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Message from our Honorary Advisor

Poonam Natarajan

Founder - Vidya Sagar, Chennai

Former Chairperson, National Trust,

Ministry of Social Justice and Empowerment,

Government of India



Pushpanjali Trust was introduced to me by its founder, Aditya Rametra, when he called with a request to visit Vidya Sagar, the organization I founded in Chennai many years ago. It was an interesting meeting and the beginning of many debates and discussions we have had over the years. During that time, I was also conceptualizing a Resource Center for developing community supports for people with disabilities to live in the community. So our goals matched, and we were looking for workable models for adults with disabilities; trying to answer a question which is a universal worry for parents with a child with disability - 'What after us?'

Aditya wanted to facilitate community living of persons with disabilities in North India, and I in Chennai, South India. This quest motivated us to visit facilities together in the UK. We wrote to Richmond Fellowship and Mencap in London. Both organizations put together a program for us, to visit different types of Group Homes and meet some of the leaders and office bearers. We spent one week with each organization. It was a valuable experience as we were able to understand some of the issues that come up when people not related to each other live together and also the roles of the support workers.

The cherry on the cake was meeting Elly Jansen, the founder of Richmond Fellowship. She was very inspiring and had much to share. She had been involved in setting up of the Richmond Fellowship in India also, so she knew many people here too.

Back home, Aditya has been pursuing with the Chandigarh Administration to set up assisted living facilities for persons with mental disabilities, and has also been working on making the Trust grow. I am sure all his efforts will someday bear fruit.

I wish Pushpanjali Trust all success in their endeavors.

From the Founder

Aditya Vikram Rametra Managing Trustee, Pushpanjali Trust



Genesis of Pushpanjali Trust

Pushpanjali Trust was born out of a crucial need for good rehabilitation services for persons with mental disabilities in North India. There was also a need felt for much more awareness and advocacy of mental health issues among the general public. Although Pushpanjali Trust was registered as a public charitable Trust in 2014 in New Delhi, the first few years were spent in learning the various aspects of mental health from professionals and voluntary organizations in India and abroad.

I had an eclectic background in engineering, management and social sciences, but no background or experience whatsoever in the field of mental health. But having witnessed the struggles and tribulations of a family member with mental illness, there was an acute need felt for much more awareness, empathy and rehabilitation services for persons with mental illnesses in our society. This felt need was the genesis of Pushpanjali Trust.

The initial years (2014 - 18)

The first few years were spent visiting different professional organizations in India and learning the various aspects, challenges in mental health and different approaches to care and rehabilitation.

The professional organizations visited in India included:

- 1.The Banyan, Chennai
- 2.Vidya Sagar, Chennai
- 3. Richmond Fellowship Society, Bangalore & Delhi
- 4.Athma Shakti Vidyalaya, Bangalore
- 5. Muskaan, New Delhi
- 6.Mental Health Action Trust, Kerala
- 7. Chellamuthu Trust, Madurai, Tamil Nadu
- 8.Sambandh Health, Gurugram, Haryana

Most of the visits to these professional organizations included short stays in their residential facilities/ group homes. This was an immersive experience and first hand learning of the day-to-day challenges, and management techniques. Among these organizations, substantial time was spent learning from Athma Shakti Vidyalaya and Richmond Fellowship Society, Bangalore.

'What after us? → 'What is a good life?' (Right to community living)

The initial years were also spent meeting a lot of parents, guardians and persons with mental illnesses (PMI) across different cities – Delhi, Bangalore, Chandigarh, Pune. I wanted to know firsthand their issues and challenges, especially with regards to long term rehabilitation.

One of the most important needs felt by persons with mental illnesses and their caregivers, was the availability of good, affordable long-term Group Homes in the community. Time and again during our meetings, we found old parents and guardians throwing up their hands in despair and asking, 'what after us?' i.e. 'what would happen to our wards once we are not around to look after them'?

We explored this issue in depth at Pushpanjali Trust, with our Trustees and Advisors. While most parents and guardians were focused on basic survival of their wards, the persons with mental illnesses (PMI) actually wanted a much more fulfilling life, where they felt useful and cared for. The PMI wanted a good life with access to residential, vocational and recreational facilities. They wanted to be part of a larger community, with care and empathy as guiding principles. Advocating for inclusive assisted living facilities in the community became the Holy Grail of Pushpanjali Trust.

2018 - 19: Taking the plunge

In 2018, I decided to work full-time as the Managing Trustee of Pushpanjali Trust. I relocated to Chandigarh, the city I grew up in, and established the Head Office in the city. I started meeting a lot more persons with mental disabilities, their guardians and mental health professionals in Chandigarh Tricity. I had long, in-depth discussions with them.

The most critical need highlighted again was for long-term assisted living facilities for persons with mental disabilities. Although there are good treatment facilities in Chandigarh, there is an acute shortage of community living facilities for adults with mental disabilities in Chandigarh Tricity.

Exposure and Training

While I had visited several organizations working in mental health and disability in the last few years, I still felt the need for more exposure and training in long-term rehabilitation, particularly in residential settings. I therefore decided to get intensive training at:

1) Athma Shakti Vidyalaya (ASV), Bangalore

2) Richmond Fellowship Society (RFS), Bangalore

Here, I learnt first-hand about 'Therapeutic Community' principles in actual practice. In a therapeutic community, the residents and staff participate in the management and operation of the community, thereby contributing to a psychologically safe living environment where healing can occur. The staff and residents share all responsibilities and chores of daily living such as cooking, cleaning, gardening, shopping for groceries, recreational activities etc., so the community life itself, through self-help and mutual support, becomes the principal means for promoting personal change in the residents.

I also visited the following professional organizations in **France and UK**:

1. Newton Dee, Camphill Community, Scotland:

Newton Dee is one of the oldest and largest residential communities based in Aberdeen, Scotland. Coworkers (live-in volunteers) and Villagers (adults with special needs) live together in different Group Homes on a 180 acre rural campus, in a mutually supportive environment. In all, some 200 people live and work within the Newton Dee community. Around half have special needs. The others are mainly coworkers and their families. I spent a week on campus and interacted with the staff and residents.

2. L'Arche, France:

This is one of the largest and well known organizations working for the rehabilitation of people with intellectual disabilities. They focus on building relationships and cultivating a sense of belonging. Persons with disabilities stay in different Group Homes, along with support staff, in a village south of Paris. There are several work and recreational options. There are different workshops, a café, a bookshop and a large farm. Here again, I spent a week on campus and interacted with the staff and residents.

3.Mencap, UK:

This is one of the largest charities in UK focused on supporting persons with learning disabilities. We visited a few of their supported housing projects in and around London.

4. Richmond Fellowship Society, UK:

This is one of the largest charities in UK focused on supporting persons with mental illnesses. We visited a few of their supported housing projects in and around London. We also met the legendary Elly Jansen, who started one of the first Group Homes in London several decades ago. She was later instrumental in establishing the Richmond Fellowship Society India Chapter in Bangalore in the late 1980s.

[During my visit to the last two organizations in and around London, I was accompanied by our Honorary Advisor, Poonam Natarajan]. The visit to the organizations in France and UK was very inspiring, and gave us fresh ideas of the various possibilities for Group Homes in India.



During a Visit to UK with Poonam Natarajan

Focus areas of work

After years of dialogue and consultation with various stakeholders, we finally zeroed in on three core areas of work:

Awareness

Advocacy

Rehabilitation

Awareness

There is a lot of ignorance regarding mental illness in the Indian society. Persons with mental disabilities and their families still experience stigma and discrimination on a daily basis. Many people have internalized the stigma, and are afraid to voice their concerns, or seek support. Creating awareness and dissemination of information on different aspects of mental health is one of our key areas of work. A lot of meetings of caregivers and sympathetic mental health professionals were held during the year on the following topics:

- Rights of persons with mental disabilities
- Various models of supported and assisted living facilities in India and abroad
- Caregiver's stress and burden: possible solutions
- Vocational opportunities for persons with mental illness in Chandigarh Tricity

'Let's talk mental health' discussion series launched for persons with mental illness and their families and mental health professionals in Chandigarh Tricity. A total of five sessions were held during the year.

The new Legal Framework

Finally in accordance with the United Nations Convention for Rights of Persons with Disabilities (UNCRPD), we have the new Rights of Persons with Disabilities Act 2016, and the Mental Healthcare Act 2017 in India. The two Acts are a radical departure from the past and for the first time enshrine several fundamental rights for persons with disabilities. One of the most important fundamental rights is the 'right to community living' i.e. persons with mental disabilities have a *right to live in and not be separated from the community*.

The two Acts also make it clear that it is the duty of the appropriate government(s) to ensure the fulfilment of these rights. We undertook a detailed study and analysis of these Acts, and started using them extensively for our Awareness and Advocacy work.

Media outreach: The Tribune Series - 'State of Mind'

We motivated a few parents, guardians, persons with mental illness and mental health professionals to share their stories and perspectives. Lots of ideas were exchanged, some writing sessions held. This gave birth to a series titled 'State of Mind', which was published in The Chandigarh Tribune. A total of 7 write-ups were published during November – December 2018. We received a lot of public support and appreciation for the series.

Some titles of articles published are as below:

- Let's talk about mental health, shall we: Dr B S Chavan
 https://www.tribuneindia.com/news/archive/chandigarh/let%E2%80%99s-talk-about-mental-health-shall-we-687116
- It's tough for caregivers, world makes it tougher: Col Ajay Mehndiratta https://www.tribuneindia.com/news/archive/chandigarh/it-s-tough-for-caregivers-world-makes-it-tougher-697660
- It's not about money, our system is rickety: Dr A K Kala
 https://www.tribuneindia.com/news/archive/chandigarh/its-not-about-money-our-system-is-rickety-701310
- Unlike West, why disdain for mental health? Dr Simmi Waraich https://www.tribuneindia.com/news/archive/chandigarh/state-of-mind-697660
- When all is not right: A brother's perspective Aditya Vikram
 https://www.tribuneindia.com/news/archive/chandigarh/when-all-is-not-right-a-brother%E2%80%99s-perspective-690734

A > CHANDIGARH

When all is not right: A brother's perspective

I was trekking when I received a series of frantic phone calls from my brother, Rohit (name changed). If you didn't take his call or missed it somehow, Rohit would keep trying incessantly some 25-30 times!

Posted:

Nov 29, 2018 02:93 AM Updated:

3 years ago



Illustration: Sandeep Joshi

Aditya Vikram Rametra

I was trekking when I received a series of frantic phone calls from my brother, Rohit (name changed).

♠ > CHANDIGARH STATE OF MIND

Let's talk about mental health, shall we

Zirakpur: A week-long sports festival was organised at Manav Mangal Smart World.

Posted: 個 Nov 22, 2018 01:09 AM Updated: 個 3 years ago



A new column that lays threadbare the concerns, challenges associated with mental illness

Prof BS Chavan

Contrary to common belief, mental illness is very common. In 2001, the World Health Organisation (WHO), during its 54th World Assembly, stated that at any given point of time, about 450 million people suffer from some kind of mental, behavioural and

CHANDIGARH

Unlike West, why disdain for mental health?

G was a doctor who got married and moved to Australia.

Posted: # Dec 27, 2018 02:14 AM Updated: # 2 years ago



Simmi Waraich

G was a doctor who got married and moved to Australia. The marriage ran into trouble and began to flounder. G moved out and started to do odd jobs and live alone. She was on a low dose antipsychotic for her Schizophrenia with which she remained well but now she began to miss it, and soon her delusions and hallucinations returned. She felt people on the street were making gestures about her and that

STATE OF MIND

It's tough for caregivers, world makes it tougher

I was married at the age of 26, but I found my wife's behaviour very strange within 24 hours. There was no happiness in her and she would rarely talk.



Col Ajay Mehndiratta

I was married at the age of 26, but I found my wife's behaviour very strange within 24 hours. There was no happiness in her and she would rarely talk. I joined my duty thereafter and my life was miserable, as she would not get up, not brush her teeth and in four to five months, I had to do my Army duty as well

Advocacy

This is our second big focus of work. We have consciously decided to be agents of change, and not get into providing a whole host of services ourselves. We believe in empowering individuals and families, so they can strive for their rights themselves. We also believe in mobilizing public support for appropriate services to be provided by the respective governments. Using the appropriate provisions of the new laws is our biggest asset. Several meetings and discussions of caregivers and sympathetic mental health professionals were held during the year on the following topics:

- Rights of persons with mental disabilities
- Using the provisions of the Rights of Persons with Disabilities Act 2016, and the
 Mental Healthcare Act 2017
- Filing RTI Applications to get the relevant information
- Sending Representations to the appropriate governments for implementation of the enabling provisions of The Rights of Persons with Disabilities Act 2016, and the Mental Healthcare Act 2017
- Public Interest Litigation and Writ petitions

Representation to UT Chandigarh

In Nov. 2018, a detailed representation was sent by Pushpanjali Trust to the Adviser to the Administrator of UT Chandigarh, requesting for framing a policy for setting up "Group Homes" in UT Chandigarh, as envisaged under The Mental Healthcare Act, 2017. Several parents and individuals were encouraged to send in their representations as well.

Meeting with H.E. the Governor of Punjab & Administrator of U.T. Chandigarh

On 6th Dec, 2018, the Managing Trustee of Pushpanjali Trust met with H.E. the Governor of Punjab & Administrator of U.T. Chandigarh in Punjab Raj Bhavan, and pleaded the case for setting up "Group Homes" in UT Chandigarh at the earliest. However, despite our best efforts, no tangible steps were taken by Chandigarh Administration.

PIL filed in the High Court

Since no tangible steps were taken by Chandigarh Administration despite multiple requests and representations, the Managing Trustee of Pushpanjali Trust and three co-petitioners (guardians of persons with mental illness in Chandigarh Tricity) filed a PIL (Public Interest Litigation) on 17th Jan, 2019 in the Punjab and Haryana High Court. The High Court issued directions to the UT Chandigarh Administration to frame a policy on Group Homes within three months from the receipt of a certified copy of the order. [This was possibly the first PIL filed in India for setting up "Group Homes" under The Mental Healthcare Act, 2017]

Meeting with the Adviser to the Administrator of UT Chandigarh

On 13th March, 2019, the Managing Trustee of Pushpanjali Trust and a few caregivers of persons with mental illness met with the Adviser in his office and pleaded the case for setting up "Group Homes" in UT Chandigarh at the earliest. Copies of the original representation, a Draft Policy prepared by Pushpanjali Trust, and the High Court order were handed over to the Adviser. The Adviser seemed sympathetic to the cause; however no decisions were taken.

Representations to the Punjab, Haryana and HP governments

In March 2019, detailed representations were also sent by Pushpanjali Trust to the Chief Secretaries of Punjab, Haryana and HP governments, requesting for framing a policy for setting up "Group Homes" in UT Chandigarh, as envisaged under The Mental Healthcare Act, 2017. To make it easier for the respective governments, a Draft Policy Note was also sent along with the representations.



Meeting of an Advocacy Group

Rehabilitation

Rehabilitation and re-integration of adults with mental disabilities in society is of fundamental importance to the Pushpanjali Trust. But instead of providing rehabilitation services directly, our approach is one of enabling and empowering people so they could help themselves.

Peer Support Groups for PMI and their Caregivers

The in-depth meetings with a lot of parents, guardians and persons with mental illnesses (PMI) revealed the need for creating peer support groups for both PMI and their Caregivers.

• Peer Support for PMIs

We found that many adults with mental illnesses are languishing in their homes. Even though they are taking regular treatment, they suffer from loneliness and meaninglessness. The vocational and volunteer opportunities are extremely limited and there is massive stigma. We found that connecting such persons with each other had a therapeutic effect on their mental and physical health. They found empathy, camaraderie and mutual support. We started with four individuals and the peer support group slowly grew to fifteen individuals. Some persons were more comfortable sharing concerns with their own gender in a small group.

• Caregivers support network

Just as persons with mental disabilities were dealing with their challenges and loneliness, so were their caregivers/ guardians. The caregivers were experiencing fatigue, burnout in addition to loneliness and stigma. Having a support group of caregivers had a similar therapeutic effect on them. They found empathy, camaraderie and mutual support. They realized they are not alone; even more they can lend support to each other, and receive help when the chips are down. The support group slowly grew to include nearly twenty caregivers, mostly mothers.

Networking with mental health professionals

We discovered that given the ignorance and misconceptions about the ability of persons with mental illnesses to live independently in the community, there was a strong need to network with sympathetic mental health professionals. These professionals could then become our valuable partners in advocating for community living of persons with mental illnesses. Two eminent professionals from Chandigarh Tricity became our valuable guides and mentors:

Dr B S Chavan

Director Principal & Prof. of Psychiatry,

Govt. Medical College & Hospital, Sector- 32, Chandigarh.

Dr Chavan has been a strong advocate of long term rehabilitation services for persons with mental illnesses in Chandigarh.



Dr Simmi Waraich

Consultant Psychiatrist

- Fortis and Landmark Hospitals.

Dr Simmi has been a strong pillar of support for persons with mental illnesses and their families. Her brief stint in Australia convinced her of the vital need for community support systems for persons with mental illnesses.



A discussion with PMIs & Caregivers

Testimonials

I am very glad that Aditya has set up Pushpanjali Trust in Chandigarh. I have been working for the cause of persons with mental illness for the last 15 years in Chandigarh. I am so glad that young people are entering this field. Pushpanjali Trust is making people aware of the new Mental Health Care Act, and the rights that persons with mental illness and their families have under the law now.

I am also glad that Pushpanjali Trust is mobilizing people and trying to reach out to many more through the media. We are working on a newspaper series so that we can make the general public more aware of mental health issues and disabilities.

I sincerely hope that the efforts of Pushpanjali Trust bear fruit. We have a network of parents who have been working for the cause for last so many years. And now with Pushpanjali Trust's help, we hope to achieve our long term goal for good assisted living facilities in Chandigarh.

Col. A.K Mehndiratta (Retd.) Parent & Mental Health Activist

I am a mother of an adult with mental disability. The initial years were a lot of struggle. I was all alone and I didn't know where to seek help and support. Thankfully with Pushpanjali Trust working on a Caregivers support group, I have found other parents and caregivers who I can get in touch with. Together, we are stronger. Alone, we are weak. I am now able to meet other parents and caregivers and know that we are all sailing in the same boat. We are sad, lonely, depressed at times but together we share our feelings, we share our emotions and we come out stronger. We are also much more aware of our rights. We now know how to send in a representation to the government. We now know how to file an RTI.

We will continue working for our goal of long term assisted living facilities in Chandigarh. We are hopeful of success in our mission. I am so happy that Pushpanjali Trust is empowering all of us. Together we shall win.

Mrs. Bhupinder Kaur Sidhu Caregiver

Financial Statement for 2018-19

	Amount in Rs. (Lakhs)
Assets	
Fixed Assets	
Loans Advances & Deposits	0.00
Cash & Cash Equivalents	7.30
	7.30
Liabilities	
Funds & Reserve	7.01
Loans & Deposits Unexpended Grants Creditors & Accruals	0.29
	7.30

	Amount in Rs. (Lakhs)
INCOME	
Donations	3.12
Otherincome	0.02
	3.14
EXPENDITURE	
Direct Program Activity	2.95
Administration	0.35
	3.30
Surplus for the year	(0.16)

Contact Details

Head office: H.No. 208, Sector 36-A, Chandigarh 160036

Email Address: pushpanjalitrust43@gmail.com

Website: Pushpanjalitrust.in

Our Bankers: Axis Bank, Sec-35, Chandigarh

IndusInd Bank, Sec-35, Chandigarh

Trust Registration No: DEL - PR26755 - 27122017

(under The Indian Trusts Act)

Tax benefits: Donations made to the Trust are exempt under

Section 80G (5)(vi) of the Income Tax Act, vide ref. No. DELHI/80G/2018-19/A/10092

