

Swabhiman: A Social Entrepreneur's Struggle for Disability Equality

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Abstract

The case describes the struggle of a social entrepreneur to bring about changes to make disability equality a reality in Odisha and the country. The case focusses on the two decades of journey of Swabhiman, the State Disability Information Centre founded by Dr Mohapatra. It describes the story of how she enabled a movement through the Centre by taking on the responsibility for counting of PWDs by training the volunteers for accurate enumeration. The case may be used to develop awareness about RPWD Act 2016 and creating sensitivity among students towards issues of inclusion of PWDs.

Key words: *people with disability, equality, inclusion, policy, census, social entrepreneurship.*

Introduction:

Sitting in her office room Dr. Sruti Mohapatra looked at the wall. The vision and mission statement of Swabhiman, the organization she had founded, hung on the wall, stared back at her. Crafted in 2001, the statements continued to guide her in trying to achieve an inclusive society, equitable and just for persons with disabilities(PWDs).

As she had stated in the profile of disability prepared by Swabhiman in 2012 for the state of Odisha in 2012; "My vision is of an inclusive world. I believe we can dream of a utopia and making it a reality. We can and must create an inclusive world, a world where the human spirit of co-existence triumphs over discord and a world in which we are all able to live a life of wellbeing and dignity. I invite you to use the evidence in this report to help this vision become a reality. Together, we can make a difference."

More specifically, the vision and mission statements of Swabhimaan reflected this ideology and read as follows

Vision: People with disabilities are equal partners in all respects and in all fields.

Mission: To strengthen the disabilities movement through research, training, advocacy, and public education for full and equal participation of people with disabilities in the country's mainstream.

It was two decades since Swabhiman started . It was started at a time when there was no policy , no dedicated state machinery to look after the interests of the people with disabilities (PWDs). Even in the census, people with disabilities were not identified or enumerated. Dr Sruti and her team had sustained this journey with wholehearted commitment and dedication to the stated purpose of their organization.

Since then, Swabhiman had come a long way in this struggle and had been able to bring about several changes in policy, governance, law, practice, capability building etc. However, the goal of changing the mindset of people to mainstream disability remained distant. Although there had been some progress in employment of PWD's in government sector, the private sector remained behind in adopting a policy of inclusion for providing gainful employment to PWD as per guidelines of the RPWD Act, 2016.

The Need for an Organization like Swabimaan

When Dr Sruti started her journey, disability as a concept was not clearly defined. Data was not available on distribution of PWDs in the state and the country to compare with other nations or states regarding the incidence and trends in disability. Whatever meagre data was available could not be retrieved for compilation and consolidation purpose due to lack of proper documentation. The status of PWDS were invisible to policy makers and stakeholders. Identification of PWDs was a challenge as family members did not report them. Consequently, the needs of persons with disabilities largely went unaddressed in India and Odisha. As a result, the PWDs did not have access to basic amenities such as healthcare, education, and employment opportunities. Their exclusion from everyday activities was all encompassing as regards persons with disabilities in Odisha.

The need for an organization as a source of information relating to all aspects of disability led to the establishment of Swabhiman, in December 2001 , in Bhubaneswar, as a disability information and resource centre. Swabhiman started with the purpose of advocating and establishing a life of self-respect, dignity equal opportunities , for disabled people.

Over the years Swabhiman, had emerged as a leading voice speaking up for the empowerment of people with disabilities. As a State Disability Information and Resource Centre, Swabhiman provided various services and much needed support and guidance to the disabled community. Swabhiman commenced with the idea people needed information more than that more than the paltry disability pension. With information in hand, at the right time, they could avail of the opportunities provided by government – be it pension, scholarship, houses, assistive device, or concessions. As more people became empowered with information, they were conscious about the violation of their rights.

Swabhiman then initiated a process of influencing public policies, by liaising with both the government and civil society on the one hand and motivating the PWDs to raise their voices on the other. This was the precursor of setting up a network of like-minded PWDs, NGOs and parents (OSdN-Odisha State disability Network). All the learnings from NDN – National Disability Network, was put to practice in OSdN and in a matter of time it was a force to reckon with in Odisha in serving as an advocacy platform that mobilized PWDs and their parents against human rights violations.

Swabhiman runs several programs across areas such as law and policy, education, health, sports, employment, accessibility, general awareness, etc. Started with a meagre sum of INR 156 thousand , Swabhiman has grown manifold in its ability to generate funding for its work, which stood at INR 24448 thousand in March 2017 (see **Exhibit 2**). Given the large number of disabled people and the lack of facilities for them, Swabhiman was taking a multifaceted approach to bridge the gaps. It had a special focus on children and young adults so that future generations have a better chance at inclusion.

Dr Sruti Mohapatra : Her Experience and the Genesis of the Idea

As a social entrepreneur experiencing disability when an accident left her quadriplegic in 1987, Dr Sruti was in the forefront of disability movement in Odisha and India. *“There were no laws in India in 1987 to protect my rights. When I lost my job, I had no laws to protect it. When I was being disqualified because my disability, there were no anti-discrimination laws to help me build my case. I learnt in training in New York, tireless grassroots advocacy and determined communitywide education would prove to be essential agents for meaningful change.”* She made it her goal to build awareness and advocate the cause of the disabled. She

Swabhiman

wrote letters to concerned departments regarding status of disability in the state and the country and what could be done. Being a voracious reader and agile learner, she learnt from her experience from worldwide travel about the steps taken by developed countries towards equal treatment of persons with disability. Sustained advocacy with right knowledge and patience, networking and awareness programs changed the landscape of disability in India & Odisha. The first law was enacted in 1995.

Dr Sruti started by volunteering with the Odisha Red Cross, visited several rehabilitation centres and was actively involved in the struggle for equality and dignity of persons with disability. She also joined the disability movement in India for advocating the passage of the Disability Act in Parliament. The National Disability Network (NDN), India chapter of DPI(Disabled Peoples International) was established in 1996. As an active member she traveled worldwide to observe and understand the quality of life of PWDs around the world.

To educate herself further, she attended conferences and addressed meetings on disability as a thought leader. Struck by the visible difference between the lifestyle of PWDs in India, South Asia, and Western countries, she made it her life goal to improve the conditions of people with disabilities in India. She got involved with disability work at grassroots after the super cyclone of 1999 in Odisha. In her words “ *In 2000 I had an opportunity to visit Erasama with the team from Action Aid, the NGO working in the area. The death, destruction and suffering of people devastated me. I could not fathom the depth of suffering of those disabled by the cyclone and those who were earlier disabled and now mutilated by the cyclone.*”

In June 2000 she attended the twenty-third special session of the General Assembly on "Women 2000: Gender equality, development and peace for the 21st century" at the United Nations Headquarters in New York as a delegate of DPI Regional Chapter. She spoke and interacted with many small groups and discussed about the issues faced by women with disabilities. She then realized the importance of inclusion and henceforth became a staunch protagonist advocating the concept of 'an inclusive world'. She emphasized and explained how exclusion caused by 'comprehensive relative deprivation fosters inequality at both social and economic front'. Creating inclusive structures was essential to become leaders at any level ; community, region or the country to foster equality of opportunities for all.

Swabhiman's Approach Towards Working for PWD

The idea to establish an NGO to work for the cause of disability occurred to Dr Sruti while working with Action Aid in 2000. Swabhiman was born in the residence office of Dr Sruti as a registered non-profit organization. A *triple 'A'* approach was adopted by Swabhiman in its endeavor to make PWDs visible and included as equal and dignified members of society :

- i. Addressing the enumeration challenge.
- ii. Advocacy for disability rights
- iii. Awareness programmes to spearhead inclusion.

i. Addressing the Enumeration Challenge in Census. It was discovered that budgetary allocation for the developmental needs of PWDs was necessary. However, the number of such persons were not counted in the census as a category for such allocation. Further research by Swabhiman led to the awareness that had never been counted. This led to several persuasion and discussion with the Census commissioner and other important government officials and ministers. Finally, the decision was made to count PWD numbers in 2001 Census. After the counting PWDs became a segregated visible statistic (1.9%) in the population data for claiming allocation of resources from the budget.

However, that was not the end. It was found that the counting was faulty, as it was done in a hurry and there was no time to train the enumerators. The major challenge was the social stigma attached to disability due to which families did not disclose the information about PWDs. Learning from the challenges of 2001 census, Swabhiman was better prepared for enumeration in 2011. The challenge was not only for the enumerators who visited the households, the challenge was also for the families to grasp the significance of counting and inclusion in Census data. Families had to be made aware that by disclosing the information and making the person visible, fund allocation for the PWD's wholesome development could be made possible.

The Census Commissioner was open to inputs from the disability sector to get accurate data about PWDs. Here, Swabhiman played a key role in providing such information to the Census Commissioner in Odisha. It collaborated with other such organizations in India for ensuring the accuracy by advocating the cause of PWDs. With inputs from disability sector, the question on having disability was moved from number 15 to number 9 and modified for clarity

in the census survey held during 2011. Also, categories of disabilities were increased from five to eight in 2011 census (**see Exhibit 3**).

Publicity campaign. Alongside a systematic publicity campaign was launched with posters, workshops, print and electronic media for people to come forward and support counting of PWDs. This created a positive atmosphere for the enumerators who could ask the question on disability with relative ease and build awareness at the same time. Swabhiman collaborated with Regional Census office, NGOs, and state machinery to support and encourage families of PWDs to come forward and give accurate data in Odisha.

State Level Consultation led by Dr Mohapatra, was attended by various stake holders, the PWDs, NGOs, Community based organizations, disability activists and govt officials. The campaign was launched with tagline of world Disability Day(3rd December) ; ‘Get yourself counted’. Disability counting was given a priority in the Census of 2011.

Training of Enumerators. Swabhiman joined hands with Census Officials voluntarily to be part of the census process in training district officials and master trainers for counting PWDs in Odisha. Young Volunteers of Swabhiman travelled across the State to build awareness and appeal for accurate counting. The training module was translated in Odia. A three-day training and mock drill sessions were held in Swabhiman Office in Bhubaneswar, the State capital. Handouts were prepared in Odia to help explain non counting of PWDs in Odisha and question number ‘9’ dealing with disability counting. In Odisha, the training schedule allocated 2 hours for disability counting as against national average of one hour.

In 2011 successful groundwork led to accurate enumeration. As a result, Odisha showed a higher percentage of PWDs (2.9%) than the national average (2.1%) in total population.

ii. Advocacy and Campaign for Disability rights. Swabhiman’s advocacy approach was for a) addressing violation of human rights, b) bringing about policy level changes and c) strengthening the capacity of NGOs and DPOs in Odisha on disability laws and rights. The challenge before Swabhiman was to spearhead constructive structural level changes for accessibility, establishment of a separate department for disability, appointment of a disability commissioner, initiating policy level changes and unifying NGOs and DPOs (Disabled Persons’ Organization) to strengthen the movement for disability equality.

From a no law scenario, Swabhiman has spearheaded movements in the last two decades to establish rights-based laws for disabled in India, a separate department for disability

in Odisha and creation of a post for a Commissioner of Disability, inclusion of disability as a separate category in the national census, making polling booths accessible, and, the formation of India's new disability rights law, the RPWD Act, 2016. Dr Sruti's consistent advocacy for accessibility for PWD's led to construction of ramps in public places, wheelchair accessible bathrooms in schools, airports and shopping malls, provision for sign language interpreters in schools, audio books and braille support. (see **Exhibit 4**)

iii. Awareness Programmes to facilitate inclusion. Swabhiman's initiatives towards building awareness among people of Odisha for inclusion of PWDs in all aspects of life with equality and dignity was commendable. The aim of the disability awareness programs was to educate people to do away with the negative attitude towards disability and making them aware that; despite disabilities they could live productive and constructive lives.

Initiatives of Swabhiman to Build Awareness and Inclusion

Swabhiman started several initiatives to build awareness and inclusion.

Anjali Festival. This is an International Children's and Youth Festival that spreads awareness about disability inclusion, rights of children with disabilities, joyful and inclusive learning, and sensitizes youth to become ambassadors of the cause.

Sashakt. This is a multi-level, multi-stakeholder campaign to build awareness on new law on disability (RPWD Act 2016), the existing government facilities for PWDs, and create awareness for an inclusive and accessible environment in society at large.

Prerana Samman. Prerana Samman honors students with disabilities who have secured 75% or above mark in the matriculation examination and +2 examinations. This is a state level program which inspires students with disabilities to strive for excellence in an environment where books and teachers are scarce for students with special needs.

IDD and other Awareness days celebration. Swabhiman and OSdN partners celebrate the International Day of Disabled Persons on December 3, every year, to promote the rights and well-being of PWDs in all spheres of society. Swabhiman celebrates the other days as well such as Braille Day, Autism Day, etc

Art for Change. Art for Change is celebrated in March, after the school finals were over. Children, disabled and non-disabled, would spend a day together creating art in many mediums on issues of environmental importance.

We Can Dance , Sing. We can Dance , Sing is held in mainstream schools in March-April every year. Children and youth with disabilities perform for students in regular schools.

Educational Initiatives. As youth with disabilities were not adequately prepared with the life skills needed to succeed in an increasingly interconnected 21st century society and economy; Swabhiman focused on building their capacities, inculcating leadership qualities, and preparing them to get good career opportunities. It also has numerous educational initiatives.

- Project Adhyayan was an education movement, dedicated to improving the quality of learning of students with disabilities. Education was one of the most effective ways to break the cycle of discrimination and poverty that children and youth with disabilities often face. Project Adhyayan's vision was to provide a support system where every child and youth with disability could grow up healthy and educated to reach their full potential, get employment, and live with dignity.
- Anjali Scholarships for College Students, Teacher Support to Special Schools, Saksham Educational Support for School Students from Slums, Audio Books Production and Braille Books Printing were some of the major initiatives undertaken by Swabhiman for capacity building of persons with disabilities.

The Way Ahead?

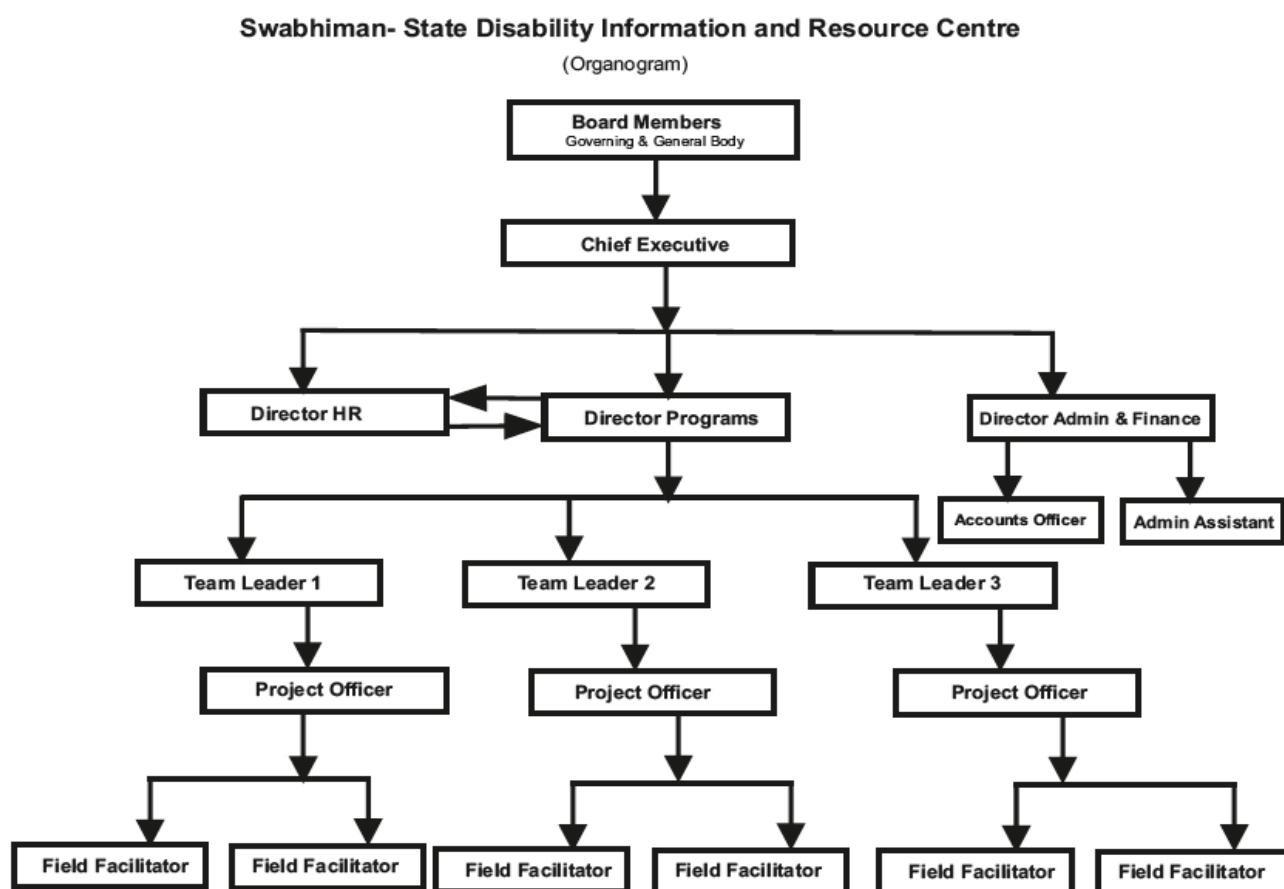
Swabhiman had come a long way in planning and implementing a multipronged strategy to not only make disabled persons visible in numbers but also to demonstrate their ability as dignified members of the society. In the process it had joined hands with various organizations such as Aditya Birla group , Site Savers, National Centre for Promotion of Employment for Disabled People (NCPEDP), Times of India, Saikat India, Labscrafts Creation, Smart Hospitality, various NGOS and the Government for advocating the cause of the disabled. The interventions undertaken for achieving disability equality spanned from distribution of assistive devices , physio and speech therapy provisions, health care of leprosy affected PWDs, sexual and reproductive rights of PWDs, achieving quality education, livelihood support, accessibility,

sensitizing people, students for inclusion of PWDs besides providing right information as the State Disability Information Centre.

Dr Sruti reflected on the journey so far. She was satisfied that she had been able to contribute to making disability visible in the state and the country. She was able to contribute towards crafting of policies and procedures of making disability equality a right to recognize. But she had not made much progress in changing the mindset of private sector towards disability and employment of PWDs. Building the right attitude towards disability seemed to be a herculean task. RPWD Act 2016 mandated 4 percent reservations for PWDs in both government and private sector. However, the effort in private sector to fill up the 4 percent reservation for PWDs was yet to take off. The PWD representation is below 0.5 percent in private sector in India as reported by Business standard (see **Exhibit 5**)

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Exhibits

Exhibit 1 : *Organogram of Swabhiman*Exhibit 2 : *Income of Swabhiman March 2002 to 2017 (in thousands in INR)*

Year	Income	Year	Income	Year	Income INR	Year	Income
2001-02	157	2005-06	1237	2009-10	1699	2013-14	5486
2002-03	105	2006-07	779	2010-11	3559	2014-15	5659
2003-04	659	2007-08	223	2011-12	5137	2015-16	12264
2004-05	1207	2008-09	1356	2012-13	5581	2016-17	24448

Exhibit 3: The Change incorporated in the Census Question*Census 2001:*

Q. 15 asked if the person is physically /mentally disabled, if so, give appropriate code number to identify, must be mentioned from the list below (Table I)

Table I from Census 2001

Type of Disability	Code
In Seeing	1
In Speech	2
In Hearing	3
In Movement	4
Mental	5

*Census 2011:***Q. 9: Disability**

9 (a) Is this person mentally/physically disabled? Yes- 1/ No- 2

9 (b) If 'YES' in 9 (a), give code in the box against 9(b) from the list (Table II):

9 (c) If multiple disability (Code 8) in 9 (b), give maximum three codes in the boxes against 9 (c) from the list (Table II)

Table II from Census 2011

The five categories were increased to eight categories as mentioned in Table II below.

Type of Disability	Code
1. In Seeing	1
2. In Hearing	2
3. In Speech	3
4. In Movement	4
5. Mental Retardation	5
6. Mental Illness	6
7. Any Other	7
8. Multiple Disability	8

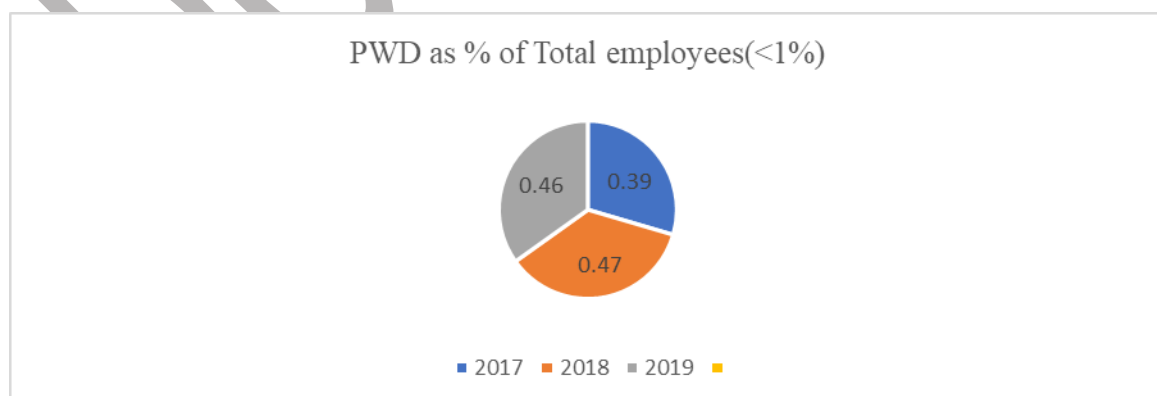
The question on disability had been moved up from No. 15 in sequence to no. 9 which gave it greater visibility as shown below(Box-1)

Disabled Population in India as per census 2011 (2016 updated) – In India PWDs constitute 2.21% of the total population.

(Source: <https://enabled.in/wp/disabled-population-in-india-as-per-census-2011-2016-updated/>)

Exhibit 4: Major Achievements

- The Rights of Persons with Disabilities Act 2016 – Drafting, monitoring progress, protesting delays and unnecessary changes, lobbying with MPs, MLAs, ministers, bringing civil society, parents, and individuals together to ensure passage in both houses of RPWD Act in December 2016.
- For the first time in India, a minister was designated as Minister for Disability in 2009, in Odisha.
- Designation of Disability commissioner and notification though secretary WCD(Women & Child Development) department was appointed.
- Appointment of independent State Commissioner for Persons with disabilities in Odisha 2010.
- Transfer of disability from WCD(Women & Child Development) Department to a directorate and finally setting up of the SSEPD (Social Security & Empowerment of Persons with Disabilities) department - 2014
- As member of NDN contributed to the ratification of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) - 2007
- As member of NDN worked towards inclusion of disability as a separate category in the Population Census of 2001. This was the first time ever that disabled people got counted in the Census.
- Played a frontline in voting process made accessible for people with disabilities, though journey was long from 2004-2019.
- As member of NDN contributed to submission of Stakeholder’s Report on Disability for India’s Universal Periodic Review
- As member of NDN contributed to submitted Parallel Report on Disability for India’s CEDAW review
- As member of NDN contributed to submitted Parallel Report on Disability for India’s CRC Review
- In 1998-99 initiated the ramp culture in India
- The only state in India to have two medical boards in a district.
- 3% Reservation in Panchayati Raj Schemes in Odisha

Exhibit 5: PWD as Percentage of Total Employees

Source: https://www.business-standard.com/article/companies/persons-with-disabilities-form-less-than-0-5-of-staff-in-india-s-top-firms-119111200206_1.htm