

Like us



Report:

**A Seminar on Serving Children with Special Needs**

August 2 and 3, 2019

Kamladevi Complex

India International Centre

New Delhi

Supported by The Rockefeller Foundation, New York



**INDIA INTERNATIONAL CENTRE**



## About Prabhat

India has the world's largest concentration of people with physical, mental and multiple challenges. The Prabhat Education Foundation has been serving children with special needs and their families since 2003 in some of Ahmedabad's most deprived locations. Beginning with one child, it now reaches out to some 3,000 persons. Prabhat offers a unique approach that begins through door-to-door identification of special children and families through area surveys conducted with expert guidance. It then offers a range of services that begin at home and continue up the ladder of counseling, assessment, therapy, education, vocational capacities, access to other specialist services, and to official schemes as well as to rights guaranteed by legislation. The emphasis is on inclusivity, ensuring that the special child can find opportunity irrespective of her physical, mental, social and economic condition.

13 years ago, Prabhat started on its journey when it found a disproportionate concentration of special children and families living in extremely inhospitable conditions in disadvantaged areas like Danilimda, Vatva and Lamba in east Ahmedabad. The mental and physical challenges have included the loss of faculties (eyesight, hearing, and speech), other physical problems (such as immobility due to paralysis), autism (a reduced ability to respond or communicate), Down's syndrome (mental and physical abnormalities due to a chromosome defect) and combinations that can manifest as multiple disorders.

Prabhat offers its services through three main programmes:

Prabhat Centres

Community-Based Rehabilitation

Advocacy through Networking



## Contents

Foreword: Poonam Natarajan	4
Introduction : Keshav Chatterjee	5
Agenda	8
Participants	13
Executive Summary	17
Seminar proceedings: a detailed record of seminar discussions on Community-Based Rehabilitation and Inclusive Education	29
Acknowledgement	Inside back cover

## Foreword

**Ms Poonam Natarajan** (Former Chair, National Trust and Founder of Vidya Sagar, Chennai)

The Like Us seminar organised by the Prabhat Education Foundation (Ahmedabad) in partnership with the India International Centre (New Delhi) has been a welcome opportunity for those serving children with special needs to come together and take stock of where we are today and where we want to go – as well as how best to work together toward our goal. That goal is a more inclusive society that gives every child the right as well as the opportunity to grow and to flourish. The so-called disability sector is so diverse, and the time at our disposal was limited. We therefore took a decision to focus on two aspects, community-based rehabilitation (CBR) and inclusive education (IE). Both are key priorities for many of us. This report brings together the richness of experience and reflection that emerged over two days. It includes many pointers to the way ahead, recorded here as action points. Hopefully, the dialogue that began at LIKE US can now be sustained not only among those who could come together at the seminar in New Delhi but also to others who can share this report and draw on it. I particularly hope that this report can reach those engaged with policy decisions at the centre in the states. That is where awareness and understanding can be so critical to our future. I also hope this will be a start for other opportunities for collective review and action. There is so much to be done to improve what we do on the ground, and then to address the challenge of more effective policy action and implementation. Recent years have seen a transformation in the legislative framework that applies to those with special needs, yet another transformation remains of bringing what is on the books to the actual service of children and families in need. The reality of their lives and hopes was brilliantly communicated to us in the work of photographer Bindi Sheth. Her Like Us photo-exhibition provided a backdrop to our discussions, reminding us constantly of those who wait.

I would like to thank the Prabhat Education Foundation, the India International Centre and all those who gave so much time and energy toward this effort of learning together. Here is an agenda for follow-up and action. The challenge now is to sustain and expand this network for sharing. Our unity of purpose may be the most important strength we now have to move ahead.

**Poonam Natarajan**

Vidya Sagar, Chennai  
September 2019  
[poonatish@gmail.com](mailto:poonatish@gmail.com)



## Introduction

**Mr Keshav Chatterjee** (Director, Prabhat Education Foundation)

The LIKE US two-day seminar at the India International Centre in New Delhi has been an opportunity to bring together experiences from several parts of the country to encourage mutual learning and partnership toward a more inclusive and just society. The seminar was made possible by a grant from The Rockefeller Foundation (New York) to enable the Prabhat Education Foundation to share its experience over 15 years through home and community-based services, and to draw on others toward strengthening service to special children and their families in some of Ahmedabad's most deprived locations. We were most fortunate to have the mentorship of Ms Poonam Natarajan in organizing the seminar. As former Chair of the National Trust for the differently able and Founder of Vidya Sagar (Chennai), Poonam Natarajan has been a guide to Prabhat from its earliest days, giving us the courage to persevere within so many constraints of awareness and resources. Our very limited means has meant that we were able to bring together only those in and around the Delhi area to strengthen a network of cooperation on behalf of special children and their families.

Understanding and responding to the needs of special persons demands greater priority in India, home to the world's largest concentration of people with physical, mental and multiple challenges. A watershed development has been the Rights of Persons with Disabilities Act 2016, which fulfills India's obligations under the UN Convention on the Rights of Persons with Disabilities. The Act became operational in April 2017, offering new opportunities for special persons as citizens with equal rights. We decided to explore through this seminar how this Act and the joint experience of participants can now be brought more directly to the service of children and families in need, and in two priority areas: CBR and Inclusive Education. We explored new developments and directions in such key areas as Early Intervention, awareness and information, parental support (with particular focus on mothers and siblings who bear much of the responsibility for care and encouragement), therapy, vocational opportunities and exercising the citizen right of access to services. The seminar sought ways to transform the future millions from despair to an ability to grow as citizens and to contribute, just LIKE US. The backdrop to the seminar was a photo-exhibition on the world of the children and families Prabhat serves in Ahmedabad, created by Bindi Sheth who immersed herself in these communities for months and then created this wonderful experience of caring and of hope. That is the spirit that has sustained Prabhat over these years, encouraging it to share and draw strength from others.

When a special child is born, the entire family's lives must revolve around the child. In our country, their situation is often exacerbated by poverty, lack of awareness, and distance from sources of support, treatment, education and vocational skills. Girls, mothers and siblings often bear the greatest burden of all. By building better systems of support through this exchange of experience, Prabhat would like this report to now take the seminar outcome to

others across the country and help build stronger networks and partnerships in a sector of such great need.

I would like to thank Ms Poonam Natarajan for her guidance, the India International Centre for their wonderful support and facilities, the Rockefeller Foundation for making this opportunity possible for all of us, Bindi Sheth for recreating through her photos the ground on which Prabhat serves, and to all the participants who gave us so much of their time, energy and wisdom. My colleagues at Prabhat have worked over months to make all this possible, and we hope this report will prove of real use and will help open the doors to ways in which we can serve and learn together. Please feel free to contact us at the links below.



**Keshav Chatterjee**

Prabhat Education Foundation, Ahmedabad  
September, 2019  
[keshav@prabhateducationfoundation.org](mailto:keshav@prabhateducationfoundation.org)





# Agenda

## Day 1

### CBR: building support from homes and communities

Duration	Session	Details	Facilitator
9:30 – 10:00	<b>Registration</b>		
10:00-10:05	Introductory remarks		Ms. Hasyalatha Mehta, Trustees, Prabhat Education Foundation
10:05 – 10:10	Introduction of the chair		Mr. Ashoke Chatterjee, Trustee, Prabhat Education Foundation
10:10 – 10:25	Seminar purpose	The focus on two aspects of a very diverse sector -- CBR and inclusive education -- using the Prabhat experience to kick-start reflection. The purpose is to share experience and learn from each other toward a more inclusive society. While the needs of special children and their families are many, in these two days we will try to focus on two aspects of experience in Ahmedabad and elsewhere which have significance for all who work in this sector. These aspects are community-based approaches to serve those with special needs in deprived locations, and the challenge of education and training opportunities for these citizens.	Ms. Poonam Natarajan, founder Vidya Sagar, Chennai and former Chair, National Trust Govt of India.
10:25 – 10:45	Participant introduction	Name, affiliations and expectation from the workshop	Mr. Narayan Menon
10:45 – 10:55	Like Us	The backdrop exhibition to the seminar: a brief introduction by Bindi Sheth on the experience of putting together a photo-exhibition on the lives of special children and their families, and what this experience has taught Prabhat.	Ms. Bindi Sheth & Mr. Keshav Chatterjee



10:55 - 11:10	Quick Q&A	To get responses on this joint collaboration and work out opportunities for guided tours of the show during these two days and the days that will follow.	Ms. Bindi/Mr. Keshav/ Mr. Narayan
<b>11:10 - 11:30</b>	<b>Tea/ coffee break</b>		
11:30 - 11:45	Introductory observations	on the two dimensions of CBR and inclusive education	Ms. Sumitra Misra (Mobile Crèche)
<b>Focus Session: CBR: building support from homes and communities</b>			
11:45 - 12:00	Presentation, Prabhat Education Foundation	Introduction to the process of home-based rehabilitation and community-mobilisation in some of Ahmedabad's most deprived locations	Mr. Keshav Chatterjee, Director Prabhat Education Foundation
12:00 - 12:20	Q&A	On Mobile Crèche and Prabhat Education Foundation experiences	
12:20 - 12:35	Presentation, Jan Madhyam	On what experience suggests as key issues/concerns in these two areas.	Ms. Jolly Rohatagi, Founder, Jan Madhyam and Ms. Ranjana Pande, Founder Jan Madhyam
12:35 - 12:50	Presentation, Astha	CBR experiences in Delhi	Ms. Radhika Alkazi , Director Astha
12:50 - 1:05	Presentation, Action for Ability Development and Inclusion (AADI)	AADI CBR experience in Delhi, AADI	Ms. Renu Anuj, Director, Rural CBR AADI
1:05 - 1:30	Q&A	On experiences of Astha, AADI, and Jan Madhyam	
1:30 - 2:00	Quick summary	Quick summary of presentations from Ahmedabad and Delhi, followed by an open discussion on CBR	Ms. Poonam Natarajan

		experiences and lessons learned.	
<b>2:00 – 2:45</b>	<b>Lunch break</b>		
2:45 – 4:00	Open Discussion	On CBR experiences, inviting comments from all participants	Ms. Poonam Natarajan
<b>4:00 – 4:20</b>	<b>Tea break</b>		
4:20 – 4:50	Summing up & Concluding remarks from the Chair	Key take-aways from CBR experiences shared. What directions emerge as future CBR priorities? What do these priorities need by way of experience, training, support? Who should be involved? What sources of learning and support can we identify? What partnerships can we make/are needed for the coming years?	Ms. Poonam Natarajan & Mr. Ashoke Chatterjee
4:50 – 5:00	Introduction to day 2: Inclusive Education, announcements and closure		Mr. Narayan

## Day 2

### Focus Session: Education for those with special needs: The challenge of inclusion

Duration	Session	Details	Facilitator
<b>9:30 – 10:00</b>	<b>Registration</b>		
10:00 – 10:05	Welcome note		Mr. Narayan
10:05 – 10:10	Quick recap of Day 1	on CBR experiences, and the link with today's theme	Mr. Ashoke Chatterjee
10:10 – 10:30	Presentation, St. Mary's School	Experience of inclusion in a mainstream school	Ms. Mary Mansukhani
10:30 – 10:45	Presentation, Vidya Sagar, Chennai	Introduction to the challenge and the experience of inclusive education	Ms. Poonam Natarajan
10:45 – 11:00	Prabhat's experience in building inclusion in Ahmedabad	Video on Buddy interaction at Riverside School and insights into the impact this beginning has made on others in the city.	Mr. Keshav Chatterjee
<b>11:00 – 11:20</b>	<b>Tea/coffee break</b>		
11:20 – 11:35	Latika Roy Foundation's experience in Dehra Dun		Ms. Sumita Nandan, Chief Operating and Child Protection Officer, Latika Roy Foundation
11:35 – 12:15	Q&A	On the Vidya Sagar/Prabhat/Latika Roy Foundation experiences	
12:15 – 12:30	Experience at CBM		Mr. Kumar Ratan
12:30 – 1:00	Q&A	CBM experiences	
<b>1:00 – 1:45</b>	<b>Lunch Break</b>		

1:45 – 2:00	Recap of the day		Mr. Ashoke Chatterjee
2:00 – 2:20	Panel discussion	What should inclusion really mean?	Dr. Sara Varughese, Director, CBM. Moderated by Ms. Poonam Natarajan
2:20 – 2:30	Open time	For intervention needs and discussions	
2:30 – 3:00	Summing up	Key take-away from experiences shared. What directions emerge to practice and promote inclusion? What support is needed? What support is available? Who should be involved? What partnerships can be made/are needed for the coming years?	Ms. Poonam Natarajan
3:00 – 3:30	Thank you note, announcements and invitation to view the photo exhibition		Mr. Narayan
<b>3:30</b>	<b>Tea/coffee break</b>		
4:00	Guided tour of Like us – photo exhibition		

## Participants

	Name	Organization	Email
1	Ms Abha Ranjan	Occupational therapist	abha.r9@gmail.com
2	Mr Abhishek Gupta	Jamia Millia Islamia, New Delhi	
3	Mr Ashish Gupta	Advocate, New Delhi	advashishgupta2018@gmail.com
4	Prof Ashoke Chatterjee	Prabhat Education Foundation, Ahmedabad	ashchat@prabhatedu.org
5	Ms Bharti Mirchandani	Designer	2manavi@gmail.com
6	Ms Bhavnisha Kherala	Prabhat Education Foundation, Ahmedabad	prabhat@prabhateducationfoundation.org
7	Ms Bindi Sheth	Photographer, Ahmedabad	bindiparekh@gmail.com
8	Mr Binod Kumar	Astha, New Delhi	binod@asthaindia.in
9	Ms Divya Wesley	Prabhat Education Foundation, Ahmedabad	divya@prabhateducationfoundation.org
10	Mr Gajinder	Advocate, New Delhi	advgsthakoral@yahoo.com
11	Ms Gita Ranjan	Indian Institute of Public Policy, (IIPP), New Delhi	info@iipp.in
12	Ms Hasyalatha Mehta	Asha School, Ahmedabad	hasyamehta@gmail.com
13	Mr Indrek Roy	Architect, New Delhi	tuhinsilvaroy@gmail.com
14	Ms Jolly Rohatagi	Jan Madhyam, New Delhi	info@janmadhyam@gmail.com
15	Ms Kanta Mehra	India International Centre, New Delhi	programme.iic@nic.in
16	Dr Kapila Vatsyayan	India International Centre, New Delhi	asiaprojectiic@gmail.com

17	Ms Karuvaki Mohanty	Iprobono, New Delhi	karuvaki.mohanty@i.probono.com
18	Mr Keshav Chatterjee	Prabhat Education Foundation, Ahmedabad	keshav@prabhateducationfoundation.org
19	Mr Kumar Ratan	Christian Blind Mission (CBM), New Delhi	kumar.ratan@cbm.org
20	Ms Lakshmi	Parent, Prabhat Education Foundation, Ahmedabad	
21	Ms LS Tochwawng	India International Centre, New Delhi	cpd.iic@nic.in
22	Ms Mary Mansukhani	St. Mary's School, New Delhi	marymansukh2005@gmail.com
23	Ms Mirai Chatterjee	Self Employed Women's Association (SEWA), Ahmedabad	social@sewass.org
24	Ms Nabeela Rizvi	Centre for Media and Alternate Communication (CMAC), New Delhi	nabeela.rizvi@gmail.com
25	Mr Narayan Menon	Prabhat Education Foundation, Ahmedabad	sunar2426@gmail.com
26	Ms Nargis	Parent, Prabhat Education Foundation, Ahmedabad	
27	Mr NH Ramachandran	India International Centre, New Delhi	asiaprojectiic@gmail.com
28	Mr Nirmal Verma	Christian Blind Mission (CBM), New Delhi	nirmal.verma@cbm.org
29	Ms Pamela Chatterjee	Activist, Kausani	pikichat@gmail.com
30	Ms Poonam Natrajan	Vidya Sagar, Chennai	poonatish@gmail.com

31	Mr Prahlad S Shekhawat	Alternative Development and Research Centre, Jaipur	prahl24@yahoo.com
32	Mr Pranav Shah	Prabhat Education Foundation, Ahmedabad	phshahhd@gmail.com
33	Mr Pranav Sheth	Activist, Ahmedabad	
34	Ms Purnima Singh	Activist, New Delhi	singhpurnima@hotmail.com
35	Ms Purnima Rai	Sohanlal Charitable Trust	purnimarai02@gmail.com
36	Ms Radhika Alkazi	Astha, New Delhi	radhika.alkazi59@gmail.com
37	Mr Raj Bala	Jan Madhyam, New Delhi	info@janmadhyam@gmail.com
38	Mr Raj Gorasia	Prabhat Education Foundation, Ahmedabad	Raj@prabhateducationfoundation.org
39	Mr Rajesh Tandon	Participatory Research in Asia (PRIA), New Delhi	rajesh.tandon@pria.org
40	Mr Ram Dhiraj	Jan Madhyam, New Delhi	info@janmadhyam@gmail.com
41	Ms Ranjana Pandey	Jan Madhyam, New Delhi	info@janmadhyam@gmail.com
42	Ms Renu Anuj	Action for Ability Development and Inclusion (AADI), New Delhi	aadi@aadi-india.org
43	Ms Reena	Mobile Crèches, New Delhi	mail@mobilecreches.org
44	Ms Richa Sharma	The Shri Ram School, New Delhi	richa.sharma@tsrs.org
45	Ms Seema	Astha, New Delhi	seema@astha.in

46	Ms Seema Kumari	Jan Madhyam, New Delhi	info@janmadhyam@gmail.com
47	Ms Sejal Anand	Prabhat Education Foundation, Ahmedabad	prabhat@prabhateducationfoundatio.org
48	Ms Shibani Jajodia	The Shri Ram School, New Delhi	shibani.jajodia@tsrs.org
49	Ms Silva Roy	Bani Jagtiani Trust, New Delhi	tuhinsilvaroy@gmail.com
50	Ms Smiti Pathak	Delhi Council for Child Welfare, New Delhi	simipthk88@gmail.com
51	Ms Sophie Ahmed	Luba Hamid Children's Foundation, Mumbai	sophie.cerc@gmail.com
52	Mr Suheil Tandon	Pro Sports Development, New Delhi	suheil.tandon@prosportdev.in
53	Ms Sumita Mishra	Mobile Crèches, New Delhi	sumitra.m@mobilecreches.org
54	Ms Sumita Nanda	Latika Roy Foundation, Dehradun	sumita@latikaroy.org
55	Ms Sunetra Deshpande	VoxPopuli, Ahmedabad	sunetra.deshpande@gmail.com
56	Mr Tarun Handa	Parent, New Delhi	tarunhanda@gmail.com
57	Ms Viswesh Murthi	Ashoka University, Alumni Riverside School, Ahmedabad	
58	Mr Vivek Daphtary	Consultant, Dubai	vivek.daphtary@gmail.com



## Executive Summary

### Day 1

The Seminar opened with an opportunity for the participants to tour the LIKE US photo exhibition<sup>1</sup> created by photographer Bindi Sheth on the world of the children and families served by Prabhat in deprived slum areas of eastern Ahmedabad. Bindi Sheth shared her year-long experience of immersing herself within this community, and its impact on her growth as a person, as an artist and as a professional. Prabhat's growth over 15 years was then summarized, leading from one child then to serving community of over 3,000 today. It is this experience that had inspired the idea of sharing through the photo exhibition invited to New Delhi by the India International Centre and the opportunity this offered of bringing sector colleagues together to share experiences, concerns and forge partnerships for all that needs to be done in a country where the scale of disability is so huge.

Discussions were flagged off by Ms Hasyalatha (Prabhat Trustee). She hoped that the discussion over two days could bring participants closer to the goal of inclusion: "let me be part of society and not apart from society". She estimated that in India almost 8M children under 19 lived with disabilities and 75% of these under the age of five years are deprived of education. In the age group between 5-19 years 25% of the CWD population is denied education. The scale of the challenge exists despite the RTE Act 2009 and the RPWD Act 2016. The challenge was clear.



<sup>1</sup> Like Us can be viewed on <https://prabhateducationfoundation.org/like-us/>

Setting the purpose of these two days, seminar Chair Ms Poonam Natarajan (Former Chair, National Trust, GOI) indicated that while the seminar would narrow its focus to CBR and inclusion, the need was to look at disability through a life-span approach. Out of 640 districts in the country only 256 have DDRCs. Even where services exist the child and the need are seldom regarded holistically: “rehabilitation is not just for the child or the adults closest to her but for everybody within her community”.



### **CBR<sup>2</sup>-Building Support from Homes and Communities**

Experiences shared included the work of Mobile Creches with migrant construction labour and the challenge of serving children and families on the move. From Ahmedabad, the Prabhat CBR experience had a focus on home-based outreach strengthened with community support as well as the huge challenges of certification. Jan Madhyam demonstrated the power of media and the performing arts within the communication challenge for change. Astha identified information deprivation as a critical factor as well as the need to integrate disability with the community’s other service requirements. The AADI experience brought in rural challenges, where implementation of legislation and policy remains poor.

Scale was a significant issue which persisted throughout the discussion, against a backdrop of huge need and the sense that each institution’s efforts often seems a drop in the ocean. Yet the need in this sector is for quality inputs rather than a rush for numbers. This becomes critical in the reality that each child and each family represents a specific need, and there are no standard solutions. Within this was another concern of understanding a life-span approach to include the prime concern among parents and care-givers: what happens once we are gone? The need for lifetime care and protection was essential to ensure against special persons being dumped or locked up in what are mistakenly called ‘homes’. Building this kind of societal understanding and support demanded that issues of special needs come out of a silo approach and be worked into other development agendas (including health, education, employment, rights) of other development workers and across government authorities. With this is the increasing need for advocacy with the medical profession, which so far has been limited in its understanding and empathy. This has become more critical with the movement toward privatization, and the threat that comes with that of reduced access to low-cost



<sup>2</sup> CBR: Community-Based Rehabilitation

services from government. Another issue in the life-span approach is building vocational opportunities that can be tailored to individual needs. A basic question is that of cost. While NGOs might seek low-cost options, should the demand instead be for public investment on scale the sector requires? In an environment of such rapid change, stakeholders are being challenged in terms of their innovative capacities, knowledge and funding levels and of impacting the overarching systems and policies upon which the wellbeing of special persons ultimately depends.



Another challenge is that for many development is a concept attached to infrastructure, not to human wellbeing. Therefore issues of special needs seldom arise within the development discourse. The opportunity now is to build advocacy strategies that take advantage of the inclusion of disability in the UN's Sustainable Development Goals (goals 4, 4.5, 4.7, 11 and 17.18) in the targets established for inclusion, equity, quality education, life-long learning, humane cities and SDG implementation. As a signatory to the SDGs, India has accepted a responsibility that the sector can now use toward greater priority as well as regular measurement of progress.

This opportunity underline the importance of building a collective vision within the sector that can impact policy and investment. Working for change demands action at so many levels of society beginning at home and building up to national policy. Concerns expressed were that in recent years

been India's movement seems to be that of slippage rather than progress. CBR efforts would need to take into account not only the diversity of individual/ family/ community needs but their inter-sectoral implications including those of education, health, water, sanitation, housing and employment. At the ground level a life-span approach that starts at 0 years requires Cadres



of trained workers and specialists, beginning within neighbourhoods and communities to build acceptance and responsibility. The family (and most particularly who so often are made to bear the burden of guilt and stigma) as the core of rehabilitation process demanded the need to build multi-purpose workers who could encourage a convergence of services, lift the knowledge base, demystify what often passes as specialization and reach-out local support systems of which schools and doctors are such critical elements. The absence of sustained referral systems is often the most immediate challenge, demanding huge efforts to provide linkages and certification. While discussions reflected experience that was largely urban, the future demanded recognition of rural needs as well as the changing patterns of villages, peri-urban centres and cities. Within this was the need to reach out to migrant children and

families, with whom contact can so often be limited in terms of time and location. New needs were emerging such as the impact of social media, of dealing with sexuality and gender, of attention to building sources of accurate information and providing security to the most vulnerable. These demands are well beyond the capacities of individuals and organizations. It is this that gives importance to opportunities such as this to build partnerships within the sector and with those outside the sector whose support can be essential to our goals.

Inclusion understood as a societal responsibility and empowered parents, aware of their rights, emerged as core goals. Within this is the need to build support system for the mother and the community, innovating vocational opportunities, and utilizing whatever experience exists in order to stretch scarce resources to maximum use. These goals require the availability to take maximum advantage of media opportunities that can build advocacy and help share critical information with those for whom the scarcity of reliable information is so often a challenge.

At the policy and donor levels, issues of scale are often encountered and pressure is most often to look at quantities rather than at qualitative issues. Given the complexity of the sector and the reality that few solutions can be easily replicated across such a diversity of situations, the importance of sharing learning and experience becomes critical. Discussions pointed to the need for activists to ensure that the child is seen as a whole person whose wellbeing depends on ending her isolation and providing opportunities for growth. It needs understanding that



inclusion starts at home and within the community, with all that community mobilization demands from activists and systems Rehabilitation efforts must include all who live in the proximity of the special child. This in turn demands EI as a permanent part of CBR and adopting a lifespan approach that takes into account the critical years between 0 and 6, and moves up to vocations as well as concern for security in adult years. To provide such change, the responsibility for NGOs will be to build multi-purpose workers who can cope with this diversity of essential needs. This includes the need for building smoother and stronger referral systems Training opportunities, building information services, RCI certification safeguards and the capacity to draw on other development agencies through partnerships emerged as essential to real change. Convergence is needed in the understanding if disability within other NGOs working in the so-called 'development' sector as well as within several Government departments and ministries will be essential if convergence of services is to take place on the ground. In addition, disability needs to move out of its current invisibility into accepted public accountability and responsibility. The SDGs offer a significant advocacy platform to demonstrate the inter-sectoral nature of our challenge. Yet how is advocacy on such a scale to succeed when human and financial resources are so limited? The immediate opportunities through such a gathering may be through joint action through sharing of

experience and information and partnerships for advocacy and mobilisation toward mechanisms and systems that seem to be holding back a sector with such huge implications for national wellbeing.

### Where can we go from here?

The focus on CBR on Day 1 suggested these actions/opportunities for change, which can be taken up at an individual/institution basis as well as form an agenda for joint action as a follow-up to the seminar:



- Adopt a rights-based approach in partnership with other activists, based on training on rights established by the Constitution and by legislation, so as to increase awareness of rights and remedial options, among families and institutions. This may need a White Paper to help educate stakeholders, perhaps through partners like the Centre for Social Justice (Ahmedabad) and others.
- Prioritise the need to reach parents (most particularly mothers) and local communities with awareness and knowledge.
- Address the critical need for building robust systems of referral through knowledge, partnerships and advocacy.
- Work out systems to update partners with new knowledge and information, including through the effective use of social media.
- Explore the rich possibilities that exist for using local and other performing arts to share knowledge as well as to influence attitudes and behaviours.
- Demystify 'specialised' knowledge which can so often be intimidating for those less informed, helping them to take ownership of knowledge and accurate information.
- Build cadres of multi-purpose workers who are trained to understand the child as a whole person, not just as one with special needs, and can work with families, communities and local systems (e.g. educators, administrators, doctors, community leaders, anganwadi and ASHA workers) to build local awareness and support.
- Develop parents and local community persons as a 'first cadre' for counseling, therapy and learning as well as role models to inspire hope and confidence.
- Empower anganwadi and ASHA workers with knowledge on special needs. This can help them to identify and refer those in need as well as to support the child and the parent.
- Help create more specialists for this sector. Identify and help build resource institutions for training therapists, counselors, special educators and others. This might require partnerships beyond local or state resources.
- RCI certification systems need attention and reform. A small working group might be needed to identify what needs to be done and how best to proceed.
- Monitoring and evaluation (M&E) skills are needed to help activists measure progress as well as to communicate effectively with those whose support they need. 'Scale' is often a preoccupation of donors, yet statistics cannot communicate the empathy and care which are at the heart of this sector. This makes M&E critical to communicate

the need for qualitative indicators, such as influence and demonstration, as even more important than mere counting of numbers. So many of the experiences recounted at the seminar point to the power of what can be achieved by changing the life of one child, mother or family. M&E can help communicate this, going beyond anecdotal reporting.

- The seminar has demonstrated the strength as well as the need for building 'communities of practice' in the sector of special needs. These can bring stakeholders together and help build the networks that are needed for change.
- The private sector is emerging as a major player in the sector's future, within government's obsession with privatizing health care. There is a need to reach out to private practitioners with opportunities for sensitization and training, as they seldom have any knowledge or exposure to special needs.
- While working with the private sector, joint advocacy is needed to ensure that government does not abandon its responsibilities as enshrined in the Constitution and in legislation. The White Paper referred to above could be a start for mobilization, bringing seminar participants and others together in partnership to represent the sector at policy levels in states and at the Centre.
- The access that those with special needs require is not only to services specific to special needs. Their urgent requirements include water, sanitation, shelter and other basics. This underlines the need for sector activists to network with other development workers, so that the needs of special persons is integrated into their agendas.

## Day 2: Education for those with special needs: The challenge of Inclusion

Seminar discussion on CBR had underlined the critical importance of educational opportunities as catalysts for hope, for encouraging achievement among special children and for mobilizing families and communities toward the broader goal of a just and inclusive society. Education, the school and the educator are clearly at the centre of this vision.



Seven institutional experiences were shared across 6 states: St Mary's (New Delhi), Vidya Sagar (Chennai), Prabhat (Ahmedabad), Sri Ram (Gurgaon), Latika Roy Foundation (Dehra Dun), CBM (New Delhi and elsewhere), and APD (Karnataka). Each faces issues others share, including widespread misunderstanding on the role of the special educator as well as managing both inclusion as well as attention to special needs. Change was also needed within existing national systems (such as the RTE Act, SSA and the NIOS). There have been slippages from past progress due to bureaucratic changes as well as new attitudes toward government's prime role in the sector, including the rise of privatization. In dealing with challenges, the clear consensus was on the importance of working with and mobilizing families as the foundation for real change.

At *St Mary's*, the focus is on getting all administrative and teaching staff on board with a common understanding of inclusive education, and activating this from the admissions process. *Vidya Sagar* serves children drawn from the city as well as Chennai's environs, with preparation for entry into the mainstream as a prime strategy. This is supported by networking with 19 schools in this region. *Prabhat* too makes mainstreaming a prime goal, and supplements this with its unique experiment in 'Buddy Interaction' which brings the mainstream child and the special child into opportunities for mutual learning and above all for sustained friendship. 'Buddy Interaction' has spread from one school to 3 others while more schools have been sensitized to take on outreach on their own. *Sri Ram School* has a record of no drop-outs. Updating the knowledge and skills of educators and staff has helped ensure joint ownership of systems of support that began with the establishment of Learning Centres, leading to classroom integration and then to innovating combinations in response to need. Alternative and functional curricula offer subject choices and streams including NCERT and NIOS. The special educator is central throughout this process, to help ensure sustained the contact toward life-skills, vocational options and a child's sense of confident independence. *Latika Roy Foundation's* early intervention (EI) policy begins at 0 years, and has included assessment of high-risk newborns at local hospitals. Walk-in assessment facilities and home support are backed by a school and child development centre serving some 300 children, as well as contact with schools toward mainstreaming. Advocacy on behalf of those with special needs includes exchange programmes, a lecture series and the formation of a Dehra Dun Disability Forum. *CBM* offers insights into the largely invisible needs of rural children and communities. Mainstreaming objectives are facilitated by turning special schools into resource centres, and supported by linkages with ICDS, rural anganwadis,

disabled peoples' organisations (DPOs) and a network of some 3,000 schools. APD concentrates on 6 districts in Karnataka to promote EI and to provide resource support for parent training, and the promotion of evidence-based best practices through an inter-disciplinary approach. To help ensure a uniform quality of service, APD includes issues of rehabilitation, capacity-building and advocacy.



IE challenges on the ground were demonstrated by the intervention of Mr and Mrs. Handa, parents of Vardhan. They recounted despair and frustration at each step of their struggle to find a place for their son the mainstream of care and education. Poonam Natarajan pointed that at least some of their sense of hopelessness was ill-founded. Vardhan's capacity to move toward an independent adulthood seems not to have been fully understood. She said a critical element in such efforts is contact and rapport with teachers and taking their perspectives into full account. The contacts made at the seminar could perhaps help support the Handa family and Vardhan in moving ahead, and participants looked forward to news of that. Vardhan asked for an opportunity to speak as well as to sing for this audience!

The Handa family's experience made real the central importance of understanding the child as a whole person, with abilities as well as disabilities. Many recalled encountering the attitude that 'nothing can be done, this child can't learn'. This was compounded by so much misunderstanding about the links between special education and mainstream education, and of the role of the special educator as a bridge between them. Creating a supportive environment through all teachers and staff as well as building strong cadres of special educators was a challenge mainstream schools must face in their commitment to inclusion. This has to be an enduring process with regular opportunities for updating knowledge and skills in a changing environment. In turn, all this can demand a commitment from school governance that reaching out to children with special needs should be regarded as a responsibility, not a choice.

External elements can impact the ability of the special child to remain in school. A common experience is the difficulty children and families to accessing aids and appliances essential for mobility into schools, and then to regular maintenance. Without regular adjustment according to a child's growth, discomfort and pain can lead to appliances being discarded. Immobility then leads on to dropping out of school.



If mainstream schools have a responsibility, it is national and state education that should set the pace and provide the models and the support. This is not happening, and changing macro level policy can require



mobilisation toward creating greater understanding and political will. An example cited was advocacy of Activity-Based Learning (ABL) within the Sarva Siksha Abhiyan (SSA). Change might need to start at Boards of Education which today focus on academics rather than on a child's growth as a person. Today IED remains separate and IED officials lack authority. In practice the RTWD does not favour inclusive education. The RTE bill offers no guidelines for special education, and its amendment to include home education does not reflect the demands of special education at home. Again, there are no standards and no guidelines to give the concept of home-based special education any rigour. As a result what happens on the ground can be sloppy and damaging. The New Education Policy (NEP) pays little attention to this sector. Even more worrying has been the experience of slippages, of moving backward rather than ahead. SSA is an example. In 2008 Government decided that NGO supports were not required, removing at one stroke an effective support system, leading to rising drop-outs after Class 8. In Jharkhand and Karnataka, special education resource centres have been closed.

These factors point to the lack of understanding within the national and state systems that govern this sector. Special education is under Welfare rather than Human Resource Development where other education is centered. In addition there is a need for several Departments and Ministries to converge in their understanding of the sector and the need for joint action toward its requirements. There is little evidence that these authorities ever speak to one another on the issues of disability that impact access by children, mothers and families to a whole range of services including water, sanitation, power, shelter, employment, social justice and rights.

Discussions underlined the importance of advocacy action that can impact policy at several levels. Critical among these are the authorities concerned with SSA, RTE, IED, NIOS and the NEP so as to make their provisions more understanding and friendlier toward the special child. Among these needs is to bring NGOs back as prime partners with government efforts. Another is to review RTE and SSA from the perspective of the child after Class 8, reform of the NEP approach to home-based education so as to make it a real option and not a farce. The latter may require NGOs working together to develop home-based standards and guidelines. Special schools should be 'mainstreamed' as part of Departments and Ministries of HRD rather than being relegated to Welfare. Boards of Education need to be reformed to be more aware and sensitive to the need for special education and its requirements.

Advocacy on this scale can be well outside the capacity of individual institutions. The initiative will need to come from civil society, as there is little



indication of aggressive government action to make special needs a national priority. This calls for collective action and joint mechanisms. The seminar could serve as a first step toward articulating what needs to be done in each major area of policy reform, then moving on from there to interaction with decision-makers at the Centre and in the states. Without such organized joint action, an effective advocacy strategy may be difficult to achieve, and the sector's environment may remain lethargic. A White Paper could be prepared on the needs of CBR and IE, drawing on the seminar outcome.

Apart from what needs to be done at the macro level, many opportunities had been identified to move ahead for improving services on the ground. The seminar had underlined the importance of training opportunities to help up-date knowledge and skills, particularly among educators and mothers. Lifting human resources through capacity-building could benefit from sustained sharing of experience among partners, as this seminar had exemplified. Identifying and sharing local and regional resources for sharing could offer a start. The forums established in Dehra Dun offer an example. Joining existing sector networks can be an immediate resource, some of which are identified below<sup>3</sup>. Mainstreaming efforts can draw on experiences like the 'Buddy Interaction' innovation in Ahmedabad (that address such important and often invisible needs of friendship and acceptance) and locality-based, easily-accessible systems for providing and maintaining aids and appliances that facilitate mobility and inclusion. Using the Tony Booth index<sup>4</sup> can enable activists to strengthen M&E capacities. The rural sector can remain neglected with current activity and experience being largely urban based. What can be done to partner with rural institutions as CBM has done, in order to understand how to reach and serve the rural child and her family? While CBR and IE were a deliberate focus in a short span of two days, other priorities demand attention. One of these is the top-of-mind anxiety for parents is to find an answer to the 'After us, what?' It reminds one of the importance of influencing broader social policies across the land. New opportunities such as Khelo India and financial independence for mothers had been flagged through interventions by Pro Sports and SEWA.



Participants were unanimous in the hope that this opportunity could lead on to sustained contact and partnership through a follow-up mechanisms that could report back on progress and concerns. Meanwhile, the Seminar Report and Proceedings could be shared with key stakeholders where participants are located and through them with others. A special effort

---

<sup>3</sup> National Disability Network: [http://www.ncpedp.org/National Disability Network \(NDN\)](http://www.ncpedp.org/National%20Disability%20Network%20(NDN))

Disability NGO Alliance: <http://www.disabilityngosalliance.org/>

Parivaar: <http://www.parivaarnfpa.org/>

National Centre for Promotion of Employment for Disabled People: [http://ncpedp.org/National Committee on the Rights of Persons with Disabilities](http://ncpedp.org/National%20Committee%20on%20the%20Rights%20of%20Persons%20with%20Disabilities)

<sup>4</sup> Ms Poonam Natarajan was involved in the research project with Tony Booth "Index to Inclusion" which can be used to evaluate a school's progress toward inclusion.

will be needed to get the Report and Proceedings to decision-makers in New Delhi, using the good offices of participants based in the capital and of the India International Centre which had hosted this opportunity.

### **Agenda for action**

The following points emerged as follow-up to the discussions:

- There is an urgent need for the form within the existing national education systems so that special education is correctly understood and supportive. This includes review of the NEP, SSA, RTE Act, NIOS and other systems operating at central and state levels, including review of current ministerial and departmental systems of governance and authority. A White Paper might help a collective approach to the Centre and at state levels.
- There is a need to ensure that Government continues to accept a central role for the quality of inclusive education in the country, in the face of increasing privatization.
- Privatization of school education demands reaching out to the private sector and building its capacities for understanding, sensitivity and real care.
- Special children in rural and peri-urban areas need to be reached.
- Interaction and partnerships with mainstream schools emerges as an important experience to be strengthened and extended. A focus is needed on building opportunities for friendship between special children and others.
- The role of the special educator requires greater understanding, opportunities for upgrading knowledge and skills is an urgent requirement.
- Schools can be encouraged to draw up on emerging role models of inclusive education so as to sensitise and train all educators and staff on roles and responsibilities.
- Use of the Tony Booth index can encourage better understanding of standards that are needed for inclusive education.
- Building local forums of local support can provide strength and support advocacy.
- New opportunities are opening for the use of sports to empower special children, including Khelo India.

## Other inputs

SEWA shared its experience in building collective mechanisms among women, which could be used to address some of the financial concerns of mothers. Mirai Chatterjee of SEWA suggested the possibility of bringing mothers of special children together in income-generation activities, as had been done by mothers and special educators in Turkey. There an analysis of needs had led to cooperative/collective efforts covering multiple revenue-generating activities including craft and food retailing as well as tourism. Marketing had been the challenge, and these groups had succeeded in mobilizing support from local business communities. Ms Chatterjee offered SEWA's support to any who would like to explore this possibility ([miraichatterjee@sewa.org](mailto:miraichatterjee@sewa.org)).

*Pro Sports* explained new opportunities emerging from a concept of 'unified sports' which adapts traditional sports to special needs. Suheil Tandon explained that this concept could be readily integrated with the Buddy Interaction scheme available in Ahmedabad. Another opportunity could be to mobilise the Khelo India programme toward inclusion, and to give the Special Olympics and the Para Olympics greater visibility, perhaps with CSR support. ([suheil.tandon@prosportdev.in](mailto:suheil.tandon@prosportdev.in))



## Seminar proceedings: A detailed report

### Day 1: CBR – Building Support from Homes and Communities

#### Welcoming remarks: Ms Hasyalatha Mehta, Trustee, Prabhat Education Foundation

**“Let me be a part of society and not be apart from society”.**

A warm welcome was extended on behalf of Prabhat Education Foundation to the Chairperson Ms Poonam Natrajan and all the other participants, speakers and guests by Ms Hasyalatha Mehta, Trustee of Prabhat Education Foundation.

Ms Mehta shared the ground realities of the Right to Education Act 2009 and the Rights of Persons with Disabilities Act 2016. Along with being a progressive Act there are many challenges in the rightful implementation of the same.

As per the Education report an analysis of the current situation indicates that an estimated 7.8 million children aged under 19 live with disabilities. 75% of the children with disabilities under age of 5 years do not go to any educational institution and nor do 25% of the CWD population aged between 5 and 19 years.

The question of getting education suitable to their needs is yet another area which is not covered. From her experience she shared that in India voluntary organizations and parents have mainly been the force behind the progress achieved in this field. Even before these laws they have been working relentlessly at different levels with passion and devotion along with professionalism amassing a rich and varied experience.

The Seminar organized by Prabhat is a platform for facilitating

- Interaction, which can lead to possible solutions towards successful rehabilitation and inclusion
- Sharing of ideas, knowledge and experiences – both good and the not so good
- Sharing concerns and issues
- New and useful technologies
- Develop new partnerships and perspectives
- New direction and impetus in the work towards facilitating the differently-abled, their families and communities and for marching forward towards realization of their full potential, independence and inclusion.

#### Introduction: Prof Ashoke Chatterjee, Trustee, Prabhat Education Foundation

Prof Chatterjee spoke how the identification of one child in an urban slum of Ahmedabad led to the realization for Mr Keshav to reach out to this invisible population residing in one corner of the city, fighting socio-economic challenges on a daily basis. At that time it was advised that it was a great risk to function without an establishment or even an office. Without much in way of resources, it was advised by the Spastic Society of Kolkata to meet with Ms Poonam Natarajan at the National Trust of India. Ms Natarajan advice was to “Carry on – there are no simple answers, and be prepared for a lot of risk, a lot of disappointment, but the approach is okay”.

Prof Chatterjee shared the significant work in the up-liftment of the disabled community in Tamil Nadu of which Ms Natarajan has been the driving force. Prabhat has had a partner in her since the very beginning. During one recent discussion the future of Prabhat was brought up, realizing that even after 14-15 years of existence Prabhat was touching only the tip of the ice-berg. What should/could be the future for the organization? A lot of the work being done in the development sector is challenged by the word ‘scale’. The institute of Prabhat is now at cross-roads. The learning from other sectors of development is to network, to partner and to share experiences and move

forward with a collective vision. Thus a platform like this will help like-minded organizations collaborate and understand the larger picture.

### **Seminar Purpose: Ms Poonam Natrajan, Former Chair, National Trust, Government of India**

Ms Natarajan said that there are many issues that need to be thought through and taken forward. This workshop gives an opportunity to do that with like-minded people. Through discussions the topics to be discussed in this interaction were narrowed down to CBR and inclusion. It is a dream of many to really see disability services spread throughout the country. In half the country there are no rehabilitation services at all. Even when the government of India talks about the DDRC<sup>5</sup>– they are only in 256 districts out of 640 districts. Most people with disability do not get any services and the question is how CBR can be spread? Everyone is looking at the lifespan approach of children between 6 to 16 years but what about 0 to 6 years? Though it is not in the WHO<sup>6</sup>matrix Early Intervention needs to be a very permanent part of CBR.

When one looks at the school going years and inclusive education – there is inclusion in some little pockets but mostly the feeling is of going backwards instead of forwards.

Another concern shared was to look at disability in the lifespan approach - there are no support systems in the community to help them participate and to live independently. There are parents' organizations whose worry is that after they are gone their children will be sent to 'homes'. But in other countries these homes are being closed down and people are moving into communities. So would India also go through the same cycle? Mostly what happens is that children and some adults with disabilities are dumped into these 'homes'. What are the solutions to this – there is no exit policy? How do we build support systems under CBR or in the community to really make sure that people with disability become active participants in their communities? It starts with their families – they have to be accepted as an equal member in the family and then only can it happen in the neighbourhood and then the community.

There are organizations fighting for the Rights of PWDs and empowering them to find their own voice. But there is still this huge lacuna. As far as professional opportunities are concerned then there are not enough PWDs employed as there are not enough opportunities for them to learn and make their way into the professional world.

The other alarming aspect is the limitation of rehabilitation services extended to children and PWDs, which are not looked at holistically. A service which should be rightfully provided by the government is now being privatized, making access to these facilities limited to those whose can afford. Even then the rehabilitation is not being carried out in a holistic manner. Rehabilitation is not just for the child or the adult but everybody who lives together. The privatisation of rehabilitation services by these clinics are coming in the way of community-based rehabilitation or community-based participation of people with disability. This is the time to think and find the way forward.

### **Like Us: Brief Introduction of the Photo Exhibition by Photographer Ms Bindi Sheth**

“As photographers what do we see – the answer will vary from photographer to photographer. However whatever the reason is, it is the experience of a world as it touches us that we seek to capture”. Ms Sheth went on to describe her year-long journey with Prabhat, mixed with varied emotions and what led her to capturing these pictures and turning them into an exhibition. She also shared how this whole journey was an eye opener for her and helped her grow as a person and as a photographer.

---

<sup>5</sup> DDRC: District Disability Rehabilitation Centres

<sup>6</sup>WHO: World Health Organization

### **CBR and Inclusive Education: Introductory Observations and Presentation by Ms Sumitra Misra, Mobile Crèche<sup>7</sup>, Delhi**

Ms Misra shared that even though MC works with children with disabilities under their Early Childhood Development program it does not have data to claim that. She went on to share that if an established Institution like MC does not have this data then there is very little scope for talking about inclusive education and inclusive systems. This in no way reflects that the organization has not deliberately taken in children with disabilities but it is the lack of attempt to specifically include children with disability. She also said that MC talks inclusion, and they do not say no to any child that comes for services. No child is excluded but then again they are also not included with affirmative action. Children with disabilities can be excluded automatically before they even reach the organization. When community assessment or need assessment is done, at that time these children are not excluded but there is no extra action taken that is reflected in the finding on these children through the survey form. As an organization it is also important for the players in the disability sector to turn the lens and see where the challenges are being faced by such generalist programmes. The need of Mobile Crèche from the sector is to help MC to really bring inclusion into practice and not talk in silos and say that this should happen.

Ms Misra spoke about the challenges faced at Mobile Crèche which range from the lack of skills of enumerators for identification, to disability being invisible due to lack of sensitivity in public spaces and limited understanding of disability within the organization owing to disability being considered too specialised and technical. But having realized this, MC is now trying to set processes which are addressing some of these issues, like modifying admission forms, training staff in basic identification, etc.

She concluded by saying, “Inclusion will happen automatically by not excluding anyone ‘Inclusion has to be part of the institutional framework’”. Unless there is institutional re-organization and re-alignment at the top, just training the committed, dedicated and very hardworking team of workers is not going to be the solution. It must be a sustained, philosophically-grounded inclusive programme rather than remaining just a project.

A presentation on Mobile Crèche’s model by Ms Reena, followed on the theme “Invest Early”. The primary model of day care programmes that MC operates is a holistic programme which is child centric. They achieve this through trained and skilled teams and work towards the overarching goal of MC to make processes sustainable by partnering with communities. They have a well-rounded programme which encompasses academics along with nutrition of a child. What is required when we talk about community rehabilitation? It includes sensitizing and working with them closely. MC has a parent-development programme which is a four and half months module. Because the majority of the population MC works with our migrant laborers, programmes are time bound. So this programme includes community members as well and is not limited to only parents. Group leaders are formed within the community. They work as a catalyst between the rest of the community and MC. They also work with government departments, especially the pre-school programme of the government anganwadi, where we train anganwadi staff to deliver qualitative outputs. All the programmes at MC are working towards bringing policy-level changes.

### **Introduction to the process of Home-based Rehabilitation and Community Mobilization: Mr Keshav Chatterjee and Team, Prabhat Education Foundation<sup>8</sup>, Ahmedabad**

During a door-to-door survey in 2 out of 48 wards in Ahmedabad, it was realized that maximum need for intervention was in the eastern part of Ahmedabad. That is when Prabhat emerged as a need based organization. The need in these areas was numerous and in variety of aspects but the strength

---

<sup>7</sup>Mobile Crèche <https://www.mobilecreches.org/>

<sup>8</sup> Prabhat Education Foundation: <https://prabhateducationfoundation.org/>

of Prabhat was working with children with special needs. Initially Prabhat struggled a lot for people to accept that they wanted to work with this 'invisible population' whose existence is not only denied by society but by their own families. This difficulty itself was the impetus that made the mandate clear for Prabhat – work with the community to bring in change in the lives of special children. The focus shifted in making Prabhat children accepted with dignity and love within their families and in their neighbourhood and community. Along with Community-Based Rehabilitation (CBR) Prabhat also does Home-based rehabilitation for those children who are not able to reach Prabhat Centres due to mobility issues.

A lot of simple workable solutions to everyday problems were found by Prabhat with the help of interns from NID<sup>9</sup> to give dignity to the Prabhat children. Prabhat also worked in nurturing ties between siblings and the special child in the family.

The biggest challenge Prabhat faced was to get a medical certificate for the disabled children. The areas where Prabhat works have a large migrant population who do not have adequate documents and that become a challenge in getting the disability certificate for their children. Prabhat has worked on aspects of public awareness, medical rehabilitation, education rehabilitation, social rehabilitation and support services. They have worked in ensuring that there is access to the government services to all those who need it.

Since 1984 in Gujarat National Council Educational Research and Training (NCERT) has been running the Integrated Education Programme. But when Prabhat started the situation was bleak, in majority of the schools there were no teachers coming in. Out of 3000 children identified in the survey 837 children were in the age group of 6 to 18 years who had never gone to school. After ten years, now there are over 500 children who have been mainstreamed because of Prabhat. The 148 children who are home bound are engaged through a multi-disciplinary approach. Resource rooms<sup>10</sup> managed by experts from Prabhat are running in a few schools in Ahmedabad. The resource rooms are an excellent way to integrate a child with special needs into a mainstream school.

Mr Chatterjee discussed about the challenges Prabhat is facing. He mentioned the nagging challenge off late has been the limitation in spreading awareness among parents on issues of sexuality good touch, bad touch, menstruation, masturbation and surgical processes adopted to avoid unwanted pregnancy. He shared that there is no available material which talks about these explicitly. Prabhat is exploring different tools from folk art to technology to communicate to children and adults. So far the response has been positive and mothers have insisted on fathers and male members of the family being a part of the conversation.

#### **Q/A and feedback session:**

*Ms Abha:* Inclusiveness is not just for organizations working in disability.

*Ms Sumitra:* It is not about Mobile Crèche being a disability organization but has to do with the internal philosophy of the organization towards inclusion and therefore the right knowledge, attitude and skills need to be imbedded within the organization to make inclusion into an integrated approach. Mobile Crèche is the perfect platform to showcase this integration I agree, but there is a fear that lies within the institutional framework because it has not specifically worked on the issue of disability. Children with disability need investment and it becomes important to find the money and allocate it. As a rights-based organization, all our models are about sustaining the models and about scaling the models through government systems

---

<sup>9</sup>National Institute of Design, Ahmedabad

<sup>10</sup> Resource Room is a separate, remedial classroom in a school where students with educational disabilities, such as specific learning disabilities, are given direct, specialized instruction and academic remediation and assistance with homework and related assignments as individuals or in groups.



*Ms Radhika:* In Delhi there is tremendous network of institutions from where support is available. The organizations may not be governmental organizations but NGOs, specialist organizations, etc. The larger issue is that it has to be something we agree upon at an institutional level. There is a lot of commonality in children who face any kind of difficulty. Being inclusive means changing – it cannot be that one operates within a fixed framework.

*Ms Poonam:* There have been instances when a Joint Secretary has told us that special children are not their responsibility but of Ministry of Social Justice! Institutions need to take that extra step towards inclusion if it is not happening. The process is not really a difficult one. Let's not make it too professionalized, let's not forget we are talking about a child a simple step like bringing the child to the anaganwadi to listen to a story, song will be a big step forward.

*Ms Sumitra:* Talk of inclusion is done in disability organizations, and not outside there. But steps are now being taken by other institutions as well, slowly and strategically. Like Mobile crèche worked on modifying the Balwadi curriculum and learning kits and making it more gender sensitive and inclusive in various ways, using a deeper lens in the curriculum and pedagogy. But once the curriculum was developed I realized that there was not even a single character with disability in it, but this realization did not strike anyone else in the team or even external experts working on this. So building this sensitivity among the members of Mobile Crèche is what we are trying to do.

#### **Key Issues and Concerns: Presentation by Ms Jolly Rohatagi and Team, Jan Madhyam<sup>11</sup>**

Ms Rohatagi shared that initially they were asked by the Secretary of the Ministry of Human Resource Development (HRD) to either work for the 'able' or the 'disabled' as they fall under different ministries of the government. They decided that instead of looking at disability support services, they would start looking at the challenges. As artists Jan Madhyam started working with the special children through puppets; speech therapy and occupational therapy. Till date they have worked with about 3 lakh children with special needs since 1982. Ms Rohatagi said "The main medium of reaching special children is through media. Media is such a strong tool that children find it very easy to grasp and learn new things". The *Katha Peti*<sup>12</sup> has proved to be a useful tool for engaging the community. Jan Madhyam uses theatre as well as music to reach out to children. Their main programmes include Vistaar, Srijan and Sahyog. They also have a scholarship programme. Rehabilitation is done at three levels in-house, where the girl child is taught household chores; small vocational skills to contribute to family income and help to find work.

#### **CBR Experiences: Ms Radhika Alkazi, Astha<sup>13</sup>, Delhi**

Ms Alkazi shared about how the idea of Astha was conceived after understanding the deprivation of information among people with disabilities and their families. Initial work started with severely disabled children, who at the time did not have any place in either schools or in organizations. The lack of information unfortunately continues till date. The organization evolved into a community-based organization, but over a period of time there was the realization that though the philosophy was about working in the community, it was actually working in isolation. When this realization, came the scope of work was widened. Astha started working on other issues that the community faced like lack of access to electricity, water by establishing linkages with other organizations working/having knowledge on these issues. The focused work was with the affected families, the children and the community people. Issues associated with the disabled were taken to other forums actively over the

---

<sup>11</sup>Jan Madhyam: <http://www.janmadhyam.org/>

<sup>12</sup>Story box

<sup>13</sup>Astha: <https://www.asthaindia.in/>

years. It has been a very rewarding strategy to be part of other alliances like Right to Education, ECCB alliance, Right to Food etc. for bringing inclusion within as well as outside the communities.

Ms Alkazi shared her experience that parents and the people of the community are the best therapists and educators because they have the most intimate knowledge of their own family and child. Astha started working with everyone and then over the years they narrowed down their focus. They are a very child-focused agency, using tools which make learning fun and also that create a lasting impact about issues. Should those working in the community be more specialized or is it possible to work with the 'whole lifespan' approach? Astha works very intensively with families so it seems very difficult for them to scale up, similar to what Prabhat faces now as shared by Mr Chatterjee. She ended by saying "Today it is time to think that the community-based models are the way the country should go".

### **Feedback Session:**

*Ms Poonam:* We need experts to demystify and make knowledge available to everybody like Asha or Anganwadi workers who should be able to understand disability and the needs thereof.

*Prof Ashoke:* Although everybody is working in disability or other sectors, these sectors are not silos – which also means that we need to build partnerships so that we don't take everything on ourselves but find people who can come in and help pick up those parts of the puzzle which maybe outside our reach. Diversity should be the most important part of our culture, which traditionally has celebrated diversity and connection. So instead of having monolithic system perhaps a model can be developed which is suited to our culture and systems, model which accommodates diversity and cultural issues.

*Ms Sumitra:* For the disability movement and disability organizations to overlap with other concerns gender violence, gender issues, caste issues, sanitation issues, water issues, overall poverty issues it is so important for this discourse to go into all those spaces to talk about real inclusion. It doesn't get factored in those platforms at all. Where are all those people? And why are we not on those platforms? This work is a public good and the government must spend on it. By trying to find low-cost or no-cost solutions we are giving a handle to the bureaucrats. It is important to advocate that services and provisions cost money. It is public accountability and it should therefore be budgeted. The families of children with disability and the community have to be empowered and it has to be ensured that the Crèche field teams are empowered. There is lack of sustained referral system even in a place like Delhi because of distances and the challenges of those families.

*Ms Poonam:* It is very difficult to build a multi-disciplinary team so it is a good strategy to create workers who are multipurpose who can work in all areas of a child – who can look at the child as a whole. At a policy level we have failed to bring in the convergence, to bring things together.

*Ms Hasyalatha:* We should work towards grouping organizations working in the same sector like education for children with special needs, to draw consensus and build a stronger community of practice.

### **CBR Experience in Delhi: Ms Renu Anuj, Rural CBR AADI<sup>14</sup>, Delhi**

Ms Anuj shared that Inclusive Education has the highest scope for development. The word rehabilitation has now been coined as Community-Based Programme at AADI as it encompasses a lot of elements. The biggest strength of this programme is that one should be ready and prepared for change. It is true that the community is changing and growing at a very fast pace. Organizations have to always be on their toes, ready for the change.

---

<sup>14</sup>AADI: <https://aadi-india.org/>

AADI is working in 81 villages that come under 67 panchayats under Vallabhghadh block of Faridabad, Haryana. RPWD ACT<sup>15</sup>2016 is a tool with which as an organization one can demand action from the Government. The Act has a lot of provisions for inclusive education but the implementation at the field level is not up to the mark.

Two major factors which influence inclusion are the physical (infrastructure – buildings, toilets, roads, etc.) and social environment.

The primary stakeholders of AADI's programmes include children with disability, children without disability and parents of children with and without disability, teachers; principals, education department from block to state, panchayat, health department; social welfare department, community at large as well as the judicial system.

Although AADI has been working with both rural and urban population for a long time now, certain challenges that come to the fore include

- Qualitative improvements in the training of educators and teachers.
- Requirement of better infrastructure – especially toilets, accessibility for people on wheel-chairs.
- Attitude of the panchayat or even the neighbourhood is often not very encouraging and supportive.
- Lack of inclusion of people with disabilities in higher specialised educational courses. This is a very essential point in addressing the now bleak future of people with disabilities. Better and inclusive higher education will equip them for better career prospects.
- In-depth sensitization about disabilities

It is very important to know that people can be empowered with information.

Challenges faced by AADI are very similar to other organizations working in the urban context, so despite geographical differences, challenges are similar. Thus platforms like these can provide a point of convergence for the sector.

**Summary by Prof Ashoke Chatterjee:** The challenges that are being faced can be segmented with quite a few things being systemic and with attitude being the most important. Attitude is a very difficult thing to change but over the past 20-30 years there has been a change. At one time no one spoke about disability, but today one cannot open a newspaper without some coverage on disability. In a systemic approach one of the issues that have come up is that where does disability fit into 'development'? In India it is still looked at as infrastructure and not the wellbeing of human beings. Disability is not mainstreamed in the development sector and the question is of how to get there. One way might be the 17 SDGs<sup>16</sup>. The discussions of the day covers at least 8 or 9 of them. These are the global benchmarks to measure progress. There is need for the disability sector to look at the SDGs and see where it fits in because the SDGs are changing the understanding of development as human wellbeing. There is need to aggressively promote an understanding of the disability sector. It will be a long haul but people are more open and they are listening. Official systems are in silos and many in the NGO sector are struggling in silos too. The disability sector is not only about disability but disability+. One of the issues is about money – do we or don't we need it. No one can say that they don't need resources. The government is withdrawing from funding the social sector and the new source is the CSR, so the sector now has to approach corporates.

Specialization and access to specialists is a huge challenge but what was heard today was an important pointer that as we try to plan for the future, can we build up cadres of 'specialists' at the community level who can function handholding. It would be empowering for these leaders to come together and gain strength too. The question is as to how they are mobilized and how they are taken

---

<sup>15</sup>RPWD ACT 2016: The Rights of Persons with Disabilities Act 2016;  
<http://www.disabilityaffairs.gov.in/upload/uploadfiles/files/RPWD%20ACT%202016.pdf>

<sup>16</sup> Sustainable Development Goals: <https://www.un.org/development/desa/disabilities/envision2030.html>

to another level. They need opportunities. How can they be given access to these opportunities collectively and which institutions can we link up? Could this be something that could be supported by both government and industry?

There is another systemic challenge: what do we mean by scaling in this sector? How can one NGO in Ahmedabad who is working in four out of 48 wards reach all wards? There is constant pressure from donors to scale up. The question is whether scaling is up is just about numbers or is there a scaling up of influence as well as of impact, which one must learn to measure. One of the biggest problems in the development sector is that we don't know how to measure progress and we still follow the traditional methods that don't reflect the quality of what we do. Is the sector looking at monitoring and evaluation as a discipline which can help everyone cope in this highly competitive environment? Yet another question is as how we get the performing arts to become strong partners in changing attitudes.

### **Closing remarks/feedback and discussion**

Ms Abha: More and more people in the community are trained and the knowledge base is raised within the social system so that they make well informed and qualitative changes in people's lives.

Ms Radhika: What are the other elements that come in when we are talking about quality, service, knowledge and type of knowledge and its standards? The knowledge base that was enough or need years ago has changed a lot over the years. At what levels should there be trainings – at the community level? At the specialist level there should also be a redefinition of the term. There should be an interaction at the national lifting the existing knowledge base and taking it forward.

Ms Abha: What do we think of RCI<sup>17</sup> – it makes it mandatory that every professional that works with special children needs to have RCI certification. This is restrictive, yet there is need to have safeguards in place for professionals from within the community who are going to be working with these children.

Ms Poonam: The community workers should be trained in such a way that they get the RCI certification. In inclusive education also you have to be a certified teacher to teach a child with disability. Mainstream teachers are not certified.

Ms Abha: The specialists need to be demystified a bit. Non-specialists need to get training of a kind which is does not overtake the specialist training. At the lowest common denominator, you have to empower the people of the community rather than distance them with heavy-handed knowledge. The mother, the community, the child, the neighbours have the fundamental, real experiential knowledge which should be acknowledged and so we have to find a way around this and have a balance. There is also need for change within specialists as well within the systems. All need to be relooked at, the way of teaching has to be looked at. The most difficult aspect is to change attitudes.

Mr Binod: It is very important to empower the community that we are working with through information so that they become capable of doing advocacy for themselves.

Ms Hasyalatha: We all have been working in the field of disability but we can see that outside it is more about mystification rather than demystification. With the opening of private clinics the children become isolated from other children. The parents also need to be empowered and all of us have a role to play in empowering parents on this issue of not to get carried away and still doing what is best for the child.

---

<sup>17</sup>Rehabilitation Council of India

Ms Poonam: There is need to work with doctors. There shouldn't be such disconnect because doctors don't seem to understand. The parents' attitude is very important but it is shaped by the doctors.

Ms Seema: CBR should not be seen with one lens because in a community every family has different needs and requirements. The interventions have to change according to families. It will be easier to work with the children if there is awareness among the parents. The inclusion of special children should start with their inclusion with the other children of the community, and also including other mothers. It is important to make these children visible in the community.

Mr Keshav: It is mostly the mothers who are blamed for having a child with special needs. There is need for a broad perspective as well as very focused and pinpointed interventions.

Ms Poonam: It is very important that there are changes that come in the special children that we are working with – a little bit of self-advocacy, on ability for demanding their rights.

Mr Binod: There is a need to work with all the stakeholders in CBR in the area as they play a very important role. If the School Management Committee (SMC) members are sensitized they can talk about the rights of these children.

Ms Poonam: SMCs can be very powerful in bringing changes for inclusive education. It is actually the synergy of stakeholders and the duty bearers to come together to really look at the issue How can we move from the margins to the centre of attention and join the other development indicators? Though disability has been left out it is part of each one of the SDGs.

## Day 2: Education for those with Special Needs: The Challenge of Inclusion

**Objective:** To understand how inclusion is happening at various levels in different organizations and mainstream schools and tackling practical challenges which come our way as an organization and also as a parent.

### Experience of Inclusion in a Mainstream School: Ms Mary Mansukhani, St. Mary's School<sup>18</sup>, Delhi

"To be a part and not to stand apart; To belong and not be isolated; To be accepted and not accommodated; To have friends and not just companions; to be needed and not just a person with needs; to be a participant and not a spectator; to have responsibility and not just enjoy rights; to have opportunities and not favors and be really included" (Quote from Madan Mohan Jha's book).

St. Mary's school is one such example of the above quote. Working in the field of education for the last 53 years, it has strived to bring in inclusion and not just restricting it to children with special needs, but has gone beyond by serving children from orphanages, homes for street children, etc. Inclusion at St. Mary's started in 1997-98 when the first student from AADI had walked in after he had finished his graduation.

The school devises strategies at the junior level itself. Strategies focus on individual needs of the child clubbed with enough exposure to everything and everyone in the school as well as class room management etc. Sensitization happens at all levels from students, teachers, support staff to senior administrative members. St. Mary's has always believed that it is a two-way learning street. Techniques (hands-on, auditory, visual and kinesthetic) are adopted to provide an all-rounded learning for a child. Collaborative learning and team-work is given a lot of emphasis like children participating in a race and placing children together in such a way that everybody is included. School-level initiatives include maintaining a committed team and working towards a shared vision. The vision begins right from the principal and moves right down to the last person. The admission policy is inclusive. Curriculum is structured as per the need of the child. The school has recently started taking in children under NIOS<sup>19</sup>. While Students of NIOS have their learning classes separately, for the rest of the activities they are part of the class.

### Introduction to the Challenge and Experience of Inclusive Education: Ms Poonam Natrajan, Vidya Sagar, Chennai<sup>20</sup>

Vidya Sagar is a 34-year-old organization. Ms Natarajan shared a unique experience where students from a mainstream private school just across Vidya Sagar and another government school down the road were invited to Vidya Sagar to experience inclusion and what they should be doing for inclusion. It was like a seminar for the children! The seminar was a wonderful platform to understand the perspective of children on what inclusion means to them. The event was so successful and that it has now become a regular feature, leading to various interesting projects taking place between Vidya Sagar and these schools. The projects led to some practical solutions on the ground like time extension at the road crossing signal near Vidya Sagar. The children made an appeal to higher authorities and sensitised them on how difficult it was for people on crutches to cross fast. This was understood and led to time extension at that signal.

Vidya Sagar has a programme where they have worked with families and trained them to provide therapy and to teach their child, especially in the early years. This makes the family more independent and empowers them.

The children at Vidya Sagar come from Chennai as well as small towns. The child is allowed to choose the school that s/he wants to go to and then Vidya Sagar starts working with that school. That is how the idea of inclusion started. The initial response was rejection from most of the schools. One of their

---

<sup>18</sup>St. Mary's School: <https://www.stmarysdelhi.org/>

<sup>19</sup>National Institute of open schooling

<sup>20</sup>Vidya Sagar: <http://www.vidyasagar.co.in/en/>

first students, GJ Siddharth<sup>21</sup>, is today a motivational speaker. Yet he was not given admission in schools because he could not write and his speech was impaired. Finally he got admitted in a school and he did well. Some children have done very well and some have not. There are a lot of students who have gone to mainstream school and the parents choose as per their comfort level which school to send them to – private or a government school.

Vidya Sagar was working with 19 schools in Chennai along with a team doing CBR and advocacy in other towns. Sarva Shiksha Abhiyan (SSA) <sup>22</sup>was introduced in the year 2000. After a lot of protest for demanding inclusion they agreed that NGOs will take charge of that component. It did not endure because it was never fully integrated into the system. Yet 43 NGOs were looking after this component in different parts in Tamil Nadu. This was a huge task with a large number of schools to be covered. There was a lot of passion with which the NGOs and the government officials worked together towards the goal of inclusion. ABL (Activity Based Learning) classrooms were introduced and they did wonderfully and owing to that inclusion happened very naturally at that time. They had 24 teachers in the community supporting mainstream classroom teachers and supporting schools. After the tsunami they started working in the Andaman and Nicobar Islands and even they were committed to ABL. So ABL became part of the lives of government school children.<sup>23</sup>

Rejection and initial hesitation is always a part of introducing inclusion, Ms Natarjan faced that when she was asked to set up a school for 35-40 children. All of them started with an attitude of resistance. Yet after sometime it became a wonderful world filled with creative ideas and brilliant minds. Working with the Teddy Trust was a learning experience for Vidya Sagar. It worked well for 8 to 9 years. Changes in management did not allow it to proceed, beautiful as it was.

Learning in terms of inclusive education was that once teachers get committed and once they understand that there is another way of teaching/learning, they are all in. It is important that they use more child-centered methodologies that will make inclusive education possible. But around 2008 SSA suddenly decided that NGOs were no longer needed. With this the funding disappeared. After that came the Right to Education Act and then an amendment came about. Today it is a sad story. There are no special children visible in government schools.

According to one of the amendments introduced in the Act, parents were given the choice between home-based education or coming to the class in a mainstream school. But unfortunately on ground this is not what is happening. Schools were deciding which child should stay home and which one should attend school. The other issue was that home-based education does not have a guideline or a curriculum or books or a mid-day meal. Any child who they find a little difficult is left out. So they are leaving out most of the kids with disabilities under the garb of home-based education. There is need to do a campaign on home-based education. The new education policy doesn't have much space for inclusive education. Inclusive education cannot work without supporting the mainstream classroom teacher. Inclusive education is not about the special educator going and taking a child out and working with that child.

Interactions with children with special needs who had been to the mainstream schools over a period of a few years revealed that they had difficulty to make friends. Their mothers said that the other mothers don't talk to them because they had children with disabilities. There are so many aspects of inclusive education and social inclusion that have not been touched upon. Systemic changes are thus essential if special children are to be a part of the mainstream.

The children who are in the SSA today are there till the 8<sup>th</sup> standard. Many of them drop out and are not able to go further than Grade 9 or 10. These children come back to Vidya Sagar and through NIOS, they study further. Some of those who do manage to complete their Grade 12 opt for vocational training, which requires finishing at least till Grade 10. The system pushes these children out at the

---

<sup>21</sup><http://siddharthjayakumar.com/about-siddharth/>

<sup>22</sup><https://www.aicte-india.org/reports/overview/Sarva-Shiksha-Abhiyan>

<sup>23</sup>Ms Natrajan was involved in the research project with Tony Booth "Index to Inclusion" – an index which can be used to work out whether the school is inclusive or not

level of Grade 8 and yet the Ministry of Skill Training says that they should have at least passed their Grade 10 boards. So where does that leave these children who have been pushed out of the system at the 8<sup>th</sup> level? There is some serious action plan that needs to be worked on to retain special children in mainstream schools.

### **Buddy Interaction<sup>24</sup> and Its Impact: Mr Keshav Chatterjee, Prabhat Education Foundation, Ahmedabad**

“Without the children of Prabhat, our schools will not look like a rainbow”

At Prabhat inclusion is approached in two ways:

- Mainstream schools and Prabhat work together through a programme called ‘Buddy Interaction’. Innovated by Prabhat the model has now been replicated with three other schools. As the name suggests, mainstream school students ‘buddy up’ with a child from Prabhat. Over the course of the year the buddies get to know each other. This model has been successfully running in Riverside School, one of the top schools of Ahmedabad for the past 10 years.
- Prabhat’s children are prepared to join regular mainstream schools through working with school administrators and support to teachers. Prabhat has successfully placed 570 children in mainstream schools.

The challenge for the second approach is when parents resist the admission of their child into a regular school which means moving out of the Prabhat Centres. They have to be convinced why it is better for the child to enter a mainstream school. Prabhat being a community-based organization has spent years sensitizing and creating awareness in the community. Thus now neighbourhood schools have opened up their doors, inviting Prabhat children to get admitted. Prabhat tries to maintain a healthy relationship with all the schools the children are admitted to. With meagre resources, Prabhat has managed to set up libraries at some of the schools. Teachers at the school are also trained in class room management and other requirements to accommodate a child with special needs. They are introduced to simple, innovative and creative teaching techniques which not only help a child with special needs but are beneficial for all children. Some very successful and inspiring stories have come out from this approach, but there are also challenges similar to those discussed by Ms Natarjan. There are several drop-outs as well. This was observed more in younger children, contrary to what had been understood that a young child will be able to mingle more easily. On closer observation it was noticed that the younger children were dropping out due to ill-fitting aids like calipers, splints, etc. A thorough research revealed that the children were out growing their aids sooner than envisaged. Understanding this urgent need and finding an appropriate partner Prabhat has started an orthotics and prosthetics unit at one of its Centre. Happily most of the children who had dropped out of school due to this reason are now back!

The Buddy Interaction programme works under Prabhat Advocacy programme. The affiliated schools are Riverside School, Rachana School, Divine Child, and Poddar International School. This approach has been a two-way learning model. Children at Prabhat learn social interaction and build tangible and intangible skills. Mainstream school students learn about empathy, patience and tolerance. Vishwesh Murthy, once a Grade 6 student of Riverside School, shared her personal growth experience with the Buddy Interaction initiative. According to her, in Buddy Interaction there were shared narratives that made them feel closer to Prabhat children. It also taught her a lot of socialization and other human skills.

Prabhat also works with mainstream schools in identifying children with special needs especially those with learning disabilities as a part of their EI initiative Prabhat trains anaganwadi staff to identify children and then to send them to Prabhat for further scrutiny and assessment.

---

<sup>24</sup>Celebrating Inclusion: <https://www.youtube.com/watch?v=EcXPRnq5WCM&t=3s>



## Q/A and discussion

Prof Ashoke: Feedback from students of Riverside School who have graduated and also from their Principal is that the mainstream students were the ones who benefitted most from the experience of Buddy Interaction and have used this experience in all kinds of ways that have nothing to do with 'disability' but rather with the ability to work with other human beings. The interesting thing about the school is that they don't see this as an add-on. They see this as core capacity which their children are gaining, which only the special child could give them.

Question to Ms Poonam – In your experience in Vidya Sagar, things were going well for 7 to 8 years and then they slipped back. So is there a learning that when we progress we need to do something to avoid these setbacks. There is need to find out why the system is rejecting these demonstrations.

Ms Poonam: There are many reason. One is the SSA when there was funding for NGOs to employ three special educators per block. Each special educator was trained for one disability. After you have done the assessment, depending on the population you have to serve and the disabilities present, accordingly you employ teachers. The government pulled out, saying that they did not need NGOs as they have not been good. There is so much of misunderstanding on the role of the special educators. Now if one goes to government schools today the whole attitude is negative. There is this class which has children with special needs and when this child tried to sit in the front, the teacher said "We can't help, we don't need to bother because they can't learn". This is the attitude that has permeated down the years. A synergy of inclusive education could be created in the state when 43 NGOs had come together to work for this cause. It was great that the whole government system had adopted ABL (Activity Based Learning)<sup>25</sup>. But the moment the supportive Municipal Commissioner left, all that stuff was put in a room and locked up. We went to ask SSA as to why they had stopped ABL. There are bureaucratic reasons and there are other reasons, which are the Home-based education and the amendment to the Right to Education (RTE). Advocacy was also done to make sure that there is no home-based education but we lost out on that. Home-based education is a reality today where children are pushed into it. They are being enrolled but the child is not in the classroom. The system has thus changed and is totally against inclusive education.

Ms Radhika: When the RTE act came many were thrilled and felt that this is the time when our kids are going to get included. What happened over the years was that the law was interpreted very narrowly, not widely, although it had a lot of potential. No guidelines were made for children with disabilities. At the practical level the SSA remained. The law was there and it gave many powers but actually in the working of it, things did not change. So the implementation of the law did not add all those things it was supposed to. IED remained a separate thing, not part of the larger education system. In the SSA also IED remains a separate component that runs parallel and there are very few intersections. It is a component which is much lower down than the larger education system. Officials of IED start at much lower levels, and don't have power. Teachers are all on contract and there is no way to move up. So the law didn't really bring change. In fact it has rolled back. The government has stopped giving money. A lot of changes have happened at the systemic level which we as a sector don't follow. We need to follow these. If we don't change what is happening on the ground, we are going to just continue doing our little work and not make the big changes. In Jharkhand and Karnataka resource centres and everything else are slowly being shut down. There was a lot of resistance to the home-based education but now the government has stopped giving money for that also. Everywhere you will find that they visit the child once in 15 days, for one hour at home. Is this education? There are huge systemic issues – if you look at the draft National Education Policy today you will see why the roll back – just look at what it says. The chapter on children with special needs talks about home-

---

<sup>25</sup>ABL: Activity Based Learning is a methodology where children of different ages are grouped together in one class and learn at their own pace through teacher-facilitated exercises.

based education, talks about the NIOS and says that one of the programmes will be to include children in schools. At the policy and thinking level, even though we have there is no mention of the RTWD Act. Whatever may be done at the micro level, at a larger level we are in a situation where actual policy and practice are not in favour of inclusive education. The RTE Act till date does not refer to the RTWD Act. Those amendments were never made. When home-based education, came there were no standards set. No guidelines were ever made.

Ms Hasyalatha: When we talk to SSA teachers, it is understood that there is very limited teaching being done. Efforts are directed towards accessing government schemes. NGOs are happy with whatever little they are doing but if one wants to bring in change then one has to work at the level of the government, at the level of the systems So unless we put in our efforts together and work towards that, and not be satisfied with the number of children we have helped at our level, we may not be able to achieve systemic changes in our favour.

Ms Poonam: The whole struggle is to get special schools to come under MHRD<sup>26</sup>. But they are still stuck under the Ministry of Welfare. Special Schools are run by the passion of people who want to make a difference in the lives of children with special needs. They usually do not have any set guidelines nor do they come under any formal education system of the government. By not having pre-designed rules to follow, teachers are not given the same pay-grade as other established schools run by guidelines of the education system. There are no systems that help us stay on track. Tony Booth, Mel Ainscow and Alan Dyson in the UK have developed this index<sup>27</sup> – now the 4<sup>th</sup> index is out. It is a set of statements. You say whether you have it in your school or not. 'Is the school welcoming to all' is one statement and these go on to attitude of children, teachers – it's a huge index. The index is a good tool for any mainstream school to look inwards and make the changes if they fall short.

### **Inclusive Sports: Mr Suheil Tandon, Founder Pro Sports Development<sup>28</sup>, Delhi**

Sports as a medium to bring in holistic change among youth has been the USP for Pro Sport Development. Pro sports has not specifically worked with children with special needs but they have had partners who have specialised working with special needs children. Pro Sports is keen on taking it to the next level with children with special needs. This will require training of trainers and coaches to make them adept to handling a child with special needs. People are now realizing the benefits of sports and how it can make a difference in the life of any child. If Pro Sport ideas are integrated in the Buddy Program it would be very interesting for all the students involved. With Khelo India there is no mention of differently-able sports as such but can it become a part of it because there is some emphasis on participating? Sport in India has been geared towards excellence but there is need to look at it from the participation angle as well.

Unified Sport is a concept where basically differently-able children and 'normal' children play together. Activities and games have to be modified slightly so that they can fit everyone. For volley ball, it is sitting volley ball where the players are seated. It is still an evolving concept and has its roots in the West but can we do similar things with our traditional sports. It is an interesting concept because it cuts across a lot of barriers and can be a very engaging medium for everyone involved.

Khelo India is the current government's flagship programme for sports at the grassroots. It has 12 components including focus on indigenous sports and on female athletes. It does not say anything about differently-able athletes including Para Olympics and Special Olympics. India has performed very well in the Special Olympics over the last 12 years but it still goes under the radar and the same is the case with Para Olympics. So if they are winning medals for the country then why not focus on

---

<sup>26</sup>Ministry of Human Resource Development, Govt of India

<sup>27</sup><https://www.tandfonline.com/doi/abs/10.1080/1360311032000158015>

<sup>28</sup>Pro Sport Development: <https://prosportdev.in/>

them? For Special Olympics individual organizations have taken the lead and have really put in efforts and resources and have worked for 10-12 years to reach where they are. Special Olympics are supported by the government but it is very fragmented. So how can that be brought into the mainstream through Khelo India which is promoting participation in the grassroots?

### **Experience of Inclusion in a Mainstream School: Ms Richa Sharma, The Shri Ram School<sup>29</sup>, Delhi**

The Shri Ram School, started in 1989, is a prestigious mainstream school in Delhi and Gurgaon. Inclusion is not just a concept at this school. It is a natural feeling that should be shared by everyone and not just for children with special needs. If one observes and contemplates one's own self we will realize that it is both instinct and emotion.

The school starts with self-introspection to find out how inclusive we all are in our personal lives. The school has been open to the needs of a child with special needs since it started. Over the years when more children started coming, there was a need for technical expertise. In 1996 a Learning Centre was established. In 2007 the School changed their model and took away the Learning Centres and integrated the children into regular classrooms. However, there were challenges, and it was realized that somewhere the School was not doing justice to the child with special needs. So in 2011 they adapted something called the combination model of inclusion and integration, which is working well till date.

Provision is made for children who cannot follow the regular curriculum. For them there is an alternate curriculum. If the child is not able to follow that, they have their own functional curriculum. Along with all this they also have NIOS option available. If the child is following the mainstream curriculum the child is part of the mainstream class. Special educators are there throughout with the child. There is a concession or accommodation of dropping Science and Math because children with learning difficulties often find it very challenging to cope with these two subjects. The child has the option of dropping Science and Math in Grade 7. A simplified curriculum is taken up e.g. Functional Math or the NCERT book which is simpler.

The emphasis for a child with special needs is on skill-building and not so much on academics, so that their strength and potential is maximized. They can go to NIOS in Grade 9. Assessment is adapted as per the child's need and again NIOS is the way forward in Grade 9. Council also provides some concessions like dropping additional languages, scribes during exams, additional time, and provision of a calculator in Grade 10.

Inclusion work in the classroom: The class teacher is the point person here even if the child is following OBE<sup>30</sup> or functional or adapted curriculum. The child is attached to a mainstream class. The class teacher and not the special educator is the point person. The role of the mainstream teacher is very important. At Shri Ram School, more than special educator it is the mainstream teachers who help the special child. The mainstream teacher has to give equal opportunity to the child to participate in all the activities: outstation trips, assemblies, etc.

Regular sensitization activities are conducted in classrooms, and the teacher needs to work in collaboration with the special educator. She is the one who is teaching the children and so the child connects to her even as the special educator is present in the class. Regular connect with the special educator is very important. The special educator supports the child by reinforcing concepts in the classroom itself, makes adaptation notes and all the technical work that needs to be. She helps the child to stay focused and works on skills, while the academic part is taken care of by the mainstream teacher. When the child is in junior school, they need more support. In middle school the special educator becomes like a shadow teacher because the endeavor is to make the child independent.

---

<sup>29</sup>The Shri Ram School: <http://www.tsrs.org/>

<sup>30</sup>Open Basic Education

Special children in senior Grades have separate classroom sessions as their subjects differ from other students, but they all gather together for other activities. Life-skill and Pre-vocation training is an important part of the curriculum they go a long way in making the child independent.

Process of Inclusion: The school works in collaboration with all stakeholders (mainstream teachers, special educators, children, support staff and parents). The school believes that 'inclusion' is not a one-time activity and thus regular trainings and sensitization workshops are conducted. Support groups for parents in the form of forums have been established, where they can come together and address their concerns and seek guidance.

Updating the skills of the special educators is also very important through professional development meetings. Parents play a very important role. There are so many students who need just a reader or writer. Since all teachers are busy with invigilation, this is where support of the parents is crucial. Parents are encouraged to come and spend time with the children.

For mild challenges, inclusion happens organically. No extra efforts need be made. For moderate to severe, it is the combination of inclusion and integration that works because the focus is on the child rather than the system. The focus of Shri Ram School is on making happy, independent children who are able to contribute in their own way without expectation or judgment. Acceptance is a human need and so inclusion is successful when each one feels accepted and are operating on their strengths.

### **CBR Experience: Ms Sumita Nandan, CEO and Child Protection officer, Latika Roy Foundation<sup>31</sup>, Dehradun**

The Latika Roy Foundation (Dehradun) believes in the power of friendship. A video portraying that beautiful relationship was showcased. The vision of The Latika Roy Foundation is a better world for children with disabilities. It works with children with autism, down syndrome, cerebral palsy and with multiple handicaps.

Gubbara is the Foundation's walk-in center for assessments and home management. When it first opened its doors, it offered, for the first time in the history of Uttarakhand, assessments for high-risk newborns at the government-run Doon Hospital. The MOU with the government is over and now they have shifted to their own premises and are now running other services also. The structure of Gubbara remains the same, giving free services for assessment. For those who can come regularly, EI is offered. Those who are from outside Dehradun are called for regular follow-up. Every month the third Saturday is closed for regular students while the whole staff is on duty. Outsiders are given home-based plans at the time of assessment for subsequent follow-up. EI is offered to children from 0 to 6 years. A lot of work is done on parents' empowerment and training. It is made sure that the parents are with the child when s/he is undergoing the therapy session. They are empowered with EI strategies so that they can deal with everyday issues.

Education and therapy are done at the special school and Child Development Centre. The age group here is 6 to 14 years. Students are taught Math and language concepts at the functional level as well as grooming. Children are identified for mainstreaming. Choice of schools is left to parents, and support is provided to them like meeting with the staff, the principal, finding out what strategies are being used and for sharing with the teachers.

A vocational centre serves children in the 14 to 21 year age group, where they are given pre-vocation skills. The emphasis is for trainees to have their individual identities and to boost their confidence level. A lot of choices are given to the children right from EI.

EI activities are started in the playgroup activities, which has children with developmental delays. Training is given to nursing students for identifying Early Intervention needs.

---

<sup>31</sup>Latika Roy Foundation: <https://latikaroy.org/>

Over the last 13-14 years, every year the Foundation organises a lecture series on inclusion to which mainstream principals and teachers are invited. The discussion is not only on inclusion and includes child development issues which are common for all. A lot of exchange programmes are being done. One mainstream school came for getting involved in inclusive education. Student sensitization programmes are also conducted in different schools to spread the message of friendship and understanding differences between strong and weak. There are about 20 organizations in Dehradun who are members of the Dehradun Disability Forum. This forum meets once a month to talk about the different issues related to disability.

Latika Vihar is the fun and creativity centre. They have weaving, art and craft, pottery, dancing, music and games. 60% of the students coming from the mainstream and 20-30% are children with disabilities. The peer and social environment that they get here is a step towards inclusion.

There are 300 children coming to the centre and everything is centre-based. Outreach work is limited to workshops and advocacy and rights-based approach, like telling the community about benefits accessible from the government. Since a year home-based visits have started like what Prabhat is doing in Ahmedabad, giving service to children who cannot come to their Centre. They have also started training Anaganwadi workers in Dehra Dun.

The ultimate goal of inclusive education is that our children become part and parcel of the community. The school isn't just about getting an education. It is about making friends and being seen.

#### **Bringing financial independence: Ms Mirai Chatterjee, SEWA<sup>32</sup>, Ahmedabad**

Ms Chatterjee shared her experience on how essential it is to form support groups of women. These can be mothers and teachers of children with special need. They can then become bigger and form cooperatives, federations and collectives. These groups can be spear-headed and managed by mothers. The first step would be to identify the need. Ms Chatterjee offered her support in facilitating a meeting with the parents of special children at Ahmedabad. There is a cooperative of mothers in Turkey of children with special needs. Both the mothers and children work on different economic activities like bakery, catering and handicrafts. They are also looking into tourism. The Turkish experience has lessons to learn. What was interesting was that all the parents came together and discussed what skills they had. It was a pooling of skills and experiences, and also seeing what skills were there among the children and how all those could also be pooled. One innovative thing that they chose was the cooperative form. 20 of the mothers formed their own cooperative under Turkish law. Under the Turkish law, one can do many economic activities which is not the same in India. In Turkey if you are a farmer you can do agriculture cooperatives, and apart from that you can do any other type of economic activity. That flexibility helped them a lot. We don't have that kind of flexibility in India as yet. The realization of being an earning member in the family/society gives the mother and the child a sense of empowerment.

---

<sup>32</sup>SEWA: <http://www.sewa.org/>

## Discussion:

Ms Poonam: There are SHGs in Tamil Nadu of people with disabilities. What happens is that for developmental disability like cerebral palsy, autism and multiple disabilities they invite the parents. They think that the people with disability will not have the capacity to join a support group. So that is also something we need to work on, to make people realize the capabilities of people with special needs.

Ms Mirai: If parents and children with special needs come together they can do multiple economic activities. The idea is to make the cooperative or the collective ultimately self-reliant and if not fully self-reliant then at least 50% to 60% definitely. A series of meetings with the parents (like we do with the women) can find out what are their needs. Start with them, rather than outsiders imposing ideas. One can start with their needs and what they can bring to the table. If they are serious about coming together for an economic activity then there should be a business plan and then step-by-step help them to register the cooperative. At least in Gujarat there are very favourable cooperative laws. That would need 51 parents to take it from there.

Ms Hasyalatha: Can SEWA work with some of the groups or canteens where women are preparing and selling things? If some of these children are trained, is there a possibility of using that avenue?

Ms Mirai: Sure. We can discuss that and other possibilities. They form their own group and we can do the handholding.

Ms Hasyalatha: There is a group in Andhra for children over 18 years –they have started a production unit – buying bajra and jowar and packing and selling it. But to make it viable and economic activity they need some training in that.

Ms Mirai: Everybody needs training. We don't have any unit in Andhra, but we can help find someone.

Jan Madhyam: The question is the practical realities of sustaining these cooperatives. Jan Madhyam is known for community engagement and making them self-reliant. They have been working since a long time with artisans and run a non-formal cooperative for food supply. Initially by girls, and then boys joined in. Nearby there was an architect's office and they used to order multiple lunches which they used to make and deliver. The problem they faced was how to cope with marketing? If Jan Madhyam did the marketing for them then they become dependent. Another programme was called 'Rozgar' and that also did not work out. Rozgar was a non-formal cooperative as it had less than 51 women. Parents of children especially girls with mental retardation find it difficult to send them out to do marketing and thus it came to a standstill.

Ms Mirai: It is difficult even for women but they have to keep putting in the effort. It has been SEWA's experience that local business communities do support the efforts. One can start marketing by concentrating on the local market. A lot of brainstorming is needed to come up with different ideas, of which some will work and some will fail.

Mr Keshav: In the diversity seen in communities with whom Prabhat works, the emphasis is on finding out the talent/interest of a child and then providing them the formal training that could help master that skill.

### **CBR Experience: Mr Kumar Ratan, CBM, Delhi<sup>33</sup>**

69% of persons with disability reside in rural India. CBM's interventions have mostly been in villages and small towns (tier 2 and 3 cities). Efforts should be taken that the 69% of persons with disability in rural India don't disappear from discussions. The data of the 9<sup>th</sup> round of the All India School Education Survey is very comprehensive (conducted in 2009 and published in 2018). In the government system there are a lot of budget cuts and reduction in facilities for the children despite RTE being a fundamental right.

CBM India has been working since last 50 years in the fields of health, education, livelihoods, empowerment and humanitarian action during disasters. Their strategy considers RTE and inclusive education as prime goals in the context of SDG 4 and UNCRPD<sup>34</sup>. They have different models. As a 50-year-old organization, the focus was once on traditional schools. Now the focus is on mainstreaming. Efforts are to find out how to transform special schools into resource centres. They are also working with government schools to promote inclusive education. More than 90% of these 3000 schools are in rural India. They develop IEC material, modules and teacher training material. They have some initiatives, of which one is Include India Campaign which promotes inclusion in government schools in villages. Another initiative is inclusive sports and recreation activities. Modules have been developed which can be played by children with disability. They are working towards evolving a resource centre where inclusive education is facilitated. The model that was developed has four major components: quality rehabilitation, human resource development, advocacy and skill development. They are working on evolving this with Telengana Angabam and Prerna Education Centre in West Bengal. In the resource centre some children after initial training are mainstreamed in government schools. There are cases where government schools are telling those who are coming directly for admission to get some training in Braille before starting school. Some teachers from government schools come to the resource centres to learn the pedagogy and skills for working in an inclusive set-up, where they work with ICDS/Anganwadi workers and teachers, after talking with the District Magistrate they also give training to asha workers and teachers. Further efforts being done in this model includes trying to calculate the cost per child for the whole year.

CBR based interventions includes participation in governance, livelihood, health and rehabilitation, infant health, extra education support through after school clubs with a tie-up with a government school. This work was done in collaboration with Mobility India. The learning from this initiative was livelihood support of the community and parent's group, leading to the ability to send children to government schools, and collaboration between teachers and the CBR workers.

Another model in Ajmer district of Rajasthan is collaboration with an organization called Sparsh. The campaign is called 'Include Vidya Campaign'. The important component is the involvement of the disabled people's organization (DPO). The DPO identified the children, talked with the Department of Social Welfare and organized a camp to help them in getting certificates. They also organized camps for assistive devices. After the children got the certificates and the assistive devices, they were enrolled in schools. DPO did not become a member of the School Management Committee (SMC) but participated in SMC meetings so that issues of the disabled children are taken up in school governance. The challenges faced included some mothers asking why they were sending their children in such sub-standard schools. It made the DPO realize that sending children to school through compliance of RTE is not what inclusion is about because it is about giving them quality education. This is very important and the focus needs to be on that, but unfortunately in this particular project the interventions of pedagogy and teacher's training component was missing. It was a campaign to make sure that the children reach school through DPO. It was an important learning that when the community owns something and they know about the law then they ensure their

---

<sup>33</sup>CBM: <https://www.cbmindia.org.in/>

<sup>34</sup>UNCRPD: United Nation's Convention on the Rights of Persons with Disabilities.

participation in inter-departmental convergence and school governance. But this is not enough, and there is need to pay attention to quality education.

There should be a forum that is formed at the end of this seminar where people can share their experience and especially their success stories.

### **Discussion and Q/A:**

Question to Shri Ram School: What is your admission policy? How many children do you have in the school, both able and disabled? Do you have a bar on the number of special children you will have in one classroom?

Ms Richa: Since the junior school is in Delhi, we follow the Delhi State government guidelines especially when it comes to children with special needs. There is no assessment (that happens later). However, we do have a campus in Gurgaon where we have the freedom to assess the child first. Right now we have more than 100 differently-able children in the school and more than 1000 mainstream children. In each form there are 5 sections. We generally have children in 2 sections. So the ratio is one special educator with three to four children and maximum 8 children per form. In junior school it is very easy – one special educator is attached to the class because at that level the teacher has knowledge of all the subjects. But when the child moves to senior school then one needs to have the subject specific knowledge. Then one special educator is not enough for the entire class. There are no dropouts in our school.

Question: what is the learning from Teacher Assistant Programme (TAP)?

Ms Richa: TAP was there for more than 4 years. The idea was to create trainees who will be absorbed outside in the society. There are five TAP trainees across Shri Ram School campus but the other schools did not induct them. Even if they were taken then it was more of a voluntary involvement.

Question: What about the sensitization of the children?

Ms Richa: That is on-going. Sensitization of children, teachers, parents and also our support staff. We have children with all kinds of special needs, learning difficulties, children on the spectrum, children with intellectual impairment, Down Syndrome, cerebral palsy. For children with learning disabilities it is easier to be mainstreamed. A child on the spectrum after doing NIOS passed out from St. Xavier's in Mumbai. This was one child who needed one-on-one attention in junior school, middle school and even at NIOS. There are children following the adapted curriculum and in case there is any modification in the curriculum or if the child is following OBE (Open Basic Education) curriculum then the subject will change because their subjects are different from the usual Physics, Science, and Chemistry. Skills are important for every child. There is a lot of emphasis on skill-building right from the junior school. The focus on skill-training is more on the children who are in the integrated set up.

Ms Radhika: I am wondering whether we need the Boards of Education the way they are. Now do we need, in your experience, changes at that level, because many kids will find it difficult to work within these parameters? All kids go through some kind of board which certifies them, and so I am wondering whether there should be more flexibility, and whether we should be asking for some changes in the way CBSC, ICSC boards function. Otherwise for some kids it will remain as informal education. Education cannot only be described only as academic. There is a fundamental flaw in the way which our societies are talking inclusion. We really have to rethink the way education is. Will we ever be successful if we are going to have this constant emphasis on academics, and that only skill that takes you from one level to another while other qualities are devalued?

Ms Richa: Four years back there was a conference and we had put this to the speaker that still the focus of the boards is on academics. Their response was 'we have given you NIOS'. Though they say NIOS is for special children, the content is humongous. NIOS only give flexibility of finishing over a period of few years.



### **CBR Experience: Ms Abha Ranjan, Association for People with Disability (APD)<sup>35</sup>, Bengaluru**

Ms Abha Ranjan was a strong part of Vidya Sagar and has worked closely with Ms Poonam. Her Karnataka experience with APD is fairly recent. She shared that an eco-system for early childhood has been established. At APD they were restructuring and looking at their longitudinals and verticals. They were thinking of how they were going to restructure, and they thought that Early Intervention would be one area which is very important. They worked on establishing parent groups and then identifying NGOs. They had worked with in 6 North Karnataka districts to build capacities for EI. APD structured itself as the resource organization in this programme. Young people from these districts/villages were identified by the nodal NGOs and trained on Early Intervention. The training took about 9 months to a year. Anaganwadi and ASHA workers were involved in the process. Fresh graduates from various field of education built a 'Trans-disciplinary' model, as mentioned in David Werner's book<sup>36</sup>. The multi-disciplinary approach led to a convergence at the grassroot level of human resource development, health, and empowerment. When there is amalgamation like this and functionaries work together, then you can take the same knowledge and information. From her experience, a lot of people working in this sector tend to say this 'our model', 'our pilot', but there is a lot of well-established and evidence-based practices freely available in the field of disability. We should take advantage of that and together build a strong way of working in the field of disability, so that a child with disability anywhere in India is receiving the same techniques and the same quality based upon certain principals and guidelines. EI is the focus for all the developed countries as well today. So the convergence of the various sector in the APD programme meant all the actors were communicating in the same voice and understood Early Intervention in the same way but approached it as per their expertise. Working with a young child is not EI unless you are following the principals of it. An essential part of Early Childhood is coaching the parents to make sure knowledge is transferred to the family so that the training of the child happens inbetween visits by experts, and not only when the experts visit. Everything happens for the child during the course of the day. Parents need to be told about the language they use, the way they communicate with child, and providing a rich environment for the child at home that encompass the elements of various therapies into everyday life. It is very important to make sure the parents are learning during the session and make them demonstrate what they have learned. More than 7000 children are receiving the benefits of this eco-system developed by APD.

### **Mainstreaming experience of a parent: Mr Tarun Handa, Delhi**

Mr Handa shared his experience as a parent to Vardhan, a child with cerebral palsy quadriplegic<sup>37</sup>. He recalled how they were unable to read the signs initially (almost 2-3 years) and thought of it as delayed milestones. Once it was identified, they started looking around for experts to guide them. His experience as a parent of a child with severe disability has not been pleasant. They realized that resources are quite sparse in our country. He said they got several rejections from schools. The schools do not explicitly say 'No' but they also didn't allow entry. The schools that did, were not equipped with the required expertise. They did not realize the different forms of disability and needs, were not able to cater to the child appropriately." Having put Vardhan in school, instead of seeing him progress we saw him going down. We had to take him out from there and we again lost a few years in finding another school for him. But we finally did. But here as well there were a lot of barriers. Unfortunately issues hamper the progress and growth of children with special needs. We as parents

---

<sup>35</sup>APD: <https://www.apd-india.org/>

<sup>36</sup><http://www.dinf.ne.jp/doc/english/global/david/dwe002/dwe00201.html>

<sup>37</sup>Spastic quadriplegia is a specific type of spastic cerebral palsy that refers to difficulty in controlling movements in the arms and the legs. Those who experience this form of Cerebral Palsy will not have paralysis of the muscles, but rather jerking motions that come from stiffness within all four limbs.

have two major concerns: how will he take his livelihood forward, and what after us? We as parents require practical solutions.

Ms Abha: Your son has got a good school. Now become friends with the teacher and support each other. Things will not always happen the way you would want them to. There is a long way for us to go before that starts happening. There is a very practical thing you can do in the school system, which is called 'Priming' – make sure you have the week or the month's plan that the teacher has prepared with you.

Mr Tarun: Does it really happen? I and my wife have tried a lot: talking to the teacher, to the principal, but nothing really comes out of it. I am not blaming the school, as I know they need to cater to some 40 odd children in a classroom.

Ms Abha: It is not an easy thing, but supporting each other is very essential. It eventually leads to a blame game between parents and teachers. School is a very difficult place for a child to grow up in – schedules change, teachers don't show up, there can be too many children and very chaotic systems. But on the other hand if you and teacher can be on the same side and you get to know a little of what's happening in the coming week and prime him at home, he will be more alert in the classroom by knowing what's going on.

Ms Poonam: What are the kind of needs of Vardhan that you have communicated to the Principal of the school, and what has not been done?

Mr Tarun: We know that he won't be able to study

Ms Poonam: How do you know he won't be able to study?

Mr Tarun: Because he has vision problems as well. His vision is impaired. Even after several years of teaching him different colours he is not able to identify them.

Ms Poonam: Tarun, let's not forget he's a child and you are always worrying about his livelihood. If you say he has visual impairment, I can tell you about judges and authors who are visually impaired and have gone on to do amazing things. There is a lot of technology available. Braille has become old fashioned. Smart phones today have disability features. We have audio books. I have children in my centres who cannot read at all but have now graduated. Their learning style is called 'auditory' – they will listen and talk to a scribe. So don't assume that Vardhan won't study. Give him a chance. So what did you ask from the Principal that didn't get done?

Mr Tarun: We asked her to give few one-on-one session to him with his regular teacher only, and teach him some life skills, make him understand about money, learn shapes, etc.

## Summing up

Prof Ashoke: It is essential to share the proceeds of these two days (including the feedback, queries, questions and concerns) with others in this sector. There are two things that we may want to decide at the end of today: first, do we want to continue networking? If so, how?

There were some wonderful stories over these two days of youngsters who have joined the mainstream. But is there any other 'mainstream' for children who cannot become lawyers or doctors and who are drop-outs? Is there any avenue for them? If not, we may have establish that. A constant question is 'What after us'? This has been brought up yet again today. Someone who wanted to be here for the seminar but couldn't make it is Aparna Das, from Dehradun. She runs a home for autistic adult women who come there after the family has moved on. Do we need to think on similar lines?

As reminded earlier in the day by Ms Natarajan, progress in this field is not guaranteed. You do good work but so many slippages can take place. Is there something we can do in the coming years to try and halt that? Sustaining what has been set up seems to depend on the individual rather than the system. So unless issues are not resolved at the top it will be even more difficult to keep any process sustainable at our NGO levels. We heard about how the education boards need to be more sensitive and systems in our country need to be more sensitive to the issue of disability. Who do we raise our concerns to? Which is the nodal agency to receive the output from here?

Ms Poonam: It is the Ministry of Social Justice and Empowerment. We need to send our recommendations to the Secretary and follow-up with her. This Ministry should converge with a lot of other Ministries like HRD, Health and Family Welfare, Labour, Rural Development. The problem is that they never converge and that's the issue. We need to join various disability networks, to be heard and hear. Home-based education is such a low priority to the Government, we need to change that.

Prof Ashoke: The issues of 'political will' are critical. Meanwhile we should join these networks, to educate ourselves about these networks and build the strength that can come from unity.

## Acknowledgement

Prabhat Education Foundation acknowledges the support and participation of all those who have helped to make this Seminar a reality. The understanding and encouragement of IIC's Programme Office through Ms L S Tochwang and the late Ms Premola Ghose has been invaluable, as has been the effort of IIC staff at every step of Seminar and exhibition management. A grant from The Rockefeller Foundation assisted preparation, logistics and this record of proceedings. Ms Poonam Natarajan mentored the entire Seminar process from idea to documentation while Bindi Sheth's evocation of the world of Prabhat children and their families created a powerful backdrop of the reality that this Seminar has been intended to serve. Prabhat hopes that this experience can strengthen the national effort to bring those with special needs into the mainstream of citizenship and development, giving them the dignity and the hope that is their right.

Photographs: cover and inside cover by Bindi Sheth. Others by Prabhat Education Foundation

## Prabhat Education Foundation

### Registered Office

A-4 Sujal Apartment, opp. Satellite Bungalows  
Ramdevnagar, Ahmedabad 380015

### Mailing Address

Prabhat Education Foundation  
B-1002 Rushin Tower  
Opp. Star Bazaar, Satellite Road, Ahmedabad 380015

**Website:** [www.prabhateducationfoundation.org](http://www.prabhateducationfoundation.org)

**Email:** [prabhat@prabhateducationfoundation.org](mailto:prabhat@prabhateducationfoundation.org)

**Phone:** + 91 79 4890 3054



<https://www.facebook.com/Prabhateducationfoundation/>



[https://www.instagram.com/prabhat\\_education\\_foundation/](https://www.instagram.com/prabhat_education_foundation/)



<https://www.youtube.com/channel/UCe1oxuBWMDvyCRk2EPzzjIA>



<https://twitter.com/PrabhatEdu>





**INDIA INTERNATIONAL CENTRE**

40 Max Muller Marg, New Delhi 110003



**PRABHAT**  
EDUCATION FOUNDATION

AN ALTERNATIVE FOR  
THOSE WITH SPECIAL NEEDS

A4 Sujal Apartments, Ramdevnagar  
Ahmedabad 380015