their speaking ability is concerned. Around 39% of beneficiaries indicated that they are satisfied to some extent, and only 0.1% reported that they are very dissatisfied with the scheme in terms of the impact on speaking ability **(table4.23).**

Table 4.23: Beneficiaries' Perception Regarding Improvement in Speaking Ability after Subscribing the Scheme

Disability Type	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Autism	45.2	35.7	17.9	0.0
Cerebral Palsy	59.3	36.4	4.4	0.0
Mental Retardation	59.3	39.5	1.1	0.1
Multiple Disabilities	45.3	33.3	10.7	0.2
Total	**57.9**	**38.6**	**2.6**	**0.1**

Source: Primary Survey, NILERD, 2020

Majority of the beneficiaries (58.5%) reported that the scheme has some extent of impact on interpersonal skills, whereas 37.8% of them reported that they are fully satisfied with the scheme as far as the impact on interpersonal skills is concerned **(table 4.24).**

Table 4.24: Beneficiaries' Perception Regarding Improvement in Interpersonal Skills after Subscribing the Scheme

Disability Type	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Autism	36.9	47.6	0.0	15.5
Cerebral Palsy	32.3	62.6	1.2	3.8
Mental Retardation	39.5	59.1	0.4	0.8
Multiple Disabilities	28.7	49.3	0.6	10.5
Total	**37.8**	**58.5**	**0.5**	**2.2**

Source: Primary Survey, NILERD, 2020

It seems the scheme has a significant impact on physical strength of the beneficiaries as 61.1% of them reported full satisfaction and 28.3% reported that they are satisfied to some extent (**table4.25**). Only 0.2% reported that they are very dissatisfied with the scheme as it does not have any impact on improving the physical strength.

Table 4.25: Beneficiaries' Perception Regarding Improvement in Physical Strength after Subscribing the Scheme

Disability Type	Fully Satisfied	Satisfied to Some Extent	No Satisfaction	Very Dissatisfied
Autism	54.8	32.1	2.4	0.0
Cerebral Palsy	55.4	37.9	1.9	0.1
Mental Retardation	62.2	35.2	0.8	0.2
Multiple Disabilities	60.4	28.3	1.4	0.2
Total	**61.1**	**34.9**	**1.0**	**0.2**

Source: Primary Survey, NILERD, 2020

An overwhelming 91.9% of the beneficiaries agreed that the scheme has been an important source of financial support for medical treatment. Importantly, 90% and above beneficiaries in all the regions reported in favour of the scheme (**table 4.26).**

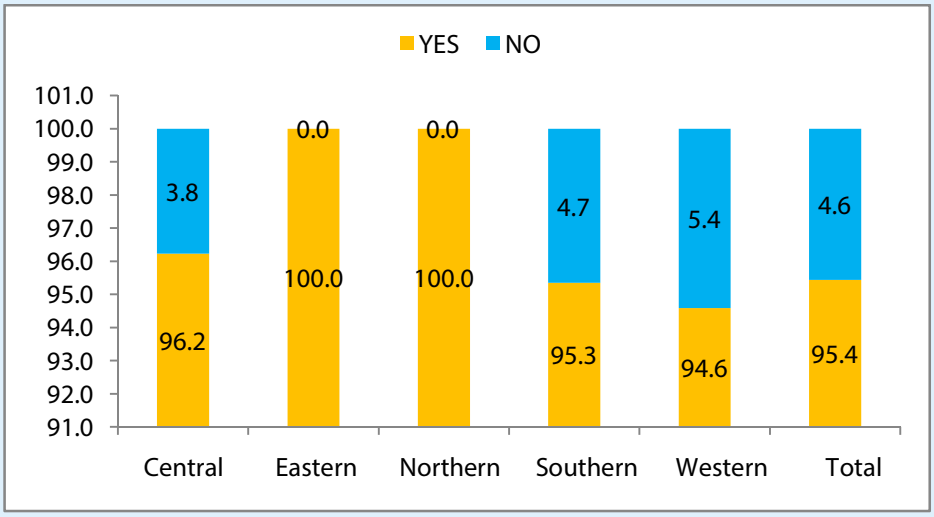
Table 4.26: Responses of Beneficiaries on Whether the Scheme is an Important Source of Financial Support for Medical Treatment (%)

Region	Yes	No
Central	93.7	6.3
Eastern	91.1	8.9
Northern	99.0	1.0
Southern	92.0	8.0
Western	90.0	10.0
Total	**91.9**	**8.1**

Source: Primary Survey, NILERD, 2020

The impact of the scheme has been captured by comparing the benefits of beneficiaries who have accessed the scheme with those who have not. A whopping 95.4% beneficiaries reported that they are better off than those who have not been able to enrol under the scheme **(figure 4.6)**. Across the regions, all sampled beneficiaries in eastern and northern regions reported that they are better off than the others.

Figure 4.6: Beneficiaries' Perception Regarding Whether They are Better Off than Other Divangjans who have not Accessed the Scheme (%)



Source: Primary Survey, NILERD, 2020

It is important to capture the impact of the scheme on beneficiary's health expenditure. Whether the scheme has fully or partially reduced the burden of health expenditure of the beneficiary after enrolling under the scheme? The results reported in **table 4.27** show that only 0.2% stated the scheme has not reduced their health expenditure burden, whereas an overwhelming 85.6% reported that it has partially reduced the burden and 13.8% reported that it has fully reduced the health expenditure burden.

Table 4.27: Beneficiaries' Perception Regarding Whether the Scheme Reduces the Burden of Health Expenditure (%)

Region	Fully	Partial	No Impact
Central	11.9	85.5	2.5
Eastern	9.8	90.2	0.0
Northern	22.9	77.1	0.0
Southern	13.8	85.6	0.1
Western	13.2	86.2	0.1
Total	**13.8**	**85.6**	**0.2**

Source: Primary Survey, NILERD, 2020

The impact of the scheme has also been captured in terms of whether the beneficiaries are able to save more of their own money after getting financial support for health treatment

under the Niramaya scheme. As discussed earlier, most beneficiaries indicated that the scheme has reduced their financial burden fully or to some extent. Hence, they have been able to save more of their own money and have deposited the surplus amount mostly in savings bank account. The results given in **table 4.28** point to the fact that more than 78% beneficiaries reported that they have deposited the own or parent's surplus money in savings bank account.

Table 4.28: Responses of Beneficiaries on How They Have Utilised the Money Saved after Enrolment under the Scheme (%)

Region	Savings Bank	Productive Asset	Self-Consumption	Any Other
Central	64.2	9.4	0.0	26.4
Eastern	88.4	3.6	0.0	8.0
Northern	97.1	1.9	1.0	0.0
Southern	77.7	10.3	2.8	9.2
Western	83.9	7.2	1.3	7.6
Total	**78.5**	**9.7**	**2.5**	**9.3**

Source: Primary Survey, NILERD, 2020

4.3.6 Challenges and the Way Forward

Despite of the overwhelming positive feedback received from beneficiaries and implementing agencies on the implementing process, quality of services, and impact of the scheme on life of the PwDs, the scheme faced certain challenges that need to be address judiciously by all stakeholders involved. Some of the key challenges of the scheme are outlined below.

- The primary data suggests that around 82% beneficiaries opined that the insured amount may be hiked to some extent to cover all medical treatments. Further, they have strongly opined that there should not be any ceiling of expenses on different heads of treatment and reimbursement. Flexibility should be given to them on spending in each head of treatment without altering the total insured cost of Rs. 1 lakh.
- The study also found that around 40% beneficiaries reported that they have paid extra fees over and above the enrolment fees to ROs during the enrolment time. Our interaction with ROs suggests that they have charged extra fees on account of making photocopies of the documents, and other documentation work. However, the ROs did not maintain any record of collecting these sums. In some cases, beneficiaries have unknowingly paid more due to lack of awareness and getting the work done. Therefore, some action plan may be needed to simplify the enrolment process without overcharging the beneficiaries, especially those have come from the BPL income group.
- The number of beneficiaries covered under the scheme is distributed unevenly across the regions and states. The results show that the southern region alone covers 79% beneficiaries and the rest of the beneficiaries (21%) belong to rest of

the five regions. States from the southern region have been quite successful because of the robust implementation system adopted by the ROs, which is unfortunately missing from the rest of the country. The Way Forward:

- Steps may be taken to enhance the sensitisation session at the grass root level in order to increase the enrolment ratio. For this, widespread sensitisation programmes addressing the parents, officials, social workers, and community at large are important.
- The most difficult part of implementing this scheme successfully is educating and handholding the beneficiaries, initially, in filing a successful reimbursement claim. This would not only invariably boost their confidence and belief in the scheme but also act as a motivating factor for other beneficiaries to enrol and submit claim reimbursement.
- Efforts may be made to enrage the scope of work of ROs, particularly in the service related to reimbursement of medical claims. In this case, the ROs will play the role of a coordinator between the beneficiary and local office of the insurance company. Continuous liaison work of the ROs is very vital to sort out issues that generally crop up with the reimbursement claim of the beneficiary and the processing-related aspect of the insurance company.
- The incentive system fixed for ROs for enrolling beneficiaries is not helping to improve the overall benefits of the scheme. This incentive system has to be rethought and revised, and it should not be based on number of enrolments done as well as number of reimbursements claimed.

4.4 Day Care and Residential Schemes

4.4.1 Disha Scheme

4.4.1.1 Regional Distribution of Beneficiaries

The regional distribution of beneficiaries under Disha scheme is presented in **table 4.29**,which shows that majority of them (41.5%) belong to the central region of the country, followed by the eastern region (16.8%) and southern region (15.6%). The lowest percentage of beneficiaries (6.9%) belongs to the northeastern region. In case of four types of PwDs, while on one hand, the highest percentage of autism cases (26.7%) is from the northeastern region. On the other hand, the highest percentages of cerebral palsy (33.3%) and mental retardation cases (44.1%) are from the eastern and central regions, respectively. The central region also has the highest percentage of multiple disability cases (57.9%) under the scheme.

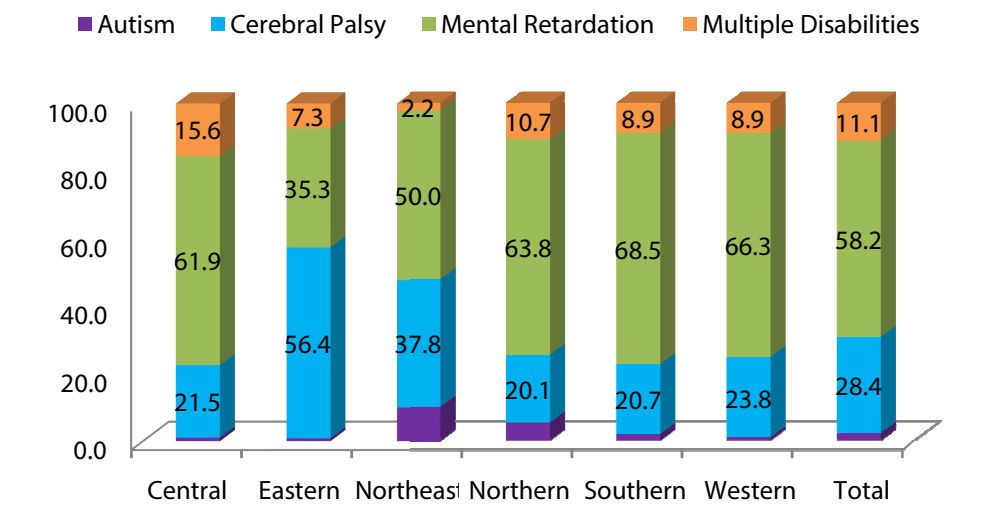
Table 4.29: Between-region Distribution of Beneficiaries by Types of Disabilities under the Disha Scheme

Region	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Total
Central	20.0	31.4	44.1	57.9	41.5
Eastern	6.7	33.3	10.2	11.0	16.8
Northeastern	30.0	9.2	5.9	1.4	6.9
Northern	26.7	8.1	12.5	11.0	11.5
Southern	13.3	11.4	18.4	12.4	15.6
Western	3.3	6.5	8.9	6.2	7.8
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

Within the region, the distribution of beneficiaries under the Disha scheme is depicted in **figure 4.7**. The data shows that except the eastern region, in all other regions, the percentage of beneficiaries of mental retardation is the highest, which falls within the range of 50%–70%. The eastern region has the highest percentage of beneficiaries (56.4%) with cerebral palsy, followed by mental retardation (35.3%) and multiple disabilities (7.3%).

Figure 4.7: Within-region Distribution of Beneficiaries by Types of Disabilities under the Disha Scheme



Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

The percentage distribution of beneficiaries by income group such as BPL and above the poverty line (non-BPL) is illustrated in **table 4.30**. In total, 80.5% beneficiaries belong to the BPL income group of families and the rest belong to the non-BPL income group

families. Under the BPL category, the highest percentage of BPL beneficiaries is from the southern region (94.1%), followed by the eastern region (91.7%) and central region (89.1%). The lowest percentage of BPL beneficiaries is from the western region (39.6%). Within the types of disabilities, the data shows that the number of mental retardation cases is the highest among the BPL beneficiaries.

Table 4.30: Distribution of Types of Disabilities of Beneficiaries by Income Group and Region under the Disha Scheme (%)

Regions	BPL					Non-BPL					Grand Total
	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	
Central	1.1	18.9	56.5	12.6	89.1	0.0	2.6	5.4	3.0	10.9	100.0
Eastern	0.5	51.8	32.6	6.9	91.7	0.5	4.6	2.8	0.5	8.3	100.0
Northeastern	4.4	21.1	22.2	2.2	50.0	5.6	16.7	27.8	0.0	50.0	100.0
Northern	1.3	16.8	38.9	6.0	63.1	4.0	3.4	24.8	4.7	36.9	100.0
Southern	1.5	20.7	64.5	7.4	94.1	0.5	0.0	3.9	1.5	5.9	100.0
Western	0.0	9.9	24.8	5.0	39.6	1.0	13.9	41.6	4.0	60.4	100.0
Total	**1.2**	**23.9**	**46.9**	**8.8**	**80.8**	**1.1**	**4.5**	**11.3**	**2.4**	**19.2**	**100.0**

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

4.4.1.2 Basic Profile of Beneficiaries

The basic socioeconomic profile of the beneficiaries under the Disha scheme is illustrated in **table 4.31**. In case of the location of the beneficiaries, more than 80% of them belong to the rural area and the rest to the urban area. By gender, the data shows that the ratio between the percentage of male and female beneficiaries is 77:23. Data of social group indicates that majority of the beneficiaries are from the OBC group (43.5%), followed by the ST (33.9%) and SC (19.4%) groups. Only 1.6% beneficiaries are each from the orphan and other castes groups.

Table 4.31: Socioeconomic Profile of Sample Beneficiaries

Characteristics	% Share
Location	
Rural	80.6
Urban	19.4
Gender	
Male	77.4
Female	22.6

Characteristics	% Share
Social group	
Scheduled caste (SC)	19.4
Scheduled tribe(ST)	33.9
Other backward castes(OBC)	43.5
Orphan	1.6
Others	**1.6**

Source: Field Survey, NILERD, 2020

4.4.1.3 Implementation Process of the Scheme

It is a well-known fact that proper implementation of any scheme is a key to success. The failure to implement the scheme in a more pragmatic and holistic way will lead to less than satisfactory outcomes. In this regard, the study collected the information on various implementation parameters. The findings of these parameters are illustrated in **table 4.32**. More than 90% ROs reported that the enrolment portal of the Ministry was user friendly and more than 83% of them said they did not face any difficulties while paying the fee online. More than 91% said the application process was not tedious, 100% reported that they officers from the Ministry were cooperative during the application process, and more than 83% opined that they did not face any difficulties while trying to reach out the concerned officer in the Ministry. All the ROs (100%) reported that the SNAC visits their office to monitor and assess the scheme and facilities available at the centre.

Table 4.32: Perception of ROs Regarding the Implementation Process of the Disha Scheme (%)

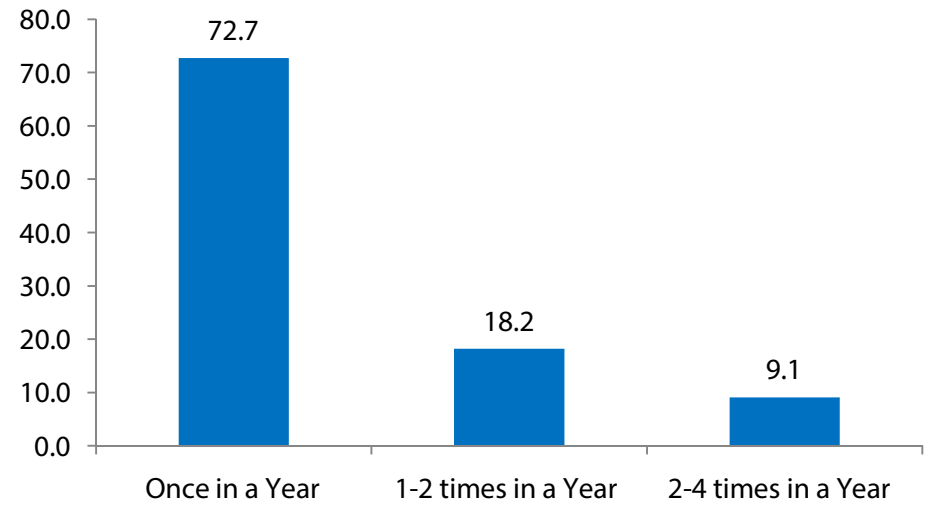
Indicators	Yes	No
1.Was the enrolment portal of the Ministry user friendly?	91.7	8.3
2. Did you face any difficulties while paying the enrolment fee online	16.7	83.3
3.Was the application process tedious?	8.3	91.7
4. Do you think the timeline given for the enrolment process was adequate?	91.7	8.3
5. Were the officers from the department cooperative during the application process?	100.0	0.0
6. Did you face any difficulties in getting the beneficiaries enrolled?	33.3	66.7
7. Did you face any difficulties in reaching out to the Ministry for any clarifications?	16.7	83.3
8. Did the SNAC visit your centre for monitoring?	100.0	0.0

Source: Field Survey, NILERD, 2020

Like implementation, monitoring is also an important part of rolling out any scheme. The

failure to monitor the scheme from time to time will lead to leakages and undesirable results. The SNACs have been given the responsibility to regularly visit the Disha centre to observe the functioning of the centre and submit the status report to the Ministry. The results of the survey data indicate that more than 72% ROs have reported that the SNAC visits their centre once in every year (**Figure 4.8**). Around 18% ROs have reported that the SNAC visits their office 1–2 times in a year. Overall, the finding suggests that the SNACs have been regularly monitoring the progress of the scheme at various Disha centres.

Figure4.8: How Frequently the SNAC Visited Your Office in a Year



Source: Field Survey, NILERD, 2020

4.4.1.4 Quality of Services

As per the guidelines of the scheme, the ROs are supposed to extend various types of services to the children at the Disha centre. It is mandatory for ROs to appoint a special educator, physiotherapist, counsellor, physical trainer, speech therapist, caregivers, and Ayas to look after the health, education, and physical and mental development of the children. However, have they done it efficiently and effectively? In this regard, the perceptions of beneficiaries/parents have been gathered to rank the quality of services at the Disha centre. A whopping 69.4% beneficiaries/parents reported that they are satisfied to some extent with the services of the special educator, which suggests that the services rendered by the special educator is not fully upto the mark **(table 4.33).** A similar result was also found in the case of the speech therapist. The situation is even worse in the case of the physiotherapist, wherein a significant percentage of beneficiaries/parents (30.6%) reported that they are not satisfied with the services. However, the services of the counsellor and physical trainer have received good support from the beneficiaries/parents as more than half of them are fully satisfied with their services. Daily activities performed at the centre also require further improvement as around 55% beneficiaries/parents reported that they are satisfied to some extent.

Table 4.33: Perceptions Regarding Quality Assessment of Services under the Scheme (%)

Indicators	Fully Satisfied	Satisfied to Some Extent	Not Satisfied	Very Dissatisfied	Can't Say
Services of a special educator	29.0	69.4	1.6	0.0	0.0
Services of a physiotherapist	30.6	38.7	30.6	0.0	0.0
Services of a counsellor	53.2	37.1	9.7	0.0	0.0
Services of a physical trainer	62.9	22.6	12.9	0.0	1.6
Services of a speech therapist	22.6	54.8	21.0	1.6	0.0
Services of caregivers and Ayas	43.5	46.8	9.7	0.0	0.0
No. of daily activities at the Disha centre	37.1	54.8	6.5	1.6	0.0

Source: Field Survey, NILERD, 2020

4.4.1.5 Quality of Infrastructure

The guidelines of the scheme suggest that ROs received one time cost to develop infrastructure at the Disha centre. The Disha should have infrastructure such as medical room/assessment room, activity room, and recreation room for the children. Are the conditions of these facilities upto the mark? Perceptions of the beneficiaries/parents reported in **table 4.34** indicate that a maximum percentage of them (66.1%) rated the conditions of the medical room as 'good', whereas the facilities available in the medical room were rated as 'average' by majority of the beneficiaries/parents (62.9%). A similar result was also observed for the conditions and facilities available in the activity room. In case of the recreation room, majority of the beneficiaries/parents rated both the conditions and facilities as 'average'.

Table 4.34: Beneficiaries' Perception Regarding Physical Infrastructure and Services (%)

Physical Infrastructure	Rank	Condition of Rooms	Condition of Facilities
Medical/assessment Room	Good	66.1	32.3
	Average	29.0	62.9
	Bad	3.2	4.8
	Very Poor	1.6	0.0
	Total	**100.0**	**100.0**
Activity room	Good	56.5	19.4
	Average	41.9	77.4
	Bad	0.0	3.2
	Very Poor	1.6	0.0
	Total	**100.0**	**100.0**
Recreation room	Good	48.4	27.4
	Average	48.4	69.4
	Bad	1.6	3.2
	Very Poor	1.6	0.0
	Total	**100.0**	**100.0**

Source: Field Survey, NILERD, 2020

4.4.1.6 Funding Pattern and Issues

As per the guidelines of the scheme, the Trust has allocated funds for different heads to the empanelled implementing agencies (ROs) to run the scheme smoothly. Information related to the funding pattern of each scheme has already been discussed in detail in chapter 2. Financial resources are one of the key inputs for rolling out any scheme. Have the resources been released on time? Is it adequate to run the scheme? These are some of the pertinent questions being asked to the ROs. The perception of ROs regarding some of these aspects is reported in **table 4.35**. The results indicate that more than 90% ROs reported that they had claimed funds in time and all of them had received funds in time in case of sustenance cost. However, a large number of them (around 44%) complained that they did not receive funds in time in case of recurring cost, particularly from the financial year 2018–19 and onwards. Further, majority of them (75%) reported that the present fund amount on different heads should increase to more than 5% and the rest of the ROs pointed out that the Ministry should increase the funds by 5%.

Table 4.35: Perception of ROs Regarding Funding Patterns (%)

Funding Pattern	Yes	No
Was the fund claimed in time?	90.0	10.0
Was the fund adequate?	66.7	33.3
Fund received for setup cost	50.0	50.0
Fund received for sustenance cost	100.0	0.0
Fund received for recurring cost	55.6	44.4
	5% increase	Above 5% increase
Expected hike infund	25.0	75.0

Source: Field Survey, NILERD, 2020

4.4.1.7 Impact of the Scheme

The findings of reported in **table 4.36** suggest that a whopping 95.2% parents reported that they are sending their child to the centre because of his/her betterment. In total, 4.8% parents reported that they have been able to attend to office/business work after sending their child to the Disha centre.

Table 4.36: Responses of Parents Regarding the Need for this Scheme

Reason for Availing Services	Responses (%)
To attend to office/business work	4.8
To attend to household work	0.0
For improvement in the conditions of the child	95.2
Any other	0.0
Total	100.0

Source: Field Survey, NILERD, 2020

Whether parents are able to save extra time and ustilise it for doing household work or office work after sending their child to the Disha centre, the results indicate that around 89% parents reported 'Yes', suggesting that the scheme has helped the parents to get extra time. The extra time has also helped the parents to utilise it for productive purposes and for generating more revenue as 98.2% parents said in favour of it (**table4.37**). Extra time saved by the parents has helped them earn nearly 5% of additional income.

Table 4.37: Responses of Parents on Utilisation of Time after Joining the Disha Child Care Scheme (%)

Responses	Responses (%)
Whether received higher opportunity to save and invest extra time in household or office work due to relief from child care	
YES	88.71
NO	11.29
Whether income improved due to utilisation of extra time in productive work	
YES	98.2
NO	1.8
If there is improvement in income, the range of increment	
<5%	100.0
5%–10%	0.0
More than 10%	0.0

Source: Field Survey, NILERD, 2020

Has the scheme improved the learning, speaking, and mental abilities of the children? As shown in **table 4.38,** majority of the parents (more than 80%) reported that the learning, speaking, eye contact, and day-to-day activities of their child have improved to 'some extent'. Because children under the Disha scheme are having more disability problems than those under any other scheme, the improvement of the child in performing day-to-day activities and eye contact itself is good achievement. Nevertheless, lot more needs to be done as far as making the child self-dependent in performing daily activities is concerned. More importantly, a whopping 82.3% parents reported that their child is better off than other children who have been left out from the scheme.

Table 4.38: Improvement in the Conditions of the Child

Parameters	Fully	Some Extent	Not at All	No Comments
Improvement in learning ability	12.9	83.9	0.0	3.2
Improvement in speaking ability	9.7	87.1	0.0	3.2
Improvement in eye contact and body balance	16.1	80.6	1.6	1.6
Improvement in day-to-day activities	3.2	90.3	6.5	0.0
Whether better off than other children in the disabled category who are deprived of this service	82.3	17.7	0.0	0.0

Source: Field Survey, NILERD, 2020

4.4.2 Vikaas Scheme

4.4.2.1 Regional Distribution of Beneficiaries

The distribution of beneficiaries under the Vikaas scheme is quite unequal across the regions. While the highest percentage of beneficiaries belongs to the central region (54.5%), the lowest percentage of beneficiaries belongs to the northeastern region (0.2%). Around 15% beneficiaries of the scheme are from the southern region (**table 4.39**). The distribution of beneficiaries by types of disabilities and region also exhibits an unequal distribution. A common factor found in case of all types of disabilities is that more than 50% beneficiaries belong to the central region and the remaining beneficiaries are distributed among all other regions. The lowest percentage of beneficiaries across all types of disabilities is found in the northeastern region.

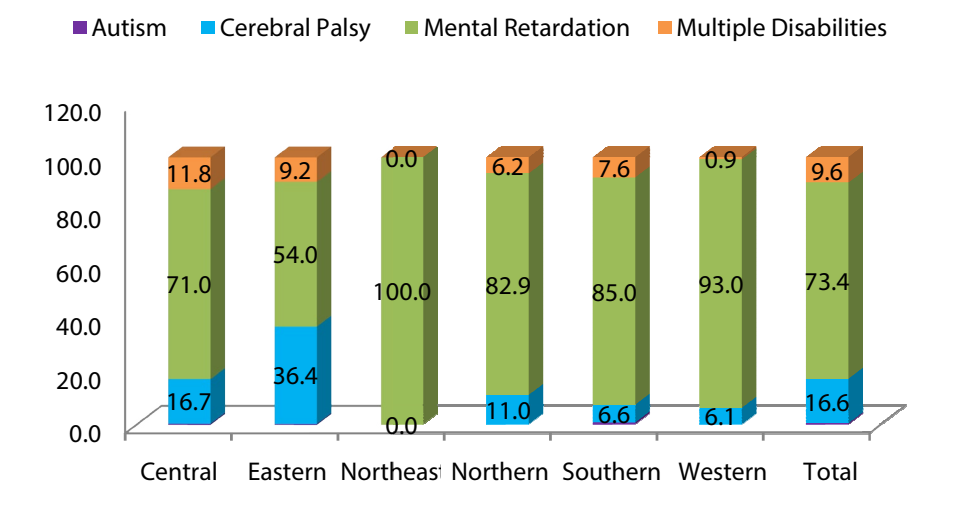
Table 4.39: Between-region Distribution of Beneficiaries by Types of Disabilities under the Vikaas Scheme

Region	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Total
Central	62.5	54.7	52.8	67.4	54.5
Eastern	12.5	30.1	10.1	13.2	13.7
Northeastern	0.0	0.0	0.3	0.0	0.2
Northern	0.0	7.0	12.0	6.8	10.6
Southern	25.0	6.1	17.6	12.1	15.2
Western	0.0	2.1	7.3	0.5	5.8
Total	100.0	100.0	100.0	100.0	100.0

Source: Database of the National Trust, Ministry of Social Justice & Empowerment

Like the Disha scheme, within the region, the distribution of beneficiaries among types of disabilities shows that maximum percentage of beneficiaries belong to the mental retardation category. Its range varies from 54% in the eastern region to 93% in the western region. The second highest percentage of beneficiaries belongs to the cerebral palsy category, and its range varies from 6.1% in the western region to 36.4% in the eastern region **(figure 4.9).**

Figure 4.9: Within-region Distribution of Beneficiaries by Types of Disabilities under the Vikaas Scheme



Source: Field Survey, NILERD, 2020

In case of beneficiaries in the category of different income groups, namely BPL and non-BPL, the study found that maximum beneficiaries belong to the BPL group in all regions other than the western region. The percentage of beneficiaries in this category of income group varies from 46.5% in the western region to 87.5% in the eastern region (**table 4.40**).

Table 4.40: Distribution of Types of Disabilities of Beneficiaries by Income Group and Region under the Vikaas Scheme (%)

Regions	BPL					Non-BPL					Grand Total
	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub- Total	
Central	0.4	15.3	61.3	10.0	87.0	0.1	1.4	9.7	1.9	13.0	100.0
Eastern	0.4	32.7	46.0	8.5	87.5	0.0	3.7	8.1	0.7	12.5	100.0
Northeastern	0.0	0.0	50.0	0.0	50.0	0.0	0.0	50.0	0.0	50.0	100.0
Northern	0.0	9.5	55.2	3.8	68.6	0.0	1.4	27.6	2.4	31.4	100.0
Southern	0.7	5.6	71.4	6.0	83.7	0.0	1.0	13.6	1.7	16.3	100.0
Western	0.0	2.6	43.0	0.9	46.5	0.0	3.5	50.0	0.0	53.5	100.0
Total	**0.4**	**14.8**	**59.0**	**8.0**	**82.2**	**0.1**	**1.8**	**14.4**	**1.6**	**17.8**	**100.0**

Source: Field Survey, NILERD, 2020

4.4.2.2 Basic Profile of Beneficiaries

The study presented the basic socioeconomic profile of the beneficiaries under the Vikaas scheme in **table 4.41**. The results show that unlike the Disha scheme, in which majority of the beneficiaries were from the rural area, under the Vikaas scheme, the ratio of rural to urban beneficiaries is nearly the unit. By gender, the data shows that the male percentage is around 75% and the female percentage is 25%. Data in terms of social group classification indicates that most beneficiaries are from the ST (55.8%) group, followed by the OBC (30.4%) and SC (10.9%) groups. Only 2.2% beneficiaries are from the general caste and 0.7% are orphans. The data on main occupation of the head of the household of beneficiaries point to the fact that majority of them are self-employed (43.5%), followed by those involved in agriculture (21.7%) and services (18.8%).

Table 4.41: Socioeconomic Profile of Sampled beneficiaries under the Vikaas Scheme

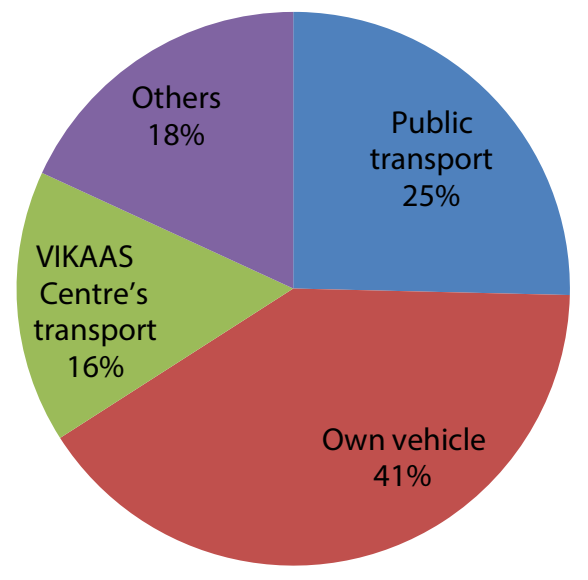
Characteristics	Responses (%)
Location	
Rural	51.4
Urban	48.6
Gender	
Male	74.6
Female	25.4
Social group	
Scheduled caste	10.9
Scheduled tribe	55.8
Other backward castes	30.4
Orphan	0.7
Others	2.2
Main occupation of the head of the household	
Agriculture	21.7
Self-employed	43.5
Service	18.8
Others	15.9

Source: Field Survey, NILERD, 2020

4.4.2.3 Implementation Process of the Scheme

In case of the implementation process of the scheme, the study collected information on various indicators pertaining to functioning of the scheme. The data presented in **figure 4.10** indicates the mode of transportation by children from their home to the Vikaas centre. Majority of the children (41%) travel by their own or parent's vehicle. Other modes of transportation used by children are public transportation (25%) and Vikaas centre transportation (16%).

Figure 4.10: Mode of Travel to the Vikaas Centre from Home(%)



Source: Field Survey, NILERD, 2020

One of the factors that has discouraged the parents to send their child to the centre is the location or distance of the centre from their houses. As shown in **table 4.42**, around 33% beneficiaries' parents reported that the centre is located between 10 and 15 km from their home. Another 32% pointed out that the centre is located between 5 and 10 km from their home. The average distance of the centre from the nearest city is 138 km, which is a matter of concern for families, particularly in rural areas.

Table 4.42: Distance of the Vikaas centre from Beneficiary's Home

Distance	Responses(%)
≤1km	1.4
>1–5 km	16.7
>5–10 km	31.9
>10–15 km	32.6
>15 km	10.9
No response	6.5
Average distance of the centre from the nearest city (km)	138

Source: Field Survey, NILERD, 2020

Capturing the data on sources of information about the scheme indicates the popularity of the scheme and the process of implementation of the scheme. It also reflects how the awareness generation programme has been effective in reaching out the public. The results in **table 4.43** suggest that maximum beneficiaries (35.4%) came to know about the scheme from newspaper advertisements, followed by 33.6% from hospital doctors. Ironically, only 1.8% of them mentioned about awareness programmes.

Table 4.43: Beneficiaries' Perception Regarding Different Sources of Information Received about the Scheme

Sources of Information	Responses(%)
Registered organisation	9.4
Hospital doctor	33.6
National Trust	2.2
Newspaper	35.4
Electronic media	6.7
Relatives	10.8
Awareness programmes	1.8

Source: Field Survey, NILERD, 2020

The perceptions of ROs on key parameters of the implementation process are presented in **table 4.44**. Majority of the ROs (85.7%) reported that the Ministry's portal was user friendly for enrolment, and 14.3% reported against it. Majority of the ROs also indicated that they did not find any difficulties while paying the enrolment fee online and the application process was tedious. The timeline given for the enrolment process was found to be adequate by 92.9% ROs. About 93% ROs reported that they did not face any difficulties in reaching out to the Ministry for any clarification during the enrolment process. The results also indicate that majority of the ROs were not only happy with the application process but also pointed out that the SNAC has been regularly visiting their centre for monitoring, which has significance as far as the success of the scheme is concerned.

Table 4.44: Perception of ROs on the Implementation Process of the Vikaas Scheme (%)

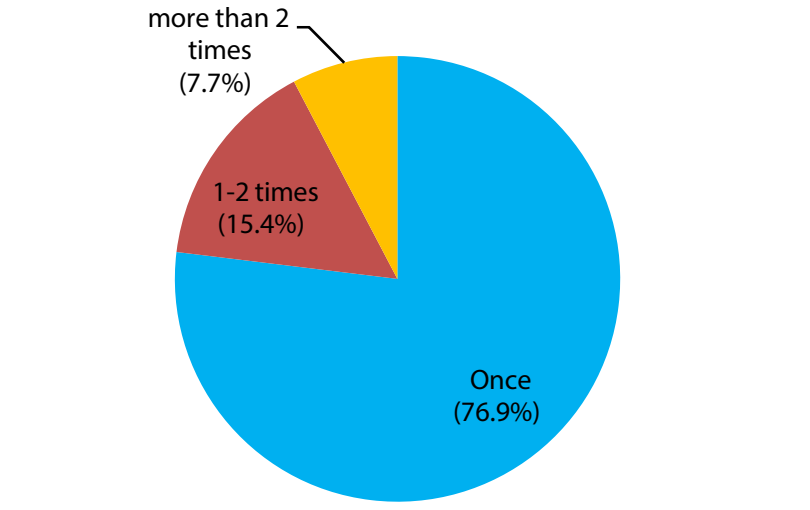
Indicators	Yes	No
1. Was the enrolment portal of the Ministry user friendly?	85.7	14.3
2. Did you face any difficulties while paying the enrolment fee online?	7.1	92.9
3. Was the application process tedious/complicated?	15.4	84.6
4. Do you think the timeline given for the enrolment process was adequate?	85.7	14.3
5. Were the officers from the department cooperative during the application process?	92.9	7.1
6. Did you face any difficulties in getting them enrolled?	14.3	85.7
7. Did you face any difficulties in reaching out to the Ministry for any clarifications?	7.1	92.9
8. Did the SNAC visit your centre for monitoring?	100.0	0.0

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

The SNAC has played an important role in monitoring the scheme. The information provided by ROs on the frequency of visit by the SNAC to their centre is depicted in **figure**

4.11. Around 80% ROs reported that the frequency of visit by the SNAC is once a year and another 15% said that the frequency of visit is1–2 times in a year.

Figure 4.11: Frequency of Visit by the SNAC to the Vikaas Centre



Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

4.4.2.3 Quality of Services

ROs provide different services to the children at the Vikaas centre. As per the guidelines of the scheme, it is mandatory for the ROs to appoint a special educator, physiotherapist, counsellor, physical trainer, speech therapist, caregivers, and Ayas to look after the health, education, and physical and mental development of the children. Data collected on the quality of services offered by these professionals and staff indicate that a substantial number of beneficiaries/parents (25%–35%) reported that they are not satisfied with the services of the physiotherapist, counsellor, speech therapist, and caregivers and Ayas, which is a matter of concern as far as the quality of the service is concerned (**table 4.45**).

Table 4.45: Quality Assessment of Services under the Scheme

Indicators	Fully Satisfied	Satisfied to Some Extent	Not Satisfied	Very Dissatisfied	Can't Say	Total
Services of a special educator	51.4	41.3	7.2	0.0	0.0	100.0
Services of a physiotherapist	21.0	52.2	26.1	0.7	0.0	100.0
Services of a counsellor	10.9	53.6	35.5	0.0	0.0	100.0
Services of a physical trainer	44.2	42.0	13.8	0.0	0.0	100.0
Services of a speech therapist	30.4	39.9	29.7	0.0	0.0	100.0
Services of caregivers and Ayas	30.4	39.9	29.0	0.7	0.0	100.0
Daily activities of the Vikaas centre	29.7	45.7	23.9	0.7	0.0	100.0

Source: Field Survey, NILERD, 2020

4.4.2.4 Quality of Infrastructure

Under the Vikaas scheme, ROs received one time setup cost to develop infrastructure at the Vikaas centre. The centre should have infrastructure such as medical room/ assessment room, activity room, and recreation room for the children. The study collected information for assessing the quality of these infrastructure and facilities. As shown in **table 4.46**, maximum percentage of beneficiaries/parents (97.8%) rated the conditions of the medical room as 'good', whereas the facilities available in the medical room were rated as 'average' by majority of the beneficiaries/parents (87%). Similar results were also reported for the conditions and facilities available in the activity and recreation rooms.

Table 4.46: Beneficiaries' Perception Regarding Physical Infrastructure and Services under the Vikaas Scheme (%)

Physical Infrastructure	Rank	Condition of Rooms	Condition of Facilities
Medical/assessment room	Good	97.8	11.6
	Average	2.2	87.0
	Bad	0.0	1.4
	Very Poor	0.0	0.0
	Total	**100.0**	**100.0**
Activity room	Good	90.6	9.4
	Average	9.4	88.4
	Bad	0.0	1.4
	Very Poor	0.0	0.7
	Total	**100.0**	**100.0**
Recreation room	Good	83.3	15.9
	Average	15.9	82.6
	Bad	0.7	2.2
	Very Poor	0.0	0.0
	Total	**100.0**	**100.0**

Source: Field Survey, NILERD, 2020

4.4.2.5 Funding Pattern and Issues

In case of funding pattern and issues, information has been collected from ROs. As shown in **table 4.47**, about 90% ROs reported they had claimed funds in time and all of them had received funds in time in case of setup cost. In case of sustenance cost, a whopping 87.5% said that they had received the funds. In case of recurring cost, a substantial number of ROs (44.4%) reported that they did not receive the funds under the same head. Further, majority of them (75%) reported that the present fund amount on different heads should increase to more than 5% and the rest of the ROs pointed out that the Ministry should increase the fund by 5%.

Table 4.47: Perception of ROs on Funding Patterns (%)

Indicators	Yes	No
Was the fund claimed in time?	90.0	10.0
Was the fund adequate?	66.7	33.3
Fund received for setup cost	100.0	0.0
Fund received sustenance cost	87.5	12.5
Fund received for recurring cost	55.6	44.4
	5% increase	Above 5% increase
Expected hike in fund	25.0	75.0

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

4.4.2.6 Impact of the Scheme

How has the scheme impacted the life both children and parents? As shown in **table 4.48**, shows that around 39% parents/relatives of beneficiaries reported that they are availing the service for the betterment of their child, 34.8% reported that they can attend to household work after sending their child to the centre, and 14.5% reported that they need the service to attend to office/business work. Overall, both parents and child have received the benefits of the scheme.

Table 4.48: Responses of Parents on the Need for this Scheme

Reason for Availing Services	Responses (%)
To attend to office/business work	14.5
To attend to housework	34.8
For improvement in the conditions of the child	39.1
Any other	0.0
Total sample	100.0

Source: Field Survey, NILERD, 2020

In continuation to previous discussion, around 40% parents reported that they have been able to save and invest extra time in household or office work due to relief from child care, whereas the rest 60.1% did not agree to it. Of the parents who said in favour of getting extra time, around 91% reported that their income has improved due to utilisation of extra time in productive work (**table 4.49**). It is also found that the extra time saved by the parents has helped them earn nearly 5% of additional income. Further, majority of the parents (92%) agreed to the view that their child is better off than other children who have been left out from the scheme.

Table 4.49: Responses of Parents on Utilisation of Time after Joining the Vikaas child care scheme

Indicators	Responses (%)
Whether received opportunity to save and invest extra time in household or office work due to relief from child care	
YES	39.9
NO	60.1
Whether income improved due to utilisation of extra time in productive work (parents those said Yes to save extra time)	
YES	90.9
NO	9.1
If there is improvement in income, the range of increment	
< 5%	82.0
5%–10%	10.0
10%–15%	8.0
Whether better off than other children in the disabled category who are deprived of this service	
YES	92.0
NO	8.0

Source: Field Survey, NILERD, 2020

The study attempted to find out the impact of the scheme on physical, mental, and overall day-to-day improvement in children at the Vikaas centre. As presented in **table 4.50**, majority of the parents (around 64%–75%) reported that the learning and speaking activities of their child have improved to 'some extent' or 'fully'. In case of improvement in eye contact or body balance, majority of the parents reported that the child's condition has not all improved. Similarly, in case of improvement in day-to-day activities, a significant proportion of parents reported no improvement. Thus, unlike the Disha scheme in which majority of the parents reported a positive impact of the scheme on their child, the Vikaas scheme relatively failed to deliver such a significant impact.

Table 4.50: Perception on Improvement in the Conditions of the Child (%)

Parameters	Fully	Some Extent	Not at All	Total
Improvement in learning ability	29.5	35.2	35.2	100.0
Improvement in speaking ability	34.3	40.3	25.4	100.0
Improvement in eye contact and body balance	6.9	40.3	52.8	100.0
Improvement in day-to-day activities	15.0	41.7	43.3	100.0

Source: Field Survey, NILERD, 2020

4.4.3 Samarth Scheme

4.4.3.1 Regional Distribution of Beneficiaries

Like the day care schemes, the residential scheme such as Samarth witnessed a significant variation in distribution of beneficiaries among the regions. While the highest percentage of beneficiaries belongs to the central region, the lowest percentage belongs to the western region (**table 4.51**). In case of types of disability, while maximum percentage of autism cases are found in the northern region (66.7%), the maximum cases of cerebral palsy, mental retardation, and multiple disabilities are found in the central region.

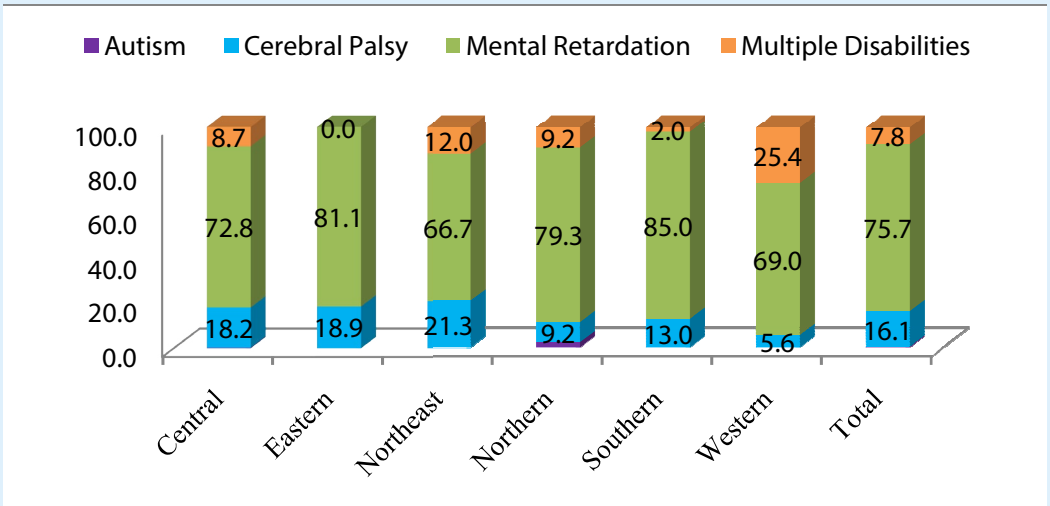
Table 4.51: Between-region Distribution of Beneficiaries by Types of Disabilities under the Samarth Scheme

Region	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Total
Central	33.3	47.2	40.2	46.4	41.8
Eastern	0.0	23.9	21.9	0.0	20.4
Northeastern	0.0	11.3	7.5	13.0	8.5
Northern	66.7	5.6	10.3	11.6	9.9
Southern	0.0	9.2	12.7	2.9	11.4
Western	0.0	2.8	7.3	26.1	8.1
Total	100.0	100.0	100.0	100.0	100.0

Source: Database of the National Trust, Ministry of Social Justice & Empowerment

The distribution of types of disabilities within the region is depicted in **figure 4.12** below. It shows that the number of mental retardation cases is the highest among the beneficiaries in all the regions, and the cases range from 66.7% in the northeastern region to 85% in the southern region. Other than cases of multiple disabilities in the western region, in all other regions, the second highest category of disability is cerebral palsy, which varies from 5.6% in the western region to 21.3% in the northeastern region.

Figure 4.12: Within-region Distribution of Beneficiaries by Types of Disabilities under the Samarth Scheme



Source: Database of the National Trust, Ministry of Social Justice & Empowerment

Like for day care schemes, maximum percentage of beneficiaries under the Samarth scheme belong to the BPL income group (79.2%), and the distribution of the said group of beneficiaries across the region shows that the highest percentage belongs to the eastern region (96.7%) and the lowest percentage to the northeastern region (46.7%) (**table 4.52**).

Table 4.52: Distribution of Types of Disabilities of Beneficiaries by Income group and Region under the Samarth Scheme (%)

Regions	BPL					Non-BPL					Grand Total
	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	
Central	0.3	15.8	57.1	7.6	80.7	0.0	2.4	15.8	1.1	19.3	100.0
Eastern	0.0	17.8	78.9	0.0	96.7	0.0	1.1	2.2	0.0	3.3	100.0
Northeastern	0.0	10.7	29.3	6.7	46.7	0.0	10.7	37.3	5.3	53.3	100.0
Northern	1.1	9.2	62.1	8.0	80.5	1.1	0.0	17.2	1.1	19.5	100.0
Southern	0.0	12.0	69.0	2.0	83.0	0.0	1.0	16.0	0.0	17.0	100.0
Western	0.0	4.2	38.0	12.7	54.9	0.0	1.4	31.0	12.7	45.1	100.0
Total	0.2	13.7	59.5	5.8	79.2	0.1	2.4	16.2	2.0	20.8	100.0

Source: Field Survey, NILERD, 2020

4.4.3.2 Basic Profile of Beneficiaries

The socioeconomic profile of the beneficiaries presented in **table 4.53** demonstrates that 80% beneficiaries are from the rural area and the remaining 20% are from the urban area, which suggests that the scheme has focused mostly on the rural population. By

gender, the data shows that the percentage of male members is nearly 96%. This in turn indicates that the scheme has not been able to cover more female PwDs. Data of social group classification indicates that majority of the beneficiaries are from the SC group (58.3%), followed by those from the ST (25%) and OBC (16.7%) groups. Beneficiaries from the orphan group represent 4.2% of the sample. The data suggests that the main occupation of the head of the household is agriculture and self-employment.

Table 4.53: Socioeconomic Profile of Sampled Beneficiaries under the Samarth Scheme

Characteristics	Reponses (%)
Location	
Rural	80.0
Urban	20.0
Gender	
Male	95.8
Female	4.2
Social group	
Scheduled caste	54.2
Scheduled tribe	25.0
Other backward castes	16.7
Orphan	4.2
Others	0.0
Total	100.0
Main occupation of the head of the household	
Agriculture	29.2
Self-employed	29.2
Service	4.2
Others	37.5
Total	100.0

Source: Field Survey, NILERD, 2020

4.4.3.3 Implementation Process of the Scheme

The average distance of the Samarth centre from beneficiaries' home is 24 km. In some of the cases, the actual distance is more than 40 km, which is quite a long distance and a huddle for the families to travel and regularly meet their relatives at the Samarth centre. As indicated in **table 4.54**, around 29.2% of the beneficiaries' parents reported the centre is located within 5 km from their home. A high percentage of respondents (41.7%) reported that the Samarth centre is located more than 15 km from their home.

Table 4.54: Distance of Samarth Centre from Beneficiary's Home

Distance	Responses (%)
≤5 km	29.2
>5–10 km	16.7
>10–15 km	12.5
>15 km	41.7
Average distance of the centre from the nearest city (km)	24

Source: Field Survey, NILERD, 2020

Do the awareness programmes conducted by the ministry and ROs have any impact at the ground level? Has it been successful in motivating and attracting the PwDs to enrol under the Samarth scheme? The results given in **table 4.55** indicate that ROs and awareness programmes are two important sources of information about the scheme. Maximum number of beneficiaries (60%) got to know about the scheme from the ROs. The reason could be that some of the beneficiaries under the Samarth scheme might have enrolled earlier under daycare schemes, and from that time, they could have got to know about the residential schemes of the Trust. The other important source of information is awareness programmes conducted by the Trust and ROs.

Table 4.55: Beneficiaries' Perception Regarding Different Sources of Information Received about the Scheme

Sources of Information	Responses(%)
Registered organisation	60.0
Hospital doctor	6.7
National Trust	6.7
Newspaper	3.3
Electronic media	3.3
Relatives	13.3
Awareness programmes	16.7

Source: Field Survey, NILERD, 2020

The perceptions of ROs on key parameters of implementation process of the Samarth scheme are reported in **table 4.56**. A whopping 87.5% of the ROs reported that the enrolment portal of the ministry was user friendly. About 75% ROs reported that they did not face any difficulties while paying the enrolment fee online and 62.5% of them reported that the application process was not tedious. The timeline given for the enrolment process was found to be adequate by all sampled ROs. Further, all sampled ROs reported that they did not face any difficulties in reaching out to the Ministry for any clarification during the enrolment process. The results also indicate that majority of the ROs were not only happy with the application process but also pointed out that the SNAC has been regularly visiting their centre for monitoring, which is quite encouraging and important for the smooth running of the scheme.

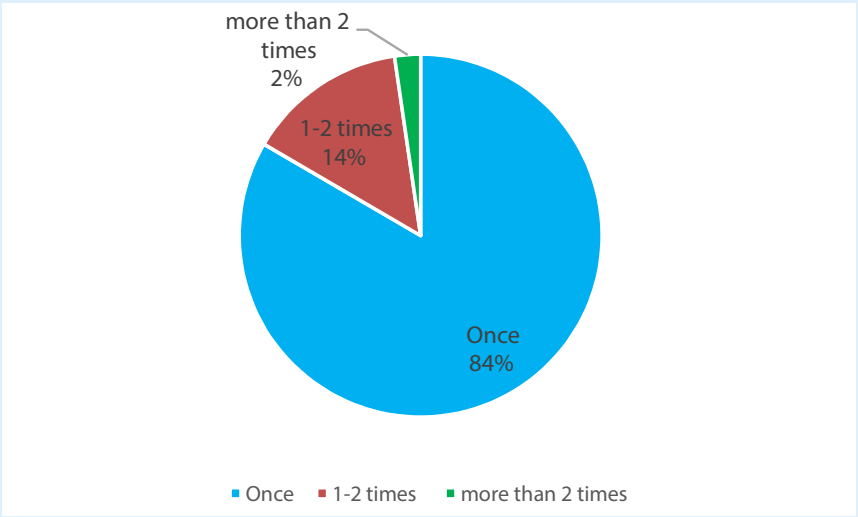
Table 4.56: Perception of ROs Regarding the Implementation Process of the Samarth Scheme (%)

Indicators	Yes	No
Was the enrolment portal of the Ministry user friendly?	87.5	12.5
Did you face any difficulties while paying the enrolment fee online?	25.0	75.0
Was the application process tedious/complicated?	37.5	62.5
Do you think the timeline given for enrolment process was adequate	0.0	100.0
Were the officers from the department cooperative during the application process?	100.0	0.0
Did you face any difficulties in getting them enrolled?	25.0	75.0
Did you face any difficulties in reaching out to the Ministry for any clarifications?	42.9	57.1
Did the SNAC visit your centre for monitoring?	100.0	0.0

Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

In terms of monitoring the scheme by the SNAC, as depicted in **figure 4.13**, about 84% ROs reported that the frequency of visit by the SNAC is once a year and another 14% said that the frequency of visit is 1–2 times in a year.

Figure 4.13: Frequency of Visit by the SNAC to the Samarth Centre



Source: Database of the National Trust, Ministry of Social Justice & Empowerment.

4.4.3.4 Quality of Services

Does the Samarth centre offer quality services to the beneficiaries as they have hired professional and other support staff to look after the beneficiaries? The study attempted to collect information on the perception of beneficiaries on different services offered to them. The results given in **table 4.57** suggest that a significantly large percentage of beneficiaries (91.7%) are fully satisfied with the services rendered by the special

educator/vocational trainer. Similarly, 83.3% beneficiaries reported that the services rendered by the cook is fully satisfactory. In case of services offered by the physiotherapist/ occupational therapist, around 83% beneficiaries are satisfied to some extent, while 79.2% said that they are satisfied to some extent with the services of caregivers and Ayas. The results also suggest that a large percentage of beneficiaries (91.7%) are fully satisfied with the vocational training being offered to them at the Samarth centre.

Table 4.57: Quality Assessment of Services under the Scheme

Indicators	Fully satisfied	Satisfied to some extent	Not satisfied	Very dissatisfied	Total
Services of special educator/ vocational trainer	91.7	8.3	0.0	0.0	100.0
Services of physiotherapist/ occupational therapist	8.3	83.3	4.2	4.2	100.0
Services of cook	83.3	12.5	4.2	0.0	100.0
Services of care givers and Ayas	8.3	79.2	8.3	4.2	100.0
Vocational activities at the Samarth centre	91.7	8.3	0.0	0.0	100.0

Source: Field Survey, NILERD, 2020

4.4.3.5 Quality of Infrastructure

The study collected information on the conditions of rooms and facilities available in the rooms at the Samarth centre. As reported in **table 4.58,** maximum beneficiaries/parents (66.7%) rated the conditions of the medical room as 'good', whereas, even a higher percentage of beneficiaries (75%) rated the facilities available in the medical room as 'good'. Similarly, a high percentage of beneficiaries (79.2%) reported the condition of the activity room as 'good' and 62.5% beneficiaries rated the conditions of facilities in the activity room as good. A high percentage of beneficiaries rated both the conditions and facilities in the recreation room as 'good'.

Table 4.58: Beneficiaries' Perception Regarding Physical Infrastructure and Services under the Samarth Scheme (%)

Physical Infrastructure	Rank	Condition of Rooms	Condition of Facilities
Medical/assessment room	Good	66.7	75.0
	Average	16.7	12.5
	Bad	16.7	12.5
	Very Poor	0.0	0.0
	Total	**100.0**	100.0

Activity room	Good	79.2	62.5
	Average	20.8	29.2
	Bad	0.0	8.3
	Very Poor	0.0	0.0
	Total	**100.0**	79.2
Recreation room	Good	62.5	66.7
	Average	37.5	33.3
	Bad	0.0	0.0
	Very Poor	0.0	0.0
	Total	**100.0**	**100.0**

Source: Field Survey, NILERD, 2020

4.4.3.6 Impact of the Scheme

The study assessed the impact of the scheme on parents' and children's life. As shown in **table 4.59,** maximum (66.7%) parents/relatives of beneficiaries reported that they are availing the service for the betterment of the child. Another significant proportion of beneficiaries (29.2%) reported that they are availing the scheme to attend to house work.

Table 4.59: Responses of Parents on the Need for this Scheme

Reason for Availing Services	Responses (%)
To attend to office/business work	4.2
To attend to housework	29.2
For improvement in the conditions of the child	66.7
Any other	0.0
Total sample	**100.0**

Source: Field Survey, NILERD, 2020

Regarding the Samarth scheme on time, work and income of the parents, the study found that a substantial number of parents (83.3%) reported that they have been able to save and invest extra time in household or office work due to relief from the responsibility of the child. Of these parents, more than 90% reported that they have been able to use the extra time in productive work, and as a result, their income has increased by 5% (**table 4.60**). Further, the study found that majority of the parents (88%) agreed that their child is better off than other children who have been left out from the scheme.

Table 4.60: Responses of Parents on Utilisation of Time after Joining the Samarth Child Care Scheme

Indicators	Responses (%)
Whether received opportunity to save and invest extra time in household or office work due to relief from child care	
YES	83.3
NO	16.7
Whether income improved due to utilisation of extra time in productive work (parents those said Yes to save extra time)	
YES	90.9
NO	9.1
If there is improvement in income, the range of increment	
<5%	84.2
5%–10%	21.1
Whether better off than other children in the disabled category who are deprived of this service	
YES	88.0
NO	12.0

Source: Field Survey, NILERD, 2020

Impact of the scheme on beneficiaries' mental and physical development was investigated and analysed by assigning different ranks. As reported in **table 4.61**, majority of the parents reported that the learning ability has improved to full extent. Similarly, a majority of the parents (83.3%) reported that the beneficiaries have completely improved in day-to-day activities. Regarding eye contact, body balance, and improvement in speaking ability, majority of the parents reported that the condition of beneficiaries has improved to some extent.

Table 4.61: Perception Regarding Improvement in the Conditions of the Child (%)

Parameters	Fully	Some Extent	Not at All	Total
Improvement in learning ability	83.3	12.5	4.2	100.0
Improvement in speaking ability	8.3	91.7	0.0	100.0
Improvement in eye contact and body balance	33.3	62.5	4.2	100.0
Improvement in day-to-day activities	83.3	12.5	4.2	100.0

Source: Field Survey, NILERD, 2020

4.4.4 Gharaunda Scheme

4.4.4.1 Regional Distribution of Beneficiaries

The regional distribution of beneficiaries under the Gharaunda scheme is reported in **table 4.62**. Across the regions, the highest percentage of Gharaunda beneficiaries is from the central region (56.6%), followed by 18.7% from the eastern region, 12.5% from the southern region, and 3.2% from the northeastern region. Like the Samarth scheme, the distribution of beneficiaries within different types of disabilities demonstrates that maximum percentage of them belongs to the central region, and its range varies from 50% in case of autism to 63.6% in multiple disabilities.

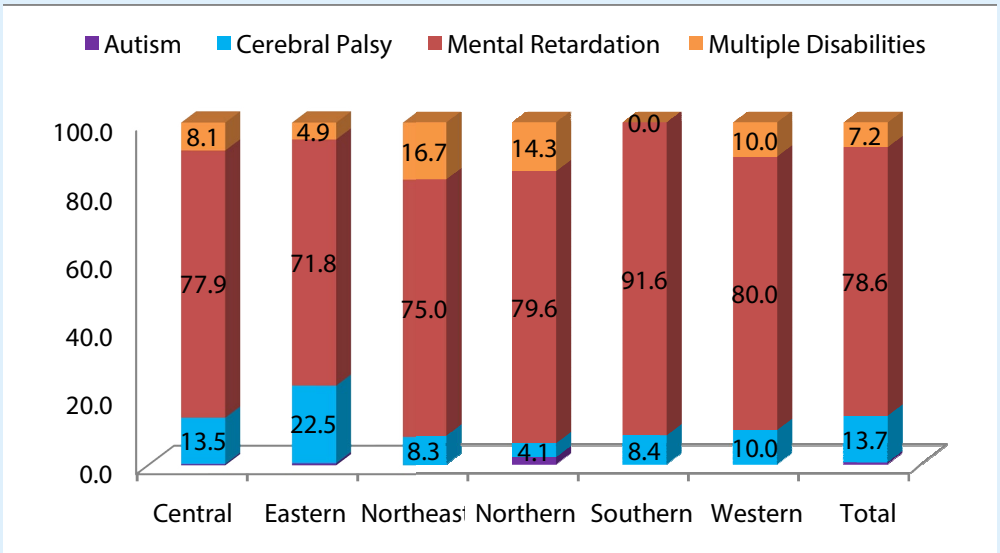
Table 4.62: Between-region Distribution of Beneficiaries by Types of Disabilities under the Gharaunda Scheme

Region	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Total
Central	50.0	55.8	56.1	63.6	56.6
Eastern	25.0	30.8	17.1	12.7	18.7
Northeastern	0.0	1.9	3.0	7.3	3.2
Northern	25.0	1.9	6.5	12.7	6.4
Southern	0.0	7.7	14.6	0.0	12.5
Western	0.0	1.9	2.7	3.6	2.6
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Source: Database of the National Trust, Ministry of Social Justice & Empowerment

Within different types of disabilities, 71.8%–91.6% beneficiaries belong to the mental retardation category of disability, followed by 4.1%–22.5% to the cerebral palsy category of disability **(Figure 4.14)**. Cases of autism are very marginal in all the regions.

Figure 4.14: Within-region Distribution of Beneficiaries by Types of Disabilities under the Gharaunda Scheme



Source: Database of the National Trust, Ministry of Social Justice & Empowerment

Like the Samarth scheme, maximum beneficiaries under the Gharaunda scheme are from the BPL income group (**table 4.63**). Across the region, the percentage of beneficiaries from the BPL income group varies from 50% in the northeastern region to 95.6% in the central region. Maximum percentage of beneficiaries belongs to the mental retardation category in all the regions.

Table 4.63: Distribution of Types of Disabilities of Beneficiaries by Income group and Region under the Gharaunda Scheme (%)

Regions	BPL					Non-BPL					Grand Total
	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	Autism	Cerebral Palsy	Mental Retardation	Multiple Disabilities	Sub-Total	
Central	0.5	13.5	74.2	7.4	95.6	0.0	0.0	3.7	0.7	4.4	100.0
Eastern	0.7	22.5	60.6	4.9	88.7	0.0	0.0	11.3	0.0	11.3	100.0
Northeastern	0.0	4.2	37.5	8.3	50.0	0.0	4.2	37.5	8.3	50.0	100.0
Northern	0.0	2.0	55.1	10.2	67.3	2.0	2.0	24.5	4.1	32.7	100.0
Southern	0.0	7.4	85.3	0.0	92.6	0.0	1.1	6.3	0.0	7.4	100.0
Western	0.0	5.0	55.0	5.0	65.0	0.0	5.0	25.0	5.0	35.0	100.0
Total	**0.4**	**13.2**	**70.1**	**6.2**	**89.9**	**0.1**	**0.5**	**8.4**	**1.1**	**10.1**	**100.0**

Source: Database of the National Trust, Ministry of Social Justice & Empowerment

4.4.4.2 Basic Profile of Beneficiaries

The basic socioeconomic profile of beneficiaries under the Gharaunda scheme is reported in **table 4.64**. The data shows that unlike the Disha scheme, majority of the beneficiaries under the Gharaunda scheme are from urban areas. The percentage of male members is nearly 3 times of that of female members at the Gharaunda centre. Data of social group

classification indicates that half of the beneficiaries belong to the OBC group, followed by 25% belonging to the SC group and 18.8% to the ST social group. The general and orphan groups represent 4.2% and 2.1% of the beneficiaries, respectively. The age group category suggests nearly 18% beneficiaries are from the age group of 18–30 years, followed by 25% who are from the age group of 40–50 years and 12.5% from the age group of 30–40 years. Educational qualification of beneficiaries suggests that maximum beneficiaries are illiterate (45.8%). Beneficiaries who have a qualification of primary level and upper primary level represent 29.2% and 16.7% of the sample, respectively.

Table 4.64: Socioeconomic Profile of Sampled Beneficiaries under the Gharaunda Scheme

Characteristics	Reponses (%)
Location	
Rural	39.6
Urban	60.4
Gender	
Male	79.2
Female	20.8
Social group	
Scheduled caste	25.0
Scheduled tribe	18.8
Other backward castes	50.0
Orphan	2.1
Others	4.2
Total	100.0
Age of beneficiaries	
>18–30 years	47.9
>30–40 years	12.5
>40–50 years	25.0
>50 years	14.6
Total	100.0
Educational qualification of parents/guardian	
Illiterate	45.8
Literate up to pre-primary	8.3
Primary	29.2
Upper primary	16.7
Higher secondary	0.0
Total	100.0

Source: Field Survey, NILERD, 2020

4.4.4.3 Implementation Process of the Scheme

Location of the Gharaunda centre is one of the key factors that influences the decisions of the parents whether to enrol their family member in the centre or not. Usually, parents become hesitant to send their family member to a centre that is located far away from home. As shown in **table 4.65**, more than 56% beneficiaries reported the centre is located between 10 and15 km from their home. Around 29% beneficiaries reported that the centre is located between 5 and10 km from their home. The average distance of a Gharaunda centre from the nearest city is 11.5 km.

Table 4.65: Distance of the Gharaunda Centre from Beneficiary's Home

Distance	Responses (%)
≤5 km	8.3
>5–10 km	29.2
>10–15 km	56.3
>15–20 km	6.3
Average distance (km) of the Gharaunda centre from beneficiaries' home	11.5

Source: Field Survey, NILERD, 2020

In case of sources of information received by the beneficiaries about the scheme, majority of the beneficiaries (>58%) reported that they came to know about the scheme from the ROs (**Table 4.66**). The second important source of information was awareness programmes, through which 10% of beneficiaries had received the information. The percentage of beneficiaries who received information from hospital doctors and relatives is 5% and 3.3%, respectively.

Table 4.66: Beneficiaries' Perception Regarding Different Sources of Information Received about the Scheme

Source	Responses (%)
Registered organisation	58.0
Hospital doctor	5.0
National Trust	1.7
Newspaper	0.3
Electronic media	1.7
Relatives	3.3
Awareness programmes	10.0

Source: Field Survey, NILERD, 2020

4.4.4.4 Quality of Services

The Gharaunda centre renders different services such as appointing a special educator/ vocational trainer, physiotherapist, cook, caregivers, and Ayas to look after the beneficiaries. It also conducts vocational activities at the centre. Have these services really helped the beneficiaries? Have the beneficiaries been satisfied with the quality of service? The results given in **table 4.67**answer these questions. A significant percentage of beneficiaries (75%) are fully satisfied with the services rendered by the special educator/vocational trainer. About 50% beneficiaries are also fully satisfied with the services of caregivers/ Ayas. In case of services offered by the physiotherapist, around 71% beneficiaries are satisfied to some extent, while 18.8% are fully satisfied with the service. The vocational activities being carried out at the centre have been viewed as fully satisfactory by 45.8% beneficiaries, and an equal number of beneficiaries have reported that they are satisfied to some extent. Only 4.2% beneficiaries reported that they are not satisfied or are very dissatisfied with the vocational activities.

Table 4.67: Quality Assessment of Services under the Scheme

Indicators	Fully Satisfied	Satisfied to Some Extent	Not Satisfied	Very Dissatisfied	Total
Services of a special educator/ vocational trainer	75.0	25.0	0.0	0.0	100.0
Services of a physiotherapist/ occupational therapist	18.8	70.8	10.4	0.0	100.0
Services of a cook	47.9	45.8	6.3	0.0	100.0
Services of caregivers and Ayas	50.0	45.8	4.2	0.0	100.0
Vocational activities at the Gharaunda centre	45.8	45.8	4.2	4.2	100.0

Source: Field Survey, NILERD, 2020

4.4.4.5 Quality of Infrastructure

The study collected information on the conditions of room and facilities available in the room at the Gharaunda centre. As reported in **table 4.68**, maximum percentage of beneficiaries/parents (85.4%) rated the conditions of the medical room as 'good', whereas an equal percentage of beneficiaries reported the facilities available in the medical room as 'good'. Similarly, a higher percentage of beneficiaries (60%– 75%) rated the condition and facilities in the activity and recreation rooms as 'good'.

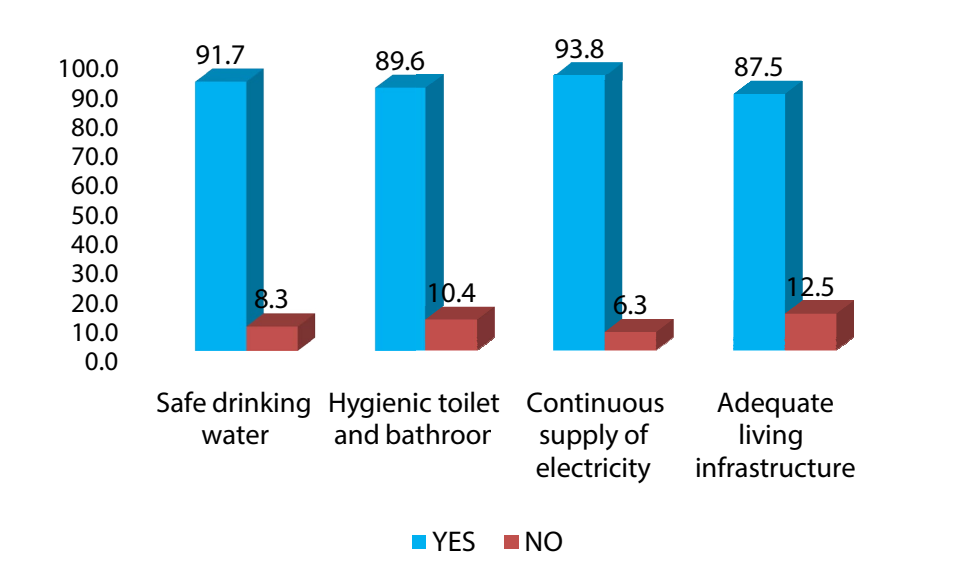
Table 4.68: Beneficiaries' Perception Regarding Physical Infrastructure and Services under the Gharaunda Scheme (%)

Physical Infrastructure	Rank	Condition of Rooms	Condition of Facilities
Medical/assessment room	Good	85.4	85.4
	Average	14.6	14.6
	Bad	0.0	0.0
	Very Poor	0.0	0.0
	Total	100.0	100.0
Activity room	Good	70.8	75.0
	Average	29.2	25.0
	Bad	0.0	0.0
	Very Poor	0.0	0.0
	Total	100.0	100.0
Recreation room	Good	64.6	70.8
	Average	35.4	29.2
	Bad	0.0	0.0
	Very Poor	0.0	0.0
	Total	100.0	100.0

Source: Field Survey, NILERD, 2020

The data collected from the field and reported **in figure 4.15** indicates that 91.7% beneficiaries reported that safe drinking water is available at the centre. Similarly, while 89.6% beneficiaries expressed that hygienic toilets and bathrooms are available at the centre, 93.8% reported continuous supply of electricity to the centre. A whopping 87.5% beneficiaries said that adequate infrastructure is available at the centre.

Figure 4.15: Availability of Basic Amenities at the Gharaunda Centre

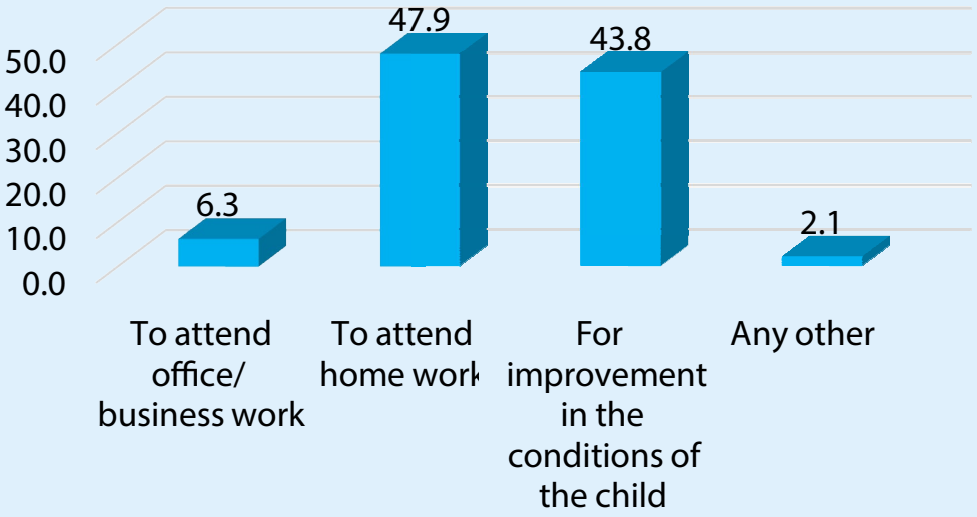


Source: Field Survey, NILERD, 2020

4.4.4.6 Impact of the Scheme

As demonstrated in **figure 4.16**,maximum (47.9%) parents/relatives of beneficiaries reported that they are availing the service to attend to house work. Another significant proportion of beneficiaries (43.8%) said that they are availing the scheme for the betterment of their child.

Figure 4.16: Responses of Parents on the Need for the Gharaunda Scheme (%)



Source: Field Survey, NILERD, 2020

Regarding the impact of the Gharaunda scheme on time, work, and income of the parents, the study found that the scheme helped 45.8% parents to save and invest extra time in household or office work due to relief from the responsibility of the child. Of these parents, more than 86% reported that they have used the extra time in productive work, and as a result, their income has increased by 5% (**table 4.69**). Further, the study found that majority of the parents (77.1%) agreed that their child is better off than other children who have been left out from the scheme.

Table 4.69: Responses of Parents on Utilisation of Time after Joining the Gharaunda Scheme

Categories	Frequency
Whether received higher opportunity to save and invest extra time in household or office work due to relief from child care	
YES	45.8
NO	54.2
Whether income improved due to utilisation of extra time in productive work	
YES	86.4
NO	13.6
If there is improvement in income, the range of increment	
<5%	68.4
5%–10%	26.3
10%–15%	5.3
Whether better off than other children in the disabled category who are deprived of this service	
YES	77.1
NO	22.9

Source: Field Survey, NILERD, 2020

Table 4.70: Perception Regarding Improvement in the Conditions of the Beneficiary (%)

Parameters	Fully	Some Extent	Not at All	Total
Improvement in learning ability	47.9	50.0	2.1	100.0
Improvement in eye contact and body balance	31.9	53.2	14.9	100.0
Improvement in day-to-day activities	39.6	43.8	16.7	100.0

Source: Field Survey, NILERD, 2020

Impact of the scheme on beneficiaries' mental and physical development has been captured and analysed by assigning different ranks. As reported in **table 4.70**, majority of the parents reported that the learning ability has improved to some extent. A similar result was also observed in case of eye contact, body balance, and improvement in day-to-day activities. Nevertheless, 30%–50% beneficiaries also viewed their condition as fully improved with respect to learning ability, eye contact, and performing day-to-day activities.

Chapter 5

Success Story of PwDs The Journey of Hope Instilled by the National Trust

People living with disabilities encounter many disadvantages in society and are often subjected to stigma and discrimination. Marginalised and disproportionately poorer, people living with disabilities are particularly vulnerable to crisis. Further, they remain largely excluded from political and civil processes and voiceless on crucial issues that affect them and their society (UNDP, 2012)[23]. In India, PwDs are not seen as a human resource who could contribute and participate in nation building. Their talent, skills, and potential mostly remain untapped, under-utilized, or underdeveloped. Further, education and employment rates for PwDs are far lower than those for non-disabled persons. The opportunities for PwDs to earn is less and their expenses are more, resulting in them being one of the more impoverished communities in India.

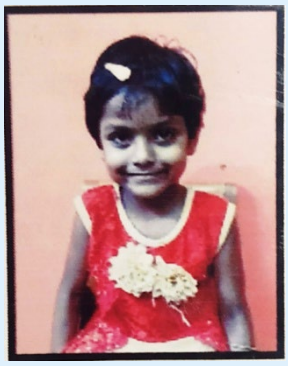
It was considered critical to document the success stories of individuals and case study of institutions working for improvement for PwDs with support from different schemes under the National Trust, which will help inform and give insights into the barriers and challenges to empowerment of PwDs. This knowledge will then help in designing, executing, and monitoring better empowerment and promotion of programmes and polices related to PwDs in India. It would also provide the relevant knowledge base required to influence policymakers, state governments, and research institutions for extending their support to PwDs for empowerment. The findings from the success stories and the challenges faced by the ROs will further be useful in the modification and improvement of the schemes.

In this chapter, we present information that was collected through FDGs with different ROs who have been associated with the National Trust in running day and residential care schemes for the past several years. From the discussion, it was found that some of the ROs have achieved a great success in empowering and instilling hope in the life of special children who otherwise would have been going through a life full of darkness. This was possible only due to the financial support extended by the National Trust to the ROs. The financial support provided by the Trust has enabled the ROs to not only maintain quality infrastructure in the centre in terms of building a medical room, activity room, recreation room, and other facilities to motivate and encourage the children but also helped them in hiring special educators, physiotherapists, counsellors, caregivers, Ayas, and trainers to keep the children physically fit and improve their learning skills and mental ability. Although funding has never been sufficient to meet the huge market demand, support

23 See file:///C:/Users/hi/Downloads/livelihood-opportunities-for-persons-with-disabilities.pdf

given by the Trust has been a great source of help to fulfil the dreams of millions. The success story of a little girl Afrin Khatununder the Disha scheme from West Bengal, Ms. Sandhya under the Samarth-cum-Gharaunda scheme from Tamil Nadu, and Mr. Rajesh under the Disha-cum-Vikaas scheme from Gujarat are heart touching examples indicating that nothing is impossible if we take care of their childhood and groom them with proper care.

Success Story 1: Disha (West Bengal)



Disha Centre

Asha Bhavan Centre, Vill.-Kathila, Dist. Howrah-711316

Name: Afrin Khatun

Date of birth: 10/01/2012

Gender: Female

Disability: Cerebral palsy

Father'sname: SK Alam

Address: Baikunthapur, Sijberia, Uluberia, Howrah-711316, WB

Disha Registration No: ABC/CRC/007/2016-2017

Afrin Khatun was born with a complication; her birth weight was only 600gmand she had birth asphyxia. These complications led her to develop cerebral palsy. At present, she is 9 years old and lives with her extend family in Baikunthapur, ward no.21 under Uluberia Municipality of Howrah District.

Her father is the only earning member of a family of seven members and he earns from selling fruits on the street of Uluberia City. When Afrin was around 2 years of age she started visiting the Asha Bhavan centre with her mother. When she came for the first time, she was able to control her head and was learning to sit. Then, Afrin was also dependent on her mother for all functions, such as eating, drinking, going to the toilet, etc. Afrin's family was much mentally disturbed and confused about their daughter's problem and visited several places looking for medical cure.

The Asha Bhavan centre took efforts and arranged numerous counselling sessions to make the parents understand Afrin's conditions and her needs. Then, Afrin was admitted to the Disha centre in 2017.At first, professionals assessed the child and covered all her need areas. As per the assessment, we found out the abilities and needs of Afrin and prepared a holistic rehabilitation plan for her optimum development. She learned preschool skills with periodical review and by updating her profile.

After rigorous sessions with her, Afrin now is able to walk with special shoes. She can perform all daily living activities independently. She can maintain social behaviour as per her age. She

is aware of personal grooming and skills to play in a peer group. Afrin now goes to a primary school (Baikunthapur Primary School) and studies in class III. She also participates in various cultural programmes at the school. She can follow simple instructions and can read and write independently.

The parents, family, and community of Afrin are happy and glad to see the development in her life and expect Afrin to become independent in life.








Success Story 2: Disha(Uttar Pradesh)

BHAWNA SOCIETY FOR DISABLED
Regd. Under society registration act, 1980
Regd. Under P.W.D Act
Regd. Under THE NATIONAL TRUST
Address:-118/553A, KAUSHALPURI, GUMTI NO.5
KANPUR NAGAR - 208012
MOB. 9839212289, 9839212389, 8960851789, 9721804514
E-Mail:- bcpiknp@gmail.com website: -www.bhawnasociety.com

मेरा नाम नूपुर चौहान है। मेरा जनम २५ मई १९९० को कानपुर में हुआ था। जनम के समय कुछ मेडिकल परिस्थितियों के कारण मैं सेरिब्रल पाल्सी से पीड़ित हूँ। मैं सिजेरियन ऑपरेशन से हुई थी। इस बीमारी की वजह से मेरे शरीर का दाया हिस्सा काम नहीं करता है मैं जनम लेने के बाद रोइ नहीं थी जिस वजह से डॉक्टर ने मुझे मृत समझ लिया था मेरी नानी और मौसी के कहने पर उन्होंने मेरी जांच की और मुझे पीठ पर मारा तो मैं रोने लगी। मुझे इसके बाद जॉन्डिस और टिटनेस हो गया था बहुत सारे इलाज के बाद हम इन् दोनों बीमारी से ठीक हुए धीरे -धीरे समय बीता मेरे उम्र के सारे बच्चे जब बैठने और पलटने लगे और हम कुछ भी नहीं कर पाते थे हम से छोटा भाई पलट लेता था तो मेरी नीलम मौसी को लगा की मेरे साथ कुछ समस्या है एक पहचान वाले के कहने पर मेरी मौसी और माँ ने हमें हैदराबाद से आये एक डॉक्टर को दिखाया डॉक्टर ने मेरे परिवार को बताया कि आप कि बेटी को सेरिब्रल पाल्सी है इससे एक्सरसाइज और इलाज की जरूरत है और बाल भवन भेज दिया थोड़े समय वहाँ एक्सरसाइज कराने के बाद वहाँ से उन लोगों ने हमें नार्मल स्कूल जाने के लिए कह दिया और एक दूसरे डॉक्टर से कुछ समय के लिए एक्सरसाइज करवाई /

सन १९९९ में मेरे परिवार को कानपुर में ही स्थित एक संस्था **"भावना सोसाइटी फॉर डिसेबल्ड"** के बारे में जानकारी मिली जो मेरे घर से लगभग १० किलोमीटर में था जहा पर दिव्यांग गरीब बच्चों का बिलकुल निःशुल्क इलाज होता था वहां के डॉक्टर तथा स्पेशल शिक्षक और फ़िज़ियोथेरेपिस्ट के इलाज तथा एक्सरसाइज और मार्गदर्शन की वजह से धीरे - धीरे हमने बिना सहारे के चलना और अपनी शिक्षा जारी रखी। संस्था **"भावना सोसाइटी फॉर डिसेबल्ड"** की मेहनत की वजह से हम आज एक नार्मल लाइफ जी पा रहे है आज हम इसी संस्था **"भावना सोसाइटी फॉर डिसेबल्ड"** की प्रेरणा के कारण हमने अपनी बी. ए. तक की शिक्षा पूरी की कंप्यूटर का डप्लोमा कोर्स किया इन् सब के साथ की वजह से आज हम आत्म निर्भर है हम अपनी कोचिंग क्लासेज चलाते है जिसमे बारहवीं तक के बच्चे आते है २०१९ में हमने सोनी टीवी पर आने वाले कार्यक्रम **"कौन बनेगा करोड़पति"** में हिस्सा लिया और **"बारह लाख पचास हजार रुपये"** जीते !

हम आज डॉक्टर रेड्डी फाउंडेशन कीतरफ से ऍम बीऍ कर रहे है।

Success Story 3: Disha (West Bengal)

Name: Mohana Das

PwD ID: BSMCH/HB/474
Year: 2019–20

Name of the organisation: Kenduadihi Bikash Society

Address: P.O. Kenduadihi, Dist. Bankura, Pin Code. 722102

Mohana, a girl with intellectual disability (Down's syndrome) of 7 years age residing in a nuclear family in Poddarpara of Bankura, illuminates the Bikash Special School premises with the ever-glowing aura of happiness, in spite of being cursed with her so called 'disability'. Being the only adorable daughter, Mohana's parents always try to keep the girl cheerful and socialised enough by spending quality time with her to gift her prosperous life.

After being admitted to the Bikash Special School, a special focus was laid on Mohana's cognitive domain specifically in the academic domain along with a target of improvising her speech. The girl was indeed achieving her domain-wise targets with a steady flow, which impressed the teachers and her parents too. However, an unpredictable hindrance was noticed when suddenly due to the COVID-19 pandemic outbreak, the school was notified to close due to the nation-wide outraging situation, that is, from 16th March, 2020. Lots of hopes and dreams of the parents and teachers were about to end because of the impediment in the continuity of development of special children due to lack of practice and isolation from the school environment.

However, the motivated teachers of Bikash never accepted this situation and they thought of alternative strategies to keep the development of the students in pace even in the lockdown, either through rigorous telephonic counselling or through a newly formed WhatsApp group with the parents. Thus, Mohana was again connected and continuously tracked by individual teachers and was provided with assignments to commensurate with her IEP and goal plan. Worksheets on different academic exercises were provided to the girl, which after her submission were properly checked by the teachers, followed by a video call to explain the laggings and mistakes of the girls. Progress and achievements for the last few months were keenly tracked and informed to the parents, augmented by the cheerful sessions with Mohana over the video calls to develop her socialisation and speech requirements.

The girl with utmost support of her parents has combated the lockdown situation and has learnt equally, achieving progressive results according to the targets. According to her parents, Mohana's attentiveness has increased. She has learnt new Bengali poems, improved jaw movements – enhancing speech, learnt more concepts on numbers, and improved writing Bengali words. However, the girl is impatient to go back to Bikash Special School and learn with the teachers there. The exercises are still carried out by

the teachers amidst the lockdown to gift the girl a better command over the academic domain.

In this devastating situation, amidst all worries, a small spark of achievement too can glitter the hopes and so as Mohana is doing with her strong will & parent's cooperation. We all wish her a bright future ahead which of course the girl will enjoy, if properly guided & intervened, making her a mainstream of the society.

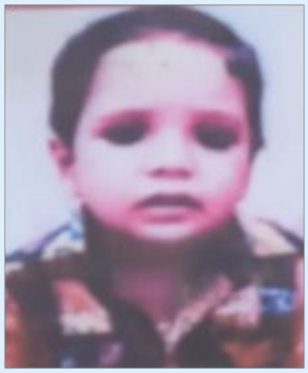
Success Story 4 : Disha-cum-Vikaas (Gujarat)

Name of the organisation: Ashihrvad Viklang Trust

Address: At- Sayla, National High Sayla, Dist- Surendranagar, Gujarat

Scheme name: Disha-Cum-Vikaas Scheme

Name of the activity and year: Identifying Fruits by Picture, Game Activity, and Education Training.



Name: Chauhan Mohammadsad Iqbal bhai

PwD ID: (13) 53143310082016

Village: Surendranagar, Behind District Panchayat, Dhobi Society

Age: 10 years

Disability: Mental retardation

Age of disability: 1 year after birth

Cause of disability: Epilepsy

Study: Std. 8

Family occupation: Labour

Number of family members: 2

Situation of the house: Mohammad sad belongs to a poor family.

Family struggle: His older brother is also handicapped. After giving training to him, he can perform his daily activities by himself. After adjusting, another child became handicapped due to stretching and he was also given medicine. The family also had difficulty in attending social and religious functions.

Need of the child: Mohammad sad is mentally retarded so he has to be taught to perform daily activities, study with other children in a normal school, and get along well with other children. His health should also be checked and stretching medicine should be started for him.

Training: First, he was admitted to the Disha-cum-Development centre and assessed. Then, knowing his need, and the goals of teaching him were accordingly decided. He was then trained accordingly in which he first brushed into daily action, such as bathing

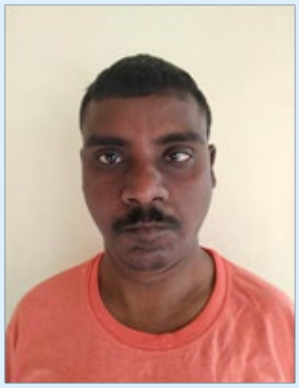
and getting ready. In educational activity, he was trained to perform number writing and colour and shape recognition and participate in sports with the children around the house. His parents were also trained in which the parents at home were taught how to train the child.

Current situation of the child: At present, the child recognises the members of his household by name. He identifies the children and teachers by name in the school and centre. He participates in group activities. He performs daily activities by himself. He also participates in social and religious events.

Supporting services: Benefits such as medical certificate, bus pass, Niramaya card, and educational kit were provided free of cost.

Success Story 5: Disha-cum-Vikaas (Gujarat)

Courtesy: Paper Dish Making under Vocational Training 2020 under Disha-cum-Vikaas Scheme at Blind Welfare Council, Mandaav Road, Opposite Hanumanjee Temple, Dahod 389151, Gujarat.



Name: Mr. Rajesh Maganbhai Harijan

PwD ID: 63/2008

Rajesh is under training at this institute since 2006. He was a young child at that time. Now, he has grown up to be a responsible citizen. Rajesh Maganbhai Harijan lovingly known as Raju was born in Village Laxmanpura, Taluka Godhra, District Panchmahals. He has a very low vision, learns slowly, and has locomotor disability. His parents were not ready to admit him to the residential set up here. They used to say that 'however our child is, he is a gift from God'. After lot of counselling by our teachers and the local primary school principal, they agreed to admit him to our special school.

He was admitted to Bahuviklang Nivashi Shala in September2006. The teachers had a tough time training and teaching him due to his multiple disabilities. He started learning the basics of primary education. With the help of all teachers, Raju became an understanding and clever child. From July 2015, he was admitted to the prevocational training centre where he was trained to make candles and paper dishes. His hard work and sincerity has given great results. He is now an active person in all facets of life. He is in-charge leader of the paper dish-making unit. Raju has all information about Who is doing what, how many numbers and which size of paper dishes are to be produced, which dealer is to be supplied what quantity and which size of paper dishes, whose order is pending?, etc. He supervises the whole unit nicely and distributes the work as per the trainees' level under the guidance of the special trainer. Other than the paper dish-making unit, Raju takes up other work. He keeps all information regarding the visits of different persons in our campus. He also has information about all employees like who is present and who is absent, which employee is working in which department, who has not yet had lunch or dinner in the hostel, etc. He keeps the management updated about all the happening in the units other than the paper dish-making unit. At present, he is working like a responsible person in our campus and that is why he is known as 'Sarpanch'. This Sarpanch will be available at all times in our campus.

Success Story 6: Disha-cum-Vikaas (Gujarat)

Name of the organisation: Smt. Parsanben Narandas Ramji Shah (Talajawala) Society for Relief

&Rehabilitation of the Disabled (PNR Society)

Address: Nataraj Research Centre and Training College Campus, Nr. Sardar Patel School,

Kaliyabid, Bhavnagar-364002, Gujarat

Scheme name: Disha-cum-Vikaas Day Care Scheme

Name of the activities and year: (1) Drawing on Chart Paper, (2) Play Time Activity, (3) Vocational Training, (4) Group Teaching–Special Education, (5) Parents Meeting, (6) Hydrotherapy, (7) Special Education, (8) Activities of Daily Living Training, (9) Physiotherapy, (10) Occupational Therapy (Sensory Training), (11) Balance Training, (12) Oral Motor Exercises, (Speech Therapy). 2019–20

Early Intervention Success Story: Humera Vasimbin Kathiri

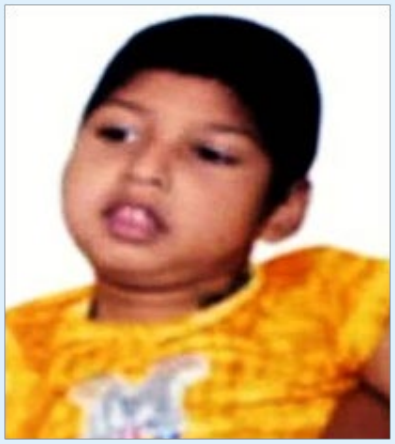
Humera Vasimbin Kathiri–A child with enormous strength to survive by fighting against all circumstances.

Age: 6 years

Diagnosis: Quadriplegic cerebral palsy with severe intellectual disability

Category: BPL

PwD ID: 79084905072016



The Journey

When Humera's parents were told by the doctors that their daughter had cerebral palsy with severe intellectual disability, prognosis against the treatment was poor, and her future looked bleak, her mother, a housewife, was stunned.

The Impact of Care Under Disha-cum-Vikaas Day Care Centre

Despite being given such tragic news, her parents refused to accept that Humera could not improve and progress, and they made plans to attend the Disha-cum-Vikaas Day Care centre supported by the National Trust, New Delhi and run by PNR Society, Bhavnagar, Gujarat. Humera's mother came to the centre first, when Humera was 2 years and 6 months old. At that time, Humera could not hold her neck and sit upright. Her mother began implementing the project's multidisciplinary programme. Her father made sure to give Humera ample opportunity to be on the floor in the prone position to help him begin the pathway towards neck holding. Her parents began to see progress day by day, and her mother made plans to start the sitting position with full support. When her mother attended the multidisciplinary programme continuously since the last 2years, Humera started making good progress. Since the last 2 months, she had started holding the neck for few minutes and could sit with full support for 10 minutes. Humera was evaluated and staff members were very impressed with her progress. Her parents were advised to follow the treatment plan at home too. Humera's progress continued to inspire her parents and the staff. Then, her parents started training her to eat solid foods with assistance. She can now hold the food and take it in the mouth with assistance. Humera has made very significant progress.

Humera Today

Although she has been on the programme for the last 2years, she has been able to hold her neck, sit with support, and eat solid foods with assistance. Her mother says, 'We have always seen daily miracles, but we're watching huge miracles now, and so I am pleased to see her sit alone. She's going to be a near healthy kid'.

We are all looking forward to see Humera continue on her pathway to wellness.

Before Early Intervention Services

Humera with severe spasticity in all four limbs

Humera had no neck control

Humera was totally irresponsive

Humera had no trunk control

Early Intervention Services Offered at Disha-cum-Vikaas Day Care Centre

After Early Intervention Services

Matrix rhythmus therapy to reduce spasticity

Humera is now able to hold the neck for few minutes

Exercise on a Physio ball to develop balance control

Humera is able to sit with support for 5minutes

She is able to performeye contact and concentrate for few minutes. She is able to eat solid foods with assitance.

Success Story 7: Disha-cum-Vikaas (Himachal Pradesh)

Name of the organisation: Ganpati educational society

Address: Near Telephone exchange, Kunihar Tehsil, Arki, Dist-Solan, HP

Scheme name:Disha-cum-Vikaas Day Care Scheme

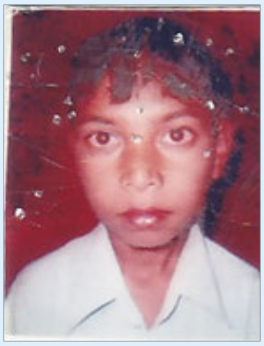
Sanjeev learning from a special educator

Group exercises

Group learning Sanjeev is in the front row

Bharat

Receiving awards in spl. Olympics



Name: Sanjeev

PwD ID: 84473107052016

Joining year: 2015

Previous history: Sanjeev was the most lazy and clumsy on arrival to the centre. He barely made any movements and neither had we seen any response from his side. He was so much afraid to go near a bus and used to cover his face when a bus approached him. His personal hygiene remained unattended for days as he was neglected by his household members.

It is understandable that in academics too Sanjeev was far behind as he was basically a slow learner since the beginning. All the aspects in academics took a great deal of time for Sanjeev to understand and grasp properly. He remained completely brain washed while and after the lessons were taught. Therefore, a play way system was adopted for Sanjeev where we did not put any stress on him, rather taught him while playing. Surprisingly, the method worked for him.

Vocational activities and sports were out of the question with such a shy and hesitant child. It took us months to make him used to the bus services and travelling. Sometimes, we too gave up hope for his progress, but in due time, Sanjeev slowly got interested in what was being done to him. Improvements were seen after years of hard work, efforts, and training. Now, Sanjeev is the most treasured child in our organisation.

a. **Personal:** Sanjeev is now independent and does most of the things on his own, like travelling, going to school, and going long distances as he now clearly remembers the bus numbers. Household and day care cleaning is done by Sanjeev as he opens and closes the day care. His personal hygiene is up to the mark, and we rarely see any faults in the activities performed by him.

b. **Socialisation:** Apart from being a favourite in his social circle, he also takes care of other special children who come to the day care centre, and we were surprised to see the way he handles children with profound mental retardation and cerebral palsy. He is ready to do anything at any time, and his sincerity in what he does is worth watching.

c. **Academic:** He has already completed his 8th grade as per Indian and state norms and also as per disability norms. He recognises all colours, currency notes, and coins. He can very well write his name, address, and phone number.

d. **Vocational:** Sanjeev is now capable of making file covers, paper bags, candles, chalks, and envelopes. We are concentrating on some vocations so that he can earn his livelihood easily. He has proven himself good in agriculture-related activities.

e. **Spl. Olympics:** He has participated in national Olympics held in Madras.

Name of the organisation: Gautam Budha Sikshan Sansthan

Address: Mudadeeha, Gonda, UP

Scheme name: Disha-cum-Vikaas Scheme

Name of the activity and year: 2019–20

Success Story 8 : Disha-cum-Vikaas (Himachal Pradesh)

Name of the organisation: Sakar Society for Differently Abled Persons

Address: Vill. Dodhwan, Gram Panchayat-Kapahi

Tehsil- Sundernagar, Dist-Mandi

HP

Scheme name: Disha-cum-Vikaas Scheme








Name of the activity and year: Vocational Training, 2020–21

Our vocational wing is a sheltered workshop where five special children of intellectually impaired category work under the supervision of our vocational teachers. Our vocational wing comprises of three girls and2 boys who are paid honorarium and are now earning members of their families. When Nikita (62110015112016), Pooja (85773015112016), and Premlata joined the Sakar Special School, they could not put a thread in the needle, but after 10 years of hard work of our special teachers, they are now able to stitch suits and knit sweaters.

Anil and Puneet can now make baskets and leaf plates. Our special children make beautiful candles of wax and gel for Diwali and make beautiful Rakhis during Rakshabandhan festival. All our students belong to poor families and their honorarium make useful contribution to the livelihood of their families.

Leaf plates are made using ahydraulic machine, which was handled by a special teacher, and our special children stitch these leaves on papers to help in this vocational work.

Pickle making is another task in which these children play a vital role. Pickle and other products made in the vocational centre at Day Care School Dodhwan are sold in Sakar Shoppee near the cinema hall chowk of Sundernagar. These special kids also help in selling these products at this Shoppee. All these activities have created awareness in these children and increased their self-confidence. These children are now important earning members of their families and have earned a respectable place in society. Sakar society also feels immense pleasure in disclosing the success story of these special children.

Success Story 9 : (Gharaunda, Uttar Pradesh)

Swami Vivekanand Shiksha Evam Samaj Kalyan Samiti(SVSESKS), Sant Kabir Nagar (UP)

SVSESKS is implementing Gharaunda scheme under The National Trust (Ministry of Social Justice & Empowerment, Govt. of India, New Delhi) to provide an assured home with acceptable living standards including basic medical care from professional doctors and adequate and quality care services and since 15 March 2016. At present, 17 beneficiaries are enrolled. We are making them capable to earn through vocational training (paper envelope) as well as proper care. All registered PwDs are under the BPL category, their income certificates are issued by SDM/Tehsildar (Revenue Department). Aadhar cards

have been issued to all registered beneficiaries (PwDs) in the camp. We offer them dress/ cloth time to time. They can write their names and address.

Behaviour change: Before enrolment in our organisation, these beneficiaries were walking on roads whole time, not washing their buttock after latrine discharge, not washing their teeth, not taking bath, and not wearing their shirts. They could not read and write. Guardians were despair for their future and social status. They now take bath regularly, wash their hands before taking food, brush their teeth in the morning, wash their buttock after latrine discharge, wear their clothes properly; all of this because of constantly living at the Gharaunda centre under discipline. Their guardians are very happy to see the change in their lives. Their social recognition has also been changed.

Education: They can now read and write Hindi. All can now write their name, father's name, and address.

Cultural programme: On the occasion of 15 August, 26 January, and National Trust Foundation Day, disabled persons enrolled under the National Trust present nukkad natak, music, dance, and sports programme before mass audience including their guardians, which influence everybody. This programme increases their interest in self-development, National Trust schemes, and social inclusion. They are enjoy by presenting their cultural activities. Some photographs are attached herewith.

Vocational training: All enrolled beneficiaries prepare paper envelopes of different sizes after receiving long-term training at our centre. Each disabled beneficiary earns at least Rs. 500on a monthly basis through this business. They influenced their guardians by earning. Photographs are attached.

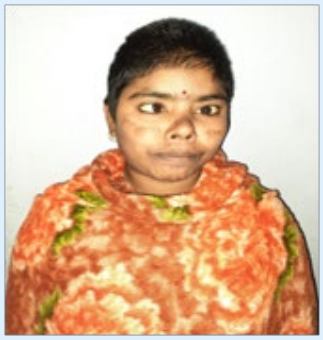
Sports competition: All enrolled beneficiaries play football, volley ball, badminton, and ludoo etc. It shows their change in life. Photographs are attached.

Yoga programme: Enrolled beneficiaries perform their yoga exercises in the morning for their good health and controlling diseases.

Feeling own programmes: Guardians feel this as their own programme. They come regularly to the centre and make good suggestions. They take the benefit of pension, free travel, and Niramaya health scheme. Their children participate in rallies for national-level programmes, for example, 'Vote awareness programme for election'. Thus, beneficiaries are changing their lives economically and socially.

Success Story 10: Gharaunda (West Bengal)

Name of the activity and year: Kantha Stitching, 2020



1.1.1 Name: Madhobi Konai

1.1.2 PwD ID: 93711530052016

1.1.3 Disability: Mental Retardation

1.1.4 Gender: Female

1.1.5 Category: BPL

1.1.6 Year: 2016

1.1.7

1.1.8 Madhobi Konai was residing at Vill. & P.O.-Dunigram, P.S.-Margram, Dist-Birbhum, West Bengal since her birth. She is a mental retarded woman.

Madhobi Konai is 27 years old now. Madhobi's mother ran away from home when Madhobi was about 10 years old. Her father's name is Ratan Konai. Ratan admitted his girl Madhobi at the Home of Rampurhat Spastics and Handicapped Society in 2003. In the meanwhile, Madhobi's father Ratan got married again and did not maintain any contact with his daughter Madhobi. At present, she is an abandoned woman. Madhobi has been residing at the Home of the society for a long period and so is familiar as Didi among the beneficiaries. At present, she can perform all types of work of a family such as cooking, cleaning, peeling of vegetables, and washing clothes. Besides, she co-operates with other beneficiaries and staff of the society. She can welcome the guests of the society.

By staying at Home for a long period, the ability and character of Madhobi has developed to some extent. She is expert in Kantha Stitching now. Her work of Kantha Stitching is sold in the market now. Society has already taken an initiative for making arrangement of disability pension for her. At present, her personal savings bank balance is Rs. 56,420. We hope she would be rehabilitated shortly.

Success Story 11: Samarth-cum-Gharaunda (Madhya Pradesh)

Name of the Organisation: Aadhar Foundation

Address: Opp. Narendra Ayush Dhaba, Panchwati Ward No. 48, Parasia Road, Poama, Chhindwara-480001, MP

Scheme name : Samarth-cum-Gharaunda Scheme

Name	–	Mr. Bhanu Sahu
PwD ID	–	15915004102018
Year	–	October 2018 to April 2019
Scheme	–	Samarth-cum-Gharaunda under the National Trust, New Delhi
Parentage	–	Mrs. Manju Sahu
Address	–	Near The Old Power House, Jhilpura, Chhindwara, MP
Date of birth	–	02/11/2000
Disability type &percentage	–	Intellectual disability & 60%
Economics status	–	BPL

Bhanu was born in a poor family. To make matters worse, Bhanu's father abandoned him and his mother Shrimati Manju Sahu. She started work as domestic help for two square meals.

We met Bhanu's mother in one of Aadhar Foundation's regular surveys in September 2018. We advised her on the possible improvements in children with similar and more severe intellectual challenges at Aadhar Foundation. With some persuasion, Bhanu joined the foundation in October 2018. When he joined the foundation, he could just attend to his personal hygiene requirements. He had difficulties in socialising and an inability to understand time and its passage; needless to say, he could not do Basic Mathematics. He could not concentrate at all.

The trained counselors at Aadhar Foundation, besides working on his social and mathematical skills, started to work on the business and daily applications of his newly gained knowledge and skills.

With the help of Aadhar Foundation, Bhanu was able to find employment at Tiwary Medicals in Chhindwara (Opposite of Police Station) in May 2019 at a starting salary of Rs. 3000 per month. His job was to move boxes of medicine and medical equipment from the

godown to the store and look after the godown and cleanliness of the store and godown. Bhanu now earns Rs. 5,500 per month. Bhanu and his mother are extremely happy now and never cease to express their gratitude towards Aadhar Foundation and Nation Trust for their happiness.

Success Story 12: Samarth-cum-Gharaunda (Madhya Pradesh)

Name of the Organisation	:	Aadhar Foundation
Address	:	Opp. Narendra Ayush Dhaba, Panchwati Ward No. 48, Parasia Road, Poama, Chhindwara-480001, MP
Scheme name	:	Samarth-cum-Gharaunda Centre of The National Trust, GoI, New Delhi

Name of the activity and year: Works as an assistant mechanic, 2020

Name	–	Rishi Vishwakarma
PwD ID	–	91973516062017
Year	–	August 2017 to April 2018
Scheme	–	Samarth-cum-Gharaunda under the National Trust, New Delhi
Parentage	–	Late Mr. Balram Vishwakarma
Address	–	Chand Road, Chourai, Chhindwara, MP
Date of birth	–	04/08/1999
Disability type &percentage	–	Intellectual disability & 50%
Economics status	–	BPL

A widow mother with three sons on the threshold of adulthood should have been able move out of poverty. Unfortunately, it was just the opposite; all three sons were intellectually challenged and were sinking deep into social and behavioural evils such as tobacco use, loitering, and unsocial activities.

The youngest of the three sons Rishi was sent to Aadhar Foundation in August 2017 for rehabilitation. At the time of admission, Rishi who was possibly the most challenged of the three brothers didnot have skills to go through daily life. Like Bhanu, Rishi had difficulty concentrating and did not have an idea of time or any mathematical skill. Behavioural skills were lacking too.

While training him through the abovementioned skills to navigate through day-to-day life, trainers at the Aadhar Foundation noticed his particular ability with construction motor skills. This was noticed when at a workshop, he showed interest and concentration towards helping with grills and doors. He was given further training in structures of agricultural equipment.

In May 2018, he was employed in Shree Engineering Works near his house in Chowrai, District Chhindwara. Today, he works as an Assistant Mechanic and earns Rs.4500 per month.

Recently, when members of the Aadhar Foundation met Rishi's mother, she was effusive of the contributions of the National Trust and Aadhar Foundation. She said 'the son who was called as retarded and good for nothing, today, helps run the family'!

Success Story 13: Samarth-cum-Gharaunda (Odisha)

Name of the organisation	:	Nilachal Seva Pratisthan
Address	:	At-Benagaon (Dayavihar), PO-Gadasahi, PS-Kanas, Dist-Puri, Odisha-752017
Scheme name	:	Samarth-cum-Gharaunda Scheme

Musical Chair Competition

Dance Practice

Paper Thunga Making

Teracotta Toy Making

Jhoti Competition

Broom Making

Name of the activity and year: Musical Chair Competition, Dance Practice, Paper Thunga Making, Teracotta Toy Making, Jhoti Competition, and Broom Making, 2020–21.

Success Story

Name	:	Papi Mohanty
Father	:	Kalandi Charan Mohanty
Mother	:	Basanti Manjari Mohanty
Date of birth	:	23/10/1990
Address	:	At-Anianka, PO-Osakana,
PS-Balikuda, Dist-Jagatsinghpur		
Date of admission:	04/12/2017	
PwD ID	:	83234512042017

Papi Mohanty, a 30-year-oldintellectually disabled girl bearing PwD ID no. 83234512042017 was brought to the Gharaunda Unit of NSP on 4 December 2017 by her father Kalandi Charan Mohanty, who is a daily wage earner. At that time, she was presenting complaints of behavioural problems such as aggressive kicking and head banging; she did not follow the instructions of others. She also spit on people and showed erratic behaviour towards every one. Papi Mohanty was not able to perform her basic daily living tasks independently.

After completion of assessment by the multidisciplinary team, she was diagnosed as having mild mental retardation with attention deficit hyperactivity disorder (ADHD). Due to her behavioural problems, she was unable to concentrate on her studies and other daily living activities. By implementation of a behavioural management plan through

the use of functional analysis, the problematic behaviour slowly reduced and positive behaviours increased. IEP sessions were organised to improve her personal skills. A marked improvement has been observed in her personal and social skills.

Her development convinced us to involve her in vocational training. She is going to be a self-dependent woman for her living. Her family's happiness knows no bound by watching such an improvement in their loving **Papi Mohanty.**

Success Story 14: Samarth-cum-Gharaunda (Tamil Nadu)

Name of the Organisation: ST Judes School for Mentally Challenged

Address: D.NO 5.5/ 40A1, Near RC Church, Tharamangalam, Dist-Salem, Tamil Nadu-636 502

Scheme name: Samarth-cum-Gharaunda Scheme

Name of the activity and year: 2019–20

I am Sandhya, a 26-year-old native of Sri Lanka. However, my parents lived in a camp built at Pavalathanoor for Sri Lankan refugees at Tharamangalam. My father's name is Velayutham and my mother's name Subhadhini. I have a younger brother and sister.

I was born as differently abled with mild mental retardation and brittle bone disease. After my brother and sister were born, my parents found it difficult to take care of me because as a 3-year-old, I was delayed in development milestones and still was lying down and could not sit, stand, or speak. My bones being brittle added to the difficulty they faced. My father could not bear the sight of me and hated me, which resulted in a misunderstanding with my mother.

One fine morning, my father left the family and settled with another woman elsewhere. My family began to suffer financially, and this forced my mother to take up some work. She worked as a maidservant in many houses and earned for our living. Luckily, she got an offer to work in the Middle East as a maid. So my brother, sister, and I came under the custody of my maternal grandmother who also lived nearby. My grandmother found it very difficult to take care of me single handedly, and I should say she too hated me like my father and my life became miserable.

A team from Ecomwel Orthopedic Centre as part of their community-based rehabilitation visited our camp. They saw my plight and informed the management. The very next day, I was in Ecomwel Orthopedic Centre and I was the first inmate of the St. Judes School for Mentally Challenged, a residential school. It was in the year 2000.

As a 4 year old, I entered the school literally as a vegetable and I was put through intensive activities of daily living, special education, and physiotherapy. Slowly, I started speaking and my mobility improved. However, I could not sit on the chair for more than 2 or 3 minutes as my pigeon chest hindered my breathing. The organisation made an adapted chair for me, and I started taking training to sit.

Luckily, my level of mental retardation was very mild and I could follow what my special educator was teaching. Therefore, the organisation decided to put me under normal syllabus and I was enrolled in the government school in Tharamangalam. The special teacher would teach me the lessons in the special school, and I was made to write the exams in the government school. I successfully passed 8th standard, and I could not pursue further education as the subjects were too complicated for my level. I am able to read and write Tamil fluently, and to some extent, English too. I am also good at Functional Mathematics.

After my 8thstandard, I was offered a 3-month computer course by the organisation where I learnt the fundamentals of computers, Windows, and Ms-Office. I am now placed in the vocational unit and I have learnt lot of trades such as knitting wire bags and telephone mats; making greeting cards, fancy jewellery, and embroidery; making handicraft items from waste silk cocoons and ice sticks; drawing; painting, and stitching buttons to dresses.

I can now sit on my specialised chair for more than 5 hours, and I can supervise other inmates of the school. I am also able to teach some of them. I would like to add some more information that showcased my speaking skills. I participated in the 'Arratai Aragam' (Debate) of Sun TV and spoke on the topic 'Yendha Naal Iniya Naal' (The best day in my opinion). I spoke about the World Disabled Day and why I liked it. I also participated in

the 'Azhagiya Tamil Magal' (Powerful daughter of Tamil) programme on Kalaignar TV.

I am now being trained as an Assistant Vocational Instructor, and in the near future, I will be working for Ecomwel Orthopedic Centre. What all I have learned or what I am now is all because of Ecomwel Orthopedic Centre and its staff members.

Earlier I was the beneficiary of the Samarth scheme of the National Trust, and now, I am a beneficiary of the Samarth-cum-Gharaunda scheme. I would like to thank Ecomwel Orthopaedic Centre and the National Trust for this opportunity. I would be grateful to them for my lifetime for without them I would not have been the Sandhya I am now, fully empowered, self-reliant, and dignified.

Chapter 6

Conclusions and Policy Suggestions

People with intellectual disabilities can live meaningful, satisfying, and productive lives within their own communities or in a care centre when provided adequate supports. Findings from our study appreciated the courage and dedication of families and ROs under the National Trust who have tirelessly worked to improve the lives of these deserving citizens.

The mission of the National Trust is to work towards providing opportunities for the capacity development of PwDs and their families, fulfilling their rights, and facilitating and promoting the creation of an enabling environment and an inclusive society. The National Trust's mission or fundamental purpose is to create an enabling environment, that is, providing opportunities for PwDs through comprehensive support systems, which can also be done by collaborating with other ministries, etc., thereby leading towards the development of an inclusive society. To continue the flagship schemes in coming years, it is imperative to understand the functioning and effectiveness of each scheme in achieving its basic objectives and goals and the effective utilisation of funds under each scheme. Further, due to shortage of funding, the Trust seeks to redesign some of the schemes in order to achieve maximum benefits with limited resources. Thus, in this regard, the DEPwD has entrusted NILERD to conduct a 360°evaluation study on 'Evaluation of Budgetary Support to the National Trust'.

This chapter will conclude by highlighting some of the major findings, bottlenecks in implementation, and future challenges and prospects as well as the need for more focused and consistent initiatives for the welfare and inclusion of PwDs within the mainstream ambit in the Indian context.

Niramaya:

- Majority of the beneficiaries (70.6%) belong to the rural area and the rest of the beneficiaries (29.4%) belong to the urban area.
- More than three-fourths of the beneficiaries (78.9%) belong to the southern region and the rest of them belong to all other regions. Within the southern region, Kerala alone represents84% of the beneficiaries.
- The distribution of beneficiaries of the Niramaya scheme under two income group categories indicates that more than 80% of them belong to the non-BPL income groups in the northern, western, and northeastern regions.
- Of the sampled beneficiaries, around 66% are male members and the rest are female members.
- Maximum of them (43.2%) are in the age group of 18–30 years, followed by 36.9% in the age group of less than 18 years and 15.7% between 30 and 45 years.

- More than 50% of the beneficiaries belong to the OBC group, followed by 19.3% to the SC group and 16.7% to the ST group. Only 1.6% belongs to the orphan group.
- Maximum beneficiaries have an educational qualification of upper primary (32.3%), followed by those who are illiterate (23.9%) and those who have higher secondary (15%), upto primary (14.1%), and secondary (13%) education. Only 1.2% of them have an educational qualification of graduation and above.
- Around 67% of the beneficiaries under the Niramaya scheme belong to the BPL group. Across the regions, while maximum BPL beneficiaries are from the eastern region (76.8%), the lowest percentage of BPL beneficiaries is from the western region (33.4%).
- Majority of the beneficiaries took the help of ROs to fill the form online. Around 88% of the beneficiaries took the help of ROs, whereas 12% of the beneficiaries filled the form themselves or their parents or relatives filled the form.
- A whopping 95.8% of the beneficiaries found the ROs were very cooperative during the application process. Only 4.2% of the beneficiaries were not happy with the service of the ROs.
- Majority of the beneficiaries (57.1%) got the health card within 15–30 days. Another 20.8% beneficiaries received the health card within 45–60 days.
- It takes on an average 29 days for renewing the health card. Across the region, while it takes 19 days in the northern region, it takes 30 days in the southern region. At the all-India level, majority of the beneficiaries (59.2%) reported that it takes less than 15 days to renew the health card.
- Majority of the beneficiaries (77.2%) reported that they are satisfied with the service only to some extent. Nearly 22% of the beneficiaries reported that they are fully satisfied with the service.
- Timely reimbursement of medical expenses is very important to encourage and attract people to join the scheme. Majority of the beneficiaries (78.4%) reported that their medical expenses are reimbursed in1–2 months.
- Regarding the enrolment process and re-imbursement procedures, majority of the beneficiaries gave the rating 'very good' in both the cases. Around 25%–34% gave the rating 'excellent' and 20%–27% gave the rating 'good'.
- Around 76% of the beneficiaries are fully satisfied with the overall benefits of the scheme. Around 22% of them reported that they are satisfied to 'some extent' in terms of the overall benefits of the scheme.
- In case of services rendered by the insurance company, majority of the beneficiaries (62%) reported that they are 'fully satisfied' with the services. Further, around 34% of the beneficiaries indicated that they are satisfied to 'some extent' with the services.
- Around 32% of the beneficiaries reported that they are 'fully satisfied' with the treatment offered under the scheme, while 65.6% reported that they are satisfied to 'some extent'.

- The quality of grievance service offered to the beneficiaries is strongly supported by the beneficiaries as 54.8% of them are 'fully satisfied' with the grievance services, while 43.7% of them are satisfied to 'some extent'.
- Majority of the beneficiaries (59.8%) indicated that they are 'fully satisfied' with the scheme as far as their health improvement is concerned after the subscription of the scheme. Around 39% reported that they are satisfied to 'some extent'.
- In case of learning ability, majority of the beneficiaries (53%) reported that they are fully satisfied with the scheme, followed by 43.8% who said they are satisfied to some extent.
- Maximum beneficiaries (57.9%) reported that they are 'fully satisfied' with the scheme as far as its impact on their speaking ability is concerned. Around 39% of them also indicated that they are satisfied to 'some extent'.
- Majority of the beneficiaries (58.5%) reported that the scheme has some extent of impact on interpersonal skills, whereas 37.8% of them reported that they are fully satisfied with the scheme as far as the impact on interpersonal skill is concerned.
- The scheme has a significant impact on the physical strength of the beneficiaries as 61.1% of them reported that they are fully satisfied and 28.3% reported satisfied to some extent.
- An overwhelming 91.9% of the beneficiaries agreed that the scheme has been an important source of financial support for medical treatment. Importantly, more than 90% of the beneficiaries in all the regions reported in favour of the scheme.
- A whopping 95.4% of the beneficiaries reported that they are better off than those who have not been able to enrol under the scheme. Across the regions, 100% of the beneficiaries reported that they are better off than the others.
- Only 0.2% said the scheme has not reduced their health expenditure burden, whereas an overwhelming 85.6% reported that it has partially reduced the burden and 13.8% reported it has completely reduced the health expenditure burden.

Disha Scheme:

- The regional distribution of beneficiaries under the Disha scheme shows that majority of them (41.5%) belong to the central region of the country, followed by the eastern region (16.8%) and southern region (15.6%). The lowest percentage of beneficiaries (6.9%) belongs to the northeastern region.
- In case of four types of PwDs, the highest percentage of autism cases (26.7%) is from the northeastern region. On the other hand, the highest percentages of cerebral palsy (33.3%) and mental retardation cases (44.1%) are from the eastern and central regions, respectively. The central region also reported the highest percentage of multiple disabilities cases (57.9%) under the scheme.
- Except the eastern region, in all other regions, the percentage of beneficiaries of mental retardation is the highest, which is within the range of 50%–70%. In case of

the eastern region, the percentage of beneficiaries (56.4%) of cerebral palsy is the highest, followed by those of mental retardation (35.3%) and multiple disabilities (7.3%).

- In total, 80.5% beneficiaries belong to the BPL income group of families and the rest belong to the non-BPL income group of families. Under the BPL category, the highest percentage of beneficiaries belongs to the southern region (94.1%), followed by those belonging to the eastern region (91.7%) and central region (89.1%).
- Majority of the beneficiaries are from the OBC group (43.5%), followed by the ST (33.9%) and SC (19.4%) groups. Only 1.6% beneficiaries are each from the orphan and other castes groups.
- More than 90% ROs reported that the enrolment portal of the ministry was user friendly and more than 83% of them said they did not face any difficulties while paying the fee online.
- More than 91% said that the application process was not tedious, 100% reported officers from the Ministry were cooperative during the application process, and more than 83% opined that they did not face any difficulties while trying to reach out to the concerned officer in the Ministry.
- More than 72% ROs reported that the SNAC visits their centre once every year. Around 18% ROs reported that the SNAC visits their office 1–2 times in a year.
- A whopping 69.4% beneficiaries/parents reported that they are satisfied to 'some extent' with the services of the special educator, which suggests that the services rendered by the special educator is not fully upto the mark.
- The situation is even worse in the case of a physiotherapist, wherein a significant percentage of beneficiaries/parents (30.6%) reported that they are not satisfied with the services.
- Around 55% beneficiaries/parents reported that they are satisfied to some extent.
- Maximum beneficiaries/parents (66.1%) rated the conditions of a medical room as 'good', whereas the facilities available in the medical room were rated as 'average' by a majority of the beneficiaries/parents (62.9%).
- More than 90% of the ROs had claimed funds in time and all of them had received funds in time in case of sustenance cost.
- Around 44% ROs complained that they did not receive funds in time in case of recurring cost, particularly from the financial year 2018–19 and onwards.
- Majority of them (75%) stated that the present fund amount on different heads should increase to more than 5% and the rest of the ROs pointed out that the Ministry should increase the fund amount by 5%.
- In total, 95.2% parents reported that they are sending their child to the centre for his/her betterment.

- A total of 4.8% parents reported that they have been able to attend to office/business work after sending their child to the Disha centre.
- Around 89% parents reported 'Yes', suggesting that the scheme has helped them get extra time. The extra time has also helped the parents complete productive tasks and generate more revenue as 98.2% parents are in favour of the scheme.
- Majority parents (more than 80%) reported that the learning, speaking, eye contact, and day-to-day activities of their child have improved to 'some extent'.
- A whopping 82.3% parents reported that their child is better off than other children who were left out from the scheme.

Vikaas Scheme:

- The regional distribution of beneficiaries under the Vikaas scheme is quite unequal as the highest percentages of beneficiaries belong to the central region (54.5%) and the lowest percentage of beneficiaries belongs to the northeastern region (0.2%).
- A common factor found in case of all types of disabilities is that more than 50% of the beneficiaries belong to the central region and the rest of the beneficiaries are distributed among all other regions.
- In terms types of disabilities, maximum beneficiaries have mental retardation. Its range varies from 54% in the eastern region to 93% in the western region.
- The second highest numbers of beneficiaries have cerebral palsy, and its range varies from 6.1% in the western region to 36.4% in the eastern region.
- Maximum beneficiaries belong to the BPL group in all regions other than the western region. The percentage of beneficiaries in this category of income group varies from 46.5% in the western region to 87.5% in the eastern region.
- By gender, the data shows that the male percentage is around 75% and the female percentage is 25%.
- In terms of social group, majority of the beneficiaries are from the ST group (55.8%), followed by the OBC group (30.4%) and the SC group (10.9%).
- Main occupation of the head of the household of beneficiaries points to the fact that majority of them are self-employed (43.5%), followed by those involved in agriculture (21.7%) and services (18.8%).
- Mode of transportation by children from their home to Vikaas centres indicates that majority of the children (41%) travel by their own or parent's vehicle.
- Other modes of transportation used by children are public transportation (25%) and Vikaas centre transportation (16%).
- Parents of around 33% beneficiaries reported that the centre is located between 10 and 15 km from their home. Another 32% pointed out that the centre is located between 5 and 10 km from their home.

- Maximum beneficiaries (35.4%) came to know about the scheme from newspaper advertisements, followed by 33.6% from hospital doctors.
- Majority of the ROs also indicated that they did not find any difficulties while paying the enrolment fee online and the application process was tedious. The timeline given for the enrolment process was adequate for 92.9% ROs.
- About 93% ROs reported that they did not face any difficulties to reach out the Ministry for any clarification during the enrolment process.
- Around 80% of them reported that the frequency of visit by the SNAC is once in a year and another 15% said the frequency of visit is 1–2 times in a year.
- A substantial number of beneficiaries/parents (25%–35%) reported that they were not satisfied with the services of the physiotherapist, counsellor, speech therapist, caregivers, and Ayas, which is a matter of concern as far as the quality of service is concerned.
- Maximum of them (97.8%) rated the conditions of a medical room as 'good', whereas the facilities available in the medical room were rated as 'average' by majority of the beneficiaries/parents (87%).
- Similar results were also reported in terms of conditions and facilities available in the activity and recreation rooms.
- About 90% ROs reported that they had claimed funds in time and all of them had received the funds in time in case of set up cost.
- In case of sustenance cost, a whopping 87.5% of the ROs said that they had received the funds. However, in case of recurring cost, a substantial number of the ROs (44.4%) reported that they did not receive the funds under the same head.
- Majority of them (75%) reported that the present fund amount on different heads should increase to more than 5% and the rest of the ROs pointed out that the Ministry should increase the fund by 5%.
- Around 39% parents/relatives of beneficiaries reported that they are availing the service for the betterment of their child, 34.8% reported that they can attend to household work after sending their child to the centre, and 14.5% reported that they need the service to attend to office/business work.
- Around 40% parents reported that they have been able to save and invest extra time in household or office work due to relief from child care, whereas the rest 60.1% of them did not agree to it.
- Unlike the Disha scheme in which majority of the parents reported a positive impact of the scheme on their child, the Vikaas scheme relatively failed to deliver such significant impact.

Samarth Scheme:

- The Samarth scheme witnessed a significant variation in the distribution of beneficiaries among the regions. While the highest percentage of beneficiaries belongs to central region, the lowest percentage belongs to the western region.
- In each case of types of disability, while the maximum percentage of autism cases are found in the northern region (66.7%), the maximum cases of cerebral palsy, mental retardation, and multiple disabilities are found in the central region.
- The number of mental retardation cases is the highest among the beneficiaries in all the regions, and the cases vary from 66.7% in the northeast region to 85% in the southern region.
- The second highest category of disability is cerebral palsy, and its range varies from 5.6% in the western region to 21.3% in the northeastern region.
- The Samarth scheme belongs to the BPL income group (79.2%), and the distribution of the said group of beneficiaries across the region shows that the highest percentage of them belongs to the eastern region (96.7%) and the lowest percentage to the northeastern region (46.7%).
- In total, 80% of the beneficiaries are from the rural area and the remaining 20% are from the urban area, which suggests that the scheme has focused mostly on the rural population.
- By gender, the data shows that the percentage of male members is nearly 96%. This in turn indicates that the scheme has not been able to cover more female PwDs.
- Majority of the beneficiaries are from the SC group (58.3%), followed by the ST (25%) and OBC (16.7%) groups.
- Main occupation of the head of the household is agriculture and self-employment.
- The average distance of the Samarth centre from the beneficiaries' home is 24 km. In some of the cases, the actual distance is more than 40 km, which is quite a long distance and a huddle for the families to travel and regularly meet their relatives at the Samarth centre.
- Around 29.2% of the beneficiaries' parents reported that the centre is located within 5 km of their house. A high percentage of respondents (41.7%) reported that the Samarth centre is located more than 15 km away.
- Maximum beneficiaries (60%) got to know about the scheme from the ROs.
- A total of 87.5% ROs reported that the enrolment portal of the Ministry was user friendly. About 75% of the ROs reported that they did not face any difficulties while paying the enrolment fee online, and 62.5% of them reported that the application process was not tedious.
- About 84% ROs reported that the frequency of visit by the SNAC is once in a year and another 14% said that the frequency of visit by the SNAC is 1–2 times in a year.

- Significant percentages of beneficiaries (91.7%) reported that they are fully satisfied with the services rendered by the special educator/vocational trainer.
- In total, 83.3% beneficiaries reported that the services rendered by the cook are fully satisfactory. In case of services offered by the physiotherapist/occupational therapist, around 83% beneficiaries reported that they are satisfied to some extent, while 79.2% said that they are satisfied to some extent with the services of caregivers and Ayas.
- A large percentage of beneficiaries (91.7%) reported that they are fully satisfied with the vocational training being offered to them at the Samarth centre.
- Maximum beneficiaries (66.7%) rated the conditions of the medical room as 'good', where as a higher percentage of beneficiaries (75%) also rated the facilities available in the medical room as 'good'.
- A high percentage of beneficiaries (79.2%) rated the condition of the activity room as 'good', and 62.5% of the beneficiaries rated the facilities available in the activity room as good.
- Maximum (66.7%) parents/relatives of beneficiaries reported that they are availing the service for the betterment of the child.
- Another significant proportion of beneficiaries (29.2%) reported that they are availing the scheme to attend to household work.
- In terms of the impact of the Samarth scheme on time, work, and income of the parents, the scheme helped a substantial percentage of parents (83.3%) save and invest extra time in household or office work due to relief from the responsibility of the child.
- Further, majority of the parents (88%) agreed that their child is better off than other children who have been left out from the scheme.
- Majority of the parents (83.3%) reported full improvement in the day-to-day activities of beneficiaries. In case of eye contact and body balance and improvement in speaking ability, majority of the parents viewed that the condition of beneficiaries improved to some extent.

Gharaunda Scheme:

- Across the regions, the highest percentage of Gharaunda beneficiaries is from the central region (56.6%), followed by 18.7% in the eastern region, 12.5% from the southern region, and 3.2% from the northeastern region.
- Maximum beneficiaries belong to the central region, and this range varies from 50% in case of autism to 63.6% in case of multiple disabilities.
- Around 71.8%–91.6% beneficiaries belong to the mental retardation category of disability, and 4.1%–22.5% beneficiaries belong to the cerebral palsy category of disability.

- Across the region, the percentage of beneficiaries from the BPL income group varies from 50% in the northeastern region to 95.6% in the central region. A maximum percentage of beneficiaries belong to the mental retardation category in all the regions.
- Majority of the beneficiaries under Gharaunda scheme are from urban areas. The percentage of male members is nearly three times that of female members at the Gharaund a centre.
- Half of the beneficiaries belong to the OBC social group, followed by 25% who belong to the SC group and 18.8% who belong to the ST social group.
- The general and orphan groups represent 4.2% and 2.1% of the beneficiaries, respectively.
- Nearly 18% of the beneficiaries are from the age group of 18–30 years, followed by 25% from the age group of 40–50 years and 12.5% from the age group of 30–40 years.
- Educational qualification of the beneficiaries suggests that maximum beneficiaries are illiterate (45.8%). Beneficiaries with primary-level and upper primary-level education, respectively, represent 29.2% and 16.7% of the sample.
- More than 56% of the beneficiaries reported that the centre is located between 10 and15 km from their home. Around 29% beneficiaries reported that the centre is located between 5 and10 km from their home.
- Majority of the beneficiaries (58%) stated that they came to know about the scheme from the ROs.
- The second important source of information was awareness programmes, where 10% beneficiaries had received the information. The percentage of beneficiaries who had received information from hospital doctors and relatives is 5% and 3.3%, respectively.
- A significant percentage of beneficiaries (75%) reported that they are fully satisfied with the services rendered by the special educator/vocational trainer.
- About 50% beneficiaries reported that they are also fully satisfied with the services of caregivers/Ayas.
- In case of services offered by the physiotherapists, around 71% beneficiaries reported that they are satisfied to some extent, while 18.8% said that they are fully satisfied with the service.
- In total, 45.8% beneficiaries reported that they are fully satisfied with the vocational activities carried out at the centre, and an equal number of beneficiaries are satisfied with these activities to some extent.
- Maximum beneficiaries (85.4%) rated the conditions of the medical room as 'good', whereas an equal percentage of beneficiaries reported the facilities available in the medical room as 'good'.

- A higher percentage of beneficiaries (60%–75%) rated the condition and facilities in the activity and recreation rooms as 'good'.
- In total, 91.7% beneficiaries reported that safe drinking water is available at the centre.
- A total of 89.6% beneficiaries expressed that hygienic toilets and bathrooms are available, and 93.8% of them reported continuous supply of electricity to the centre.
- In total, 87.5% beneficiaries stated that adequate infrastructure is available at the centre.
- Maximum (47.9%) parents/relatives of beneficiaries reported that they are availing the service to attend to house work.
- A significant proportion of beneficiaries (43.8%) also said that they are availing the scheme for the betterment of their child.
- As far as the impact of Gharaunda scheme on time, work, and income of the parents is concerned, the scheme helped 45.8% parents to save and invest extra time in household or office work due to relief from the responsibility of the child.
- In total, 86% parents/relatives reported that they have used the extra time in productive work, and as a result, their income has increased by 5%.
- Majority of the parents (77.1%) agreed that their child is better off than other children who have been left out from the scheme.
- Majority of the parents reported that the learning ability of their child has improved to some extent.
- A total of 30%–50% of the beneficiaries also rated their condition as fully improved with respect to learning ability, eye contact, and performing day-to-day activities.

Success Stories of PwDs:

- It is critical to document the success stories of individuals and case study of institutions working for the improvement of PwDs with the support from different schemes under the National Trust, which will help inform and give insights into the barriers and challenges to empowerment of PwDs.
- This knowledge will then help design, execute, and monitor better empowerment of PwDs and promotion of programmes and polices related to PwDs in India. It would also provide the relevant knowledge base required to influence policymakers, state governments, and research institutions for extending their support to PwDs for empowerment.
- The findings from the success stories and the challenges faced by the ROs will further be useful in the modification and improvement of the schemes.
- The success story of the little girl Afrin Khatun under the Disha scheme from West Bengal, Ms. Sandhya under the Samarth-cum-Gharaunda scheme from Tamil Nadu,

and Mr. Rajesh under the Disha-cum-Vikaas scheme from Gujarat are heart touching examples of nothing is impossible if we take care of their childhood and groom them with proper care.

Bottlenecks

- The present insurance amount under the Niramaya scheme cannot cover the requirement of the PwDs and should be increased. The scheme can be linked with the best insurance company that clears the claims of the PwDs on time.
- Early identified children who are below 3 years of age cannot avail the benefit of this scheme just because a disability certificate is not issued for children.
- The most important part of the development of a beneficiary is therapy, but its coverage charges offered is Rs. 10,000 per year, which is very less. This amount should be increased under the Niramaya scheme. The scheme should also include aid and appliance in the coverage area.
- Many technical problems are faced while submitting the application. Even after transferring fees online, it does not reflect in the system. Therefore, the ROs have to follow-up repeatedly and provide details by emails and on phone calls. There should be a help desk at the National Trust for providing assistance to the ROs.
- The system does not generate the latest status of the application if there are any deficiencies in the application. This can be rectified at the end of the National Trust.
- Many disabled people so far have not been enrolled in the schemes because of the lack of knowledge of the scheme. Awareness regarding the schemes under the National Trust should be increased and should focus more on rural areas.
- The insurance company does not reimburse the claim timely and rejects many bills.
- Reimbursement amount is quite less compared with the amount the parents actually spend for the treatment of their children under the Niramaya scheme.
- Transport bills are difficult to arrange. This head should be given unanimously in the Niramaya scheme.
- Beneficiaries covered under the scheme should be given the benefit of this scheme free of cost. No premium of any kind should be taken from the beneficiary.
- Poor people usually do not have enough money for emergency medical expenses of their child under the Niramaya scheme. Hence, a cash voucher of Rs. 10,000 may be allowed to mitigate the medical expenses at emergency.

Policy Suggestions:

On Awareness:

- ✓ Ministry should allocate more funds for promoting different schemes of the National Trust through non-governmental organisations (NGOs) working in the field of intellectual disability.
- ✓ For awareness the State government can also play a major role in faster spreading information on different schemes of the National Trust.
- ✓ Advertisement through television, social media, workshops, and seminar will be more beneficial in terms of achievement of more coverage of all the schemes of the National Trust.
- ✓ Some mechanism should be implemented at the village level to spread awareness about the scheme and the process to get the benefits under the scheme.
- ✓ More advertisement brochures printed in Hindi/English and local languages should be given to the ROs for distribution among the PwDs and their parents.
- ✓ For effective awareness generation, the State Department of Social Welfare needs to be involved.
- ✓ Awareness should be created to the Social defense department, physiotherapists and pediatricians' clinics, as well as schools and village panchayats.
- ✓ The Badhte Kadam scheme should be sanctioned to all ROs for awareness generation.

On Implementation:

- ✓ The claim settlement process should be faster in the Niramaya scheme. For this, a cashless card may be issued in place of reimbursement.
- ✓ Special online treatment should be provided to students with intellectual disability, especially those are not able to come to the centre.
- ✓ The place where the disability certificate is issued such as CDMO etc., should have some information or address of the nearest RO where enrolment can be done.
- ✓ The scheme should be a cashless voucher of Rs. 10,000as maximum beneficiaries are from the BPL category and do not have the capacity to pay the bills of treatment in advance.
- ✓ In the absence of NGO's support, PWDs from villages find it difficult to avail the scheme. For example, while filling the claim form with proper bills and required documents such as medical certificate, ration card, bank passbook, and Niramaya health card. In such cases, NGO's role is very important.
- ✓ Enrolment charges may be waived off. There should be no restriction on the type of diseases. All types of medical problems should be considered under the scheme.

- ✓ The rule to submit claims within 30 days may be relaxed to 3 months so that the claim for OPD medicines and therapy charges can be claimed quarterly. The insurance agency contract should be renewed every 3years so that better service can be ensured.
- ✓ The insurance company should respond to the queries and reimbursement process on time. Also, the documentation process should be user friendly. The process of cancel cheque should be banned in reimbursement of medicines.
- ✓ The state government has the entire data of PwDs. The scheme will be more efficiently implemented under the government. The scheme will be implemented through ROs, but the process should be recorded and fostered under the PwD department of each state government.
- ✓ The district's Social Welfare Department should be involved in the enrolment of PwDs under the Niramaya scheme in whichever district the ROs are unavailable. Thus, one can avail the scheme at their district level itself rather than approaching other district officials.
- ✓ The hospitals involved in the process of issuing a disability certificate should also be given an authority to enrol PwDs into the Niramaya scheme. This will also help parents to avail the scheme at their nearest landmark.
- ✓ Registration application needs to be done at the beginning of the month of the year and the insurance card should be issued immediately.

On Funding:

- ✓ In Niramaya, the enrolment fee of Rs. 40 is not sufficient and should be increased to Rs. 200 for the ROs, and this amount should be provided on time.
- ✓ The sum amount of the insurance should be increased to Rs. 4 lakhs under the Niramaya scheme, and the bifurcation of the amount on different heads should be removed.
- ✓ Eye problems and women's reproductive problems are currently not covered under the Niramaya scheme. However, they should be included.
- ✓ The reimbursement should be within 15–20 days, or cashless insurance can be introduced.
- ✓ Coverage therapy charges should be increased. The PWDs need more amount for OPD as some of the PwDs have serious health problems.
- ✓ There should be an instant reimbursement process (at least on a quarterly basis).
- ✓ General treatment under this scheme must be extended.
- ✓ For OPD, the limit may be extended from Rs. 15,000 to 20,000 under the Niramaya scheme.
- ✓ The amount Rs. 8,000 for medication under Niramaya is not sufficient since a lot of PwDs are on treatment involving neurological drugs. It should be at least minimum Rs. 50,000/- yearly.

- ✓ Now-a-days, all pedagogy is on smart class and through e-learning. The National Trust should provide systems such as smart board, laptop, projectors, and tablets under the Vikaas scheme.
- ✓ The funding pattern of the Gharaunda scheme should be can be modified. It will pay for the same number of LIG (including BPL) PwDsas above LIG enrolled beneficiaries in the scheme. This funding pattern of the Gharaunda Scheme wherein the RO has to maintain a ratio of 1:1 for LIG (including BPL) and above LIG PwDs makes it difficult to enrol PwDs who are in actual need of the scheme, that is, BPL and LIG. Those who can pay are able to find other support. If the cap on the ratio can be removed, the National Trust and the required Gharaunda scheme holder would be able to help a larger number of PwDs.
- ✓ Under the Disha-cum-Vikaas scheme, the APL beneficiaries should also get some financial benefits.

On Application Process:

- ✓ The ROs feel that the online application process can be made more simple and easily accessible for them.
- ✓ The health ID of every beneficiary should be issued at the earliest so that they can get the benefits of the policy.
- ✓ To follow-up the process of application at the National Trust, there should be a designated help desk.
- ✓ Premium charges for all beneficiaries under Niramaya should be waived off.
- ✓ The beneficiaries are to be renewed every year. Duration of renewal can be extended.
- ✓ The applicant should get an intimation as soon as his/her application gets processed under Niramaya.
- ✓ The Ministry may send circular to all the banks to allow all PwDs to open their account with zero balance to get the benefits under Niramaya.
- ✓ It would be easier to cover all categories of PwDs for claiming the benefit. It should be covered by a health card, allowing the beneficiaries access to free treatment and medication.
- ✓ Offline/manual enrolment of Niramaya may be permitted directly other than through the ROs.