

## A Decade and a Half of Day Care Service for Persons with Psychiatric Disabilities: The RFS (I) Experience

**Kamlesh Kumar Sahu, M.A., M.Phil. PSW**  
Assistant Professor  
Dept. of Psychiatric Social Worker  
Institute of Psychiatry, Kolkata, India  
Former Lecturer, RFPG College for PSR, Bangalore, India

**S. Niveditha, MSW, M.Phil. PSW**  
Lecturer, Richmond Fellowship PG College for Psychosocial Rehabilitation (RFPG College for PSR),  
Bangalore, India

**R. Dharitri, M.A., D M&SP, Ph.D**  
Professor, RFPG College for PSR, Bangalore, India

**S. Kalyanasundaram, M.D.**  
Professor of Psychiatry & Principal, RFPG College for PSR, Bangalore, India

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**\*Correspondence:**

Kamlesh Kumar Sahu  
Assistant Professor  
Department of Psychiatric Social Worker  
Institute of Psychiatry  
7 D.L. Khan Road  
Kolkata - 70025 India  
Email: withkamlesh@gmail.com

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### Abstract

**Background:** Day care is a cost-effective service offering daytime care and support to persons with psychiatric and intellectual disabilities. It is effective in building users' self-esteem and in improving their social functioning and community integration. It is also effective in reducing caregiver's burden.

**Objective:** To appraise the services provided by the 'Chetana' Day Care Centre with Vocational training run by the Richmond Fellowship Society (India), Bangalore.

**Materials and Methods:** A retrospective approach was adopted. Individual case files of 228 users who were

formally admitted into the centre over last 15 years were reviewed to identify benefits to them due to attending the centre. Routine entries made by professional staff in the case record files, other periodical reports, staff assessment reports of users, and feedbacks from users and families were used to identify the benefits derived.

**Conclusion:** The users and their families reported widespread benefits that have accrued either directly or indirectly by being in the day care programme. Staff feedback about the programme performance was also identified. Important areas of learning and challenges were derived from the 15-year experience of offering day care rehabilitation services for persons with psychiatric and intellectual disabilities.

**Key words:** Schizophrenia, psychiatric disability, rehabilitation, day care

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## Introduction

Day care is an important component of community care services offered to those suffering from psychiatric and intellectual disabilities. Day care forms a vital component of any good quality community-orientated psychiatric service (Holloway, 1988). Such a rehabilitation setting is synonymously referred to as 'partial hospitalization' in American literature. These are "ambulatory treatment programmes that include psychiatric, psychosocial and prevocational treatment modalities designed for patients with severe mental illness". They offer more intensive multidisciplinary interventions and treatment, which are not provided in an outpatient or inpatient setting. A day care centre may be located in a psychiatric hospital, a general hospital, a community health centre or be free-standing. Usually, the former provide for more 'acute' short term care, while the latter provide a more supportive, long-term management and maintenance oriented service for the chronic patient (Gopinath and Rao, 1994).

It has not gained as much prominence or popularity as residential set-ups but for many persons with psychiatric and intellectual disabilities, day care offers a welcome relief from an otherwise aimless existence. In a society where many of the persons with mental illness need structured daily programme of activities, day care centres fulfil that need. Long-term day care services are planned so as to provide a sustained non-threatening social support for persons suffering from chronic schizophrenia (and other similar disabling illnesses) by means of a programme of activities individually tailored to provide the optimum degree of stimulation, together with practical help for families (Holloway, 1988).

Such a centre with vocational activities as part of its programme, can improve social skills for persons with psychiatric disabilities. These people are otherwise unemployed at the best of times, and feel isolated and friendless. Day care services offer a coherent support system that is vital to persons with chronic mental illnesses functioning successfully in the community. Often, day centres provide support, supervision and monitoring for users in transition between hospitalization and life at home. It is a source of long-term structure and support for those with chronic handicaps, preferably in a friendly, low-pressure environment. The components of support include crisis interventions, relapse prevention, improving social competence, fostering social networks, and coordination of care. For some users, the day care centre is a site for short-term focused rehabilitation or for relatively brief intensive therapy (Holloway, 1988).

To the mental health service provider agency, day care is a cost-effective way of monitoring patients' progress and ensuring they maintain well by means of early identification and redressal of problems. It is a viable option for long-term management in the community of persons with chronic psychiatric disabilities, who are symptomatically less acute and have greater long term social or vocational problems.

Various authors have identified key features of what makes day care effective. Some of these are the importance of creating and maintaining a therapeutic environment, emphasis on the therapeutic role of work, a problem-orientated approach, normalisation (providing users with a positive socially valued role), developing personal competence and social relationships, and the provision of opportunities for the user to engage in appropriate leisure, educational and

work-related activities. (Hollway, 1988).

Work, in a day care setting, is used to refer to any structured, purposeful and productive activity. Ideally there should be facilities for the assessment of work performance for training and preparation in vocational skills and placement in open or sheltered work settings. However, more often than not in the case of chronic mental illness, individuals may not be in a position to pursue competitive, paid employment. For such persons, sheltered work provided in the day care centre in the form of subcontract packing and assembly jobs are useful. For those users who may not be able to pursue any work related activity, the day programme can still be beneficial as they can be engaged in social, leisure and recreational activities. They can be taught basic self-help skills or domestic living skills and provided a place to meet and be with people without necessarily having to make close relationships (Gopinath and Rao, 1994).

Day care is a felt need in the community (Shihabuddeen and Mehar, 2008) which is expressed quite often by local families. Increasingly, day care programmes fill the void left by the lack of open employment opportunities or the shortage of sheltered work placements. A day care programme is most likely to be effective in building users' self-esteem and in improving their social functioning and community integration. It is also effective in reducing care giver's burden (Warner, 1985). In spite of these obvious benefits, one of the limitations of day care is that severely disabled people attending a day unit often lead dependent institutional lives for many years (Ekdawi, 1981). Day care settings have the tough task of balancing adequate work oriented care and a non-threatening social environment (Gopinath and Rao, 1994).

There is dearth of outcome studies particularly randomized control trails (Catty et al., 2007) and very less research publications specifically in India related to day care centre. This paper is based on an appraisal of services provided by the 'Chetana' day care centre run by the Richmond Fellowship Society (India), Bangalore and also lessons learned in running the facility over 15 years.

### About The Facility and Programme

The day care centre with vocational training "Chetana" was started by the Richmond Fellowship Society (India), Bangalore in September 1997. It is located in a residential community in south Bangalore. Persons with psychiatric and intellectual disabilities are looked after during the day (9.00 a.m. to 4.00 p.m.) and return home in the evening.

The centre offers a wide range of psychosocial rehabilitation services with the goal of making users self-reliant and contributing members of their families and community. To facilitate reintegration, individual and group based family-oriented interventions are taken up along with training in pre-vocational and vocational skills and job placements. Users are offered training in various trades such as tailoring, embroidery, hand block printing, paper cover-making, greeting card-making, handicraft work, book binding, screen printing, basic computers, and plastic welding and moulding.

The service centre is run on the Therapeutic Community (TC) approach with focus on the living-learning experience based on certain principles namely: flattening of hierarchy, democratic way of decision making, sharing the responsibility, permissiveness, easy accessibility, reality confrontation and communalism/group living (Sophia et al. 2012). The programme follows a well-organized schedule for activities of daily living, social skills training, various group therapies to enhance participation in activities, sharing responsibilities, peer group as role model for motivation and recovery, individual sessions, family sessions, psychoeducation sessions for users and families, family support group meetings, vocational training facilities, leisure-time pursuits and planned recreation. Users are referred through treating psychiatrists or mental health professionals for both short-term as well as long-term care. Users are given a fifteen days trial period before they are admitted to the centre. The duration of stay at the centre is flexible, and based on the needs of the user. Admission is purely voluntary and based on consent of the user and family. A well-qualified professional staff team along with experienced vocational instructors and support staff members work with the users. The centre offers long-term support, and is also a sheltered workshop for users with persisting disabilities who are

unable to get job placements outside.

## Method and Materials Used

A retrospective approach was adopted to identify benefits to users. Individual case files of 228 users who were formally admitted into the centre over last 15 years were reviewed to identify benefits to users due to attending the centre. Routine entries made by professional staff in the case files, other periodical reports, staff assessment of users, and feedback from users and families were used to identify the benefits derived. This paper is more of an experiential account or service provided.

## Results and Discussion

### Users Profile and Service Utilization Pattern

Since inception in 1997 till 2012, 228 users (Table 1) have participated in the day care programme. This includes users who were formally admitted into the Day Care Centre, and does not include those who did not complete the trial stay period. An average per year of 5 users dropped out during trial stay period for various reasons. The numbers do not include users from the residential facilities run by the agency.

Currently the centre can accommodate 45 users, an average of 38 users direct from community utilized the facility daily and rest of the users were from residential facilities run by the agency (halfway home and long stay home) who attend the centre for vocational training. The centre was attended by 67.5% men and 32.5% women aged between 19 to 69 years majority of (78.9%) were between the age 21-40 years, followed by 11.5% who were aged 41-60 years, 8.7% were less than 20 years and only 0.9% were above 60 years. Most of the users (78.6%, that is, 179 out of 228 users) suffered from mental illness; majority of them (58.3%) were diagnosed as schizophrenia, 20.3% had other psychiatric illnesses, 17.1% of users were having mild and moderate mental retardation. 33.3% of total users had co-morbidity or additional diagnoses (Table 2).

Most users belonged to middle and lower socioeconomic strata and one-fourth of the day care users availed a range of fee concessions. Majority of the users (63.16%) utilized the services up to one year followed by 14.47% up to two years and 8.77% up to three years (Table 3). There were various reasons for leaving the centre (Table 4).

**Table 1. Yearly Service User, Admissions and Discharge from the Centre (1997 – 2012)**

\*some users continued in next year, 15 users had second admission and 2 had 3rd admission.

Year	No. of users	Admissions	Discharged
1997	05	05	00
1998	20	15	08
1999	27	15	08
2000	39	20	21
2001	30	12	14
2002	28	12	08
2003	40	20	11
2004	44	15	15
2005	44	15	13
2006	45	14	11
2007	42	08	22
2008	33	13	09
2009	41	17	10
2010	43	12	13
2011	43	13	21
2012	44	22	10
Total	568*	228	194

**Table 2: Diagnosis-wise Profile of Users**

Primary diagnosis	No.	%
Schizophrenia	133	58.3
BPAD / Depression	20	8.8
Schizoaffective disorder	13	5.7
OCD	7	3.1
Mental retardation (mild and moderate)	39	17.1
Personality disorder	4	1.8
Psychosis NOS	2	0.9
Others	10	4.3
Total	228	100.0

**Table 3. Duration of Stay**

Duration of Stay in Months	No. of Users	%
1 – 12	144	63.16
13 – 24	33	14.47
25 – 36	20	8.77
37 – 48	11	4.82
49 – 60	5	2.19
61 - 72	3	1.31
73 - 84	4	1.75
85 – 96	2	0.88
97 – 108	0	0
109 - 120	3	1.32
Over 120	3	1.32
Total	228	100%

**Table 4. Reasons for Leaving the Centre**

Reasons for discharge / Leaving the Centre	No. (%)
Got a job (includes joining family business)	31 (13.60%)
User was symptomatic / had a relapse	30 (13.16%)
Family relocated / settled outside of Bangalore / returned to hometown	25 (10.96%)
Joined Asha	16 (7.02%)
Financial difficulties	14 (6.14%)
User was not interested in continuing at Chetana	11 (4.82%)
Trying for a job	10 (4.39%)
Joined computer course outside	11 (4.82%)
Joined another rehabilitation centre (in Bangalore)	11 (4.82%)
Distance of the centre from home	9 (3.95%)
Trial job placement	7 (3.07%)
Information not available	7 (3.07%)
Staying at home to look after ill parent	5 (2.19%)
User doing well, staying at home	4 (1.75%)

To continue further studies	3 (1.32%)
Difficulty reaching the centre	3 (1.32%)
User's physical health reasons	3 (1.32%)
Joined another residential care facility (out of Bangalore)	2 (0.88%)
User joined Chetana as a volunteer	1 (0.44%)
Family planned to place the user in a residential facility	1 (0.44%)
User could not be managed at Chetana	1 (0.44%)
Completed term	1 (0.44%)
Family arranged a helper to look after user at home	1 (0.44%)
Plans to enroll in a computer course outside	1 (0.44%)
Plans to resume studies	1 (0.44%)
User went missing from home	1 (0.44%)
User expired	1 (0.44%)
Total	210*

\*some users cited more than one reason for leaving

### Benefits for Users

The users and their families have perceived or reported widespread benefits that have accrued either directly or indirectly by the centre through the wide-ranging psychosocial rehabilitation services offered to them. The following areas were identified based on feedback collected from them:

- **Development of a routine and work habit:** Users get into a structured routine over a period of time as they regularise their attendance at the centre. The day is structured to facilitate users to be engaged gainfully during the day, which helps them develop a work habit. A timetable is individualised for each user and periodically reviewed with the user and family to make the user maximise his/her time at the centre.
- **Reduction in family burden:** Families expressed that the centre offers respite care; having this place available to send their wards to during the day had helped reduce their anxieties about providing a safe and secure environment for the user. They felt they need not be worried about making arrangements to have one family member stay at home to supervise the user during the day. This also gave them more time for themselves and to be able to look after their own routine. They also noticed that as users stabilised symptomatically and improved in various areas (personal care, social interaction, communication, work and leisure time activities, etc.) it helped to reduce or prevent relapses. This contributes to reducing costs otherwise incurred on repeated visits to the psychiatrist, hospitalisations, travel, and so on.
- **Opportunities for developing social and interpersonal skills:** Though the centre is primarily meant for vocational training, activities are structured in such a manner that it offers optimum scope for social interaction. Peer interaction is woven into the day-to-day routine of the user, be it starting with a group meeting in the mornings, or working together in groups in the vocational unit, familiarizing with others during the breaks, enjoying a group outing such as a movie or a picnic. Interpersonal skills are also honed through formal and informal interventions under staff supervision.
- **Vocational inputs:** Around 17% users got a job/ self employment/placed for job during last 15 years of service (table 3). Job-related inputs such as prevocational and vocational skills training enhanced users' work behaviour and performance. Vocational guidance, job placement and retention helped users become independent. These are crucial in the rehabilitation process. Job-oriented interventions benefited the user as a placement in a job improves his/her self-esteem and confidence, facilitates financial independence, reduces the extent of the person's emotional dependence on the family, keeps the person functional and prevents relapse of the illness. All these factors hasten the

process of reintegration of the affected individual into the family and community. In a study Suresh (2008) concluded that vocational rehabilitation significantly improves social functioning, cognitive functioning and psychopathology in persons with chronic schizophrenia which in turn help these patients to integrate into the society so as to function efficiently in their roles as parents, home makers and social beings.

- **A supportive and non-threatening environment for skill acquisition:** The centre offers opportunities for learning, correcting and relearning various crucial day-to-day skills. The learning is facilitated by staff belonging to professional, non-professional, as well as volunteer groups. A supportive environment is fostered and users are encouraged to learn albeit through errors, corrective feedback, social reinforcements (through peers, staff and family members).
- **Reducing the extent of stressful contact: In most users with chronic illnesses, there are areas of day-to-day friction.** Family members feel stressed out due to prolonged care-giving, and users too feel constantly under pressure when in the midst of family members all the time. Being away for six to seven hours of the day at the centre helps relieve some of the tension for both parties that would otherwise be caused due to constantly being in each other's presence. It also helped in reducing negative expressed emotions.
- **Family support group:** There are regular meetings for the family members. These interactions serve as a source of support for the members, and an opportunity for sharing, expressing and learning, both for staff as well as families. Families can derive various advantages from such self-help groups (Shihabuddeen and Gopinath, 2003) and this is an area that needs to be further worked on. A previous study at this day care centre on benefits of being in such support groups found that participation in a support group meeting positively affected the family members' adaptation to mental illness in a relative. In this study, members reported that they developed a 'feeling of togetherness' as a result of being a member of a group with common aims, and gained in learning adaptive coping skills, resulting in more emotional support and improvement in the relationship with the ill member (Ponnuchamy et al., 2005).
- **Availability of a range of concessions that makes care affordable and accessible:** Nearly one-fourth of the users accessed day care facility with fee concessions. Fee concession rates varied from total exemption of fees to 10% of the fees payable. The rate of concession was decided based on genuineness of the need and ability to pay. Families noted that this benefit helped in maintaining functional levels of users, as without these concessions, the users would have dropped out of the centre and been idling away at home.
- **Community/group living skills:** The focus at the centre is not only skill acquisition as an end result, but also the process of facilitating this. Users took up various roles and responsibilities as part of their training programme, be it personal, familial, related to work or maintenance of the centre. Being part of a group, be it while learning, interacting, spending leisure time, group play, etc. helped users immensely. The group situation, fostered through the TC approach, encouraged peer acceptance, corrective experiences, and importantly, offered scope for modifying behaviour through peer pressure and social reinforcements, which were found to be effective, sustained, and also accepted more constructively by users.
- **Increased knowledge about illness and its management:** It is known from previous studies that improved caregivers' knowledge about the illness leads to decrease in relapse and re-hospitalization. The increased knowledge gained through psychoeducation may have improved the mental health as well as resulted in decrease in perceived level of distress. Caregivers become more tolerant of client behavior resulting in better acceptance of persons with mental illness. Family sessions have also helped in minimizing negative expressed emotions and unrealistic high expectations (Leff, 1994; Cassidy et al., 2001; Hegde, 2012).

## Learning

Over the years, there have been several crucial learning aspects. These include factors that have contributed to the

effectiveness of the programme, as well as pointers to areas where there is scope for improvement:

- **Staff sensitisation is crucial for the programmes to be effective.** Staff members at all levels (professional, vocational instructors, volunteers, office and support staff) need to be aware of the nature of difficulties users at the centre have, and basic ways of interacting with the users. In this context, regular ongoing psychoeducation sessions for non-professional staff are facilitated at the centre.
- **The therapeutic community approach has been found effective for users.** It has made the programme more transparent and flexible to suit the users' needs. There is a sense of 'ownership' from users as it increases their participation and involvement in the day-to-day running of the programme.
- **Work orders facilitate on-the-job training.** Though not financially profitable, work orders from outside give users practical inputs where they simultaneously learn and get work experience. This exposure is important for them to adjust to work demands such as fixing and fulfilling individual and group output targets, meeting deadlines, handling delivery of the consignment, collecting payments, and so on. The presence / visibility of the agency is also improved by such contacts in the community.
- **Varied activities in the routine make the learning/work environment stimulating.** Shifting a user between two vocational units at least in a day reduces monotony of tasks. Apart from routine work, introduction of varied activities such as music sessions, group work sessions, creative activities such as collage making pertaining to relevant themes have been introduced. These help sustain interest of the users and staff in the programmes, and prevent the routinisation and inflexibility of daily activities.
- **Introduction of cognitive retraining.** Cognitive remediation tasks are inbuilt into the daily day care programme to improve cognitive skills such as attention span and concentration, though in an informal manner. Tasks like reading, drawing and colouring, solving puzzles, computer-based games serve the purpose. Plans are afoot to include cognitive retraining as a formal routine intervention in the rehabilitation programme itself.
- **Involvement of the family in rehabilitation care is important.** Families are seen as partners in the process of rehabilitation, and are a vital resource that is often undervalued or unrecognised. Regular family sessions and family meetings help the centre keep them informed and involved in a variety of ways such as fund-raising, advocacy, volunteering services at the centre, etc. Recently, family volunteers are also helping with executing work orders e.g. supplying paper covers. The idea is to encourage family members to learn vocational skills and ultimately form user work cooperatives.
- **Integrating services for the mentally ill and the mentally retarded have been effective.** Users realise that others too have difficulties, become more sensitive to their special needs. There is greater acceptance of differences.
- **Involvement of volunteers at the centre has been very advantageous as they create bridges between the agency and the community.** Working with volunteers has been a learning experience for staff as they come from varied fields (such as art, computers, special education, etc.). In some cases, volunteers have moved on to become regular staff of the agency.
- **The centre doubles as a sheltered workshop for some users with severe or chronic disabilities, who are unable to find suitable employment outside.** This has been advantageous for this group, as they have a simulated work environment, which is at the same time supportive. A few users also get a minimal honorarium for their work done.
- **The agency offers opportunities for fieldwork training for students.** Post graduate students from the

Richmond Fellowship PG College and from all over the country and abroad have postings at the centre for practical exposure.

- **Networking with other agencies is another essential area.** The centre has been working with various voluntary agencies in the disability sector, as well as funding agencies, individual donors, and agencies in the community (such as local hospitals) that place job orders with the centre. This is another area of work that needs to be improved upon in future.
- **Incentives have been useful in motivating users.** The Assessment Schedule for Incentives (ASI), a rating scale developed at the centre, is being used to assess users monthly progress. The monetary incentive they get is based on their overall score on the scale that assesses performance on areas like attendance, self-care, work performance, social interaction and participation in programmes. The incentive scores are discussed with the users in one-to-one as well as group sessions and the feedback is used to improve performance further.
- **Burnout amongst staff, both professional as well as non-professional, is also an area of concern while working with users with chronic difficulties.** Activities to address staff stress and burnout include regular staff meetings and recreation activities for staff to help them share experiences, manage stress, and retain motivation for work. The staff psychoeducation sessions also help address staff concerns, especially coping with difficult behaviours / illness-related behavioural problems of users, by offering skills training in these areas for staff.
- **Fee concessions have made the centre accessible to many users who would otherwise be left out solely due to their inability to afford the services.** Due to the financial constraints of the centre however, this benefit has been limited to about one-fourth of the users. There are many more who require day care or vocational training, but remain unreached because of financial difficulties.
- **The centre has external experts on various committees, such as the Advisory and the Admission committees.** The experts offer their suggestions and review the programme functioning periodically through these meetings. This helps in improving programme effectiveness, as well as making the agency accountable, transparent and credible.
- **Documentation plays a vital role in maintaining continuity of care.** Users at the centre stay for varied lengths of time, staff members are posted to various facilities of the agency on rotation. However, staff turnover is high. All these make continuity of care difficult. Systematic documentation of user progress in individual case files has proven invaluable, also from the research point of view.

## Difficulties & Hurdles

- The centre has not been able to provide intensive / comprehensive inputs for mentally challenged users. Staff members need to gear up to meet their specific demands.
- The growing number of users, especially with some of them requiring more supervision than others (due to the nature of their symptoms) has led to shortage of professional staff
- Bridging the growing financial deficit each month has been a significant hurdle. This is due to various factors like imposition of VAT (which we are unable to recover from our customers), offering fee concessions to nearly one-fourth of users, increasing costs of day-to-day maintenance of the premises, high wastage and frequent wear and tear of equipment during on-the-job training, and consequent heavy investment on maintenance.
- The returns on investment are marginal, and often the centre only manages to break even, owing to the small scale

of production.

## Challenges Ahead

In the background of the experiences of the centre so far, there are a few areas that remain as challenges:

- Making services cost effective and available to as many users as possible
- Increasing visibility for the centre in the community
- Proactive involvement of family support group in mobilizing resources, and increasing the self-help component in the family groups
- Marketing of products made at the centre to be structured and formalised
- Making the sheltered workshop economically viable, given the high running costs (due to high wastage levels, recurrent repairs or replacements of machine parts, limited scale of production, etc.)
- Job placements and follow-up for users have to be made more formal
- With regard to vocational training, increasing the options offered, updating and modernising the training facilities so as to make it suitable to the market demands
- Funding to increase the number of vocational trades for training.
- Research and development of standard tools for assessment of work behaviour and performance and facilitate effective group activity for heterogeneous groups.

## Conclusions

In spite of having a huge need for such day care services in the community there are very few facilities that are available. It is evident that day care services for persons with psychiatric disabilities are beneficial, and the positive impact extends not only to the user but to the family as well. Day care interventions are feasible but there are few challenges as well.

## Limitations

A major limitation of this paper is that it included only qualitative subjective account of outcome; no systematic quantitative outcome assessment was undertaken. Being a retrospective account it has its own limitations.

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