

IN REFLECTION : MAKING SENSE OF ACHIEVEMENTS AND FAILURES OF A CBR INITIATIVE

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ABSTRACT

This paper presents lessons that were learnt while carrying out a CBR project for rehabilitation of physically disabled members of a village community. The outcomes of this project are narrated in a reflective manner without categorising them as either achievements or failures. The purpose of this paper, therefore, is to share our understanding of the performance of a CBR programme.

“The modest amount published about CBR continues to be mostly on ‘What A great Job we Did’, i.e. the heroic struggle to get things going, urgent pleas for funds to expand, anecdotes from grateful clients, etc. No doubt this literature has its place, but the genre seldom contains any serious, critical thinking” (1).

For over five years during the early nineties we were committed to setting up a Community Based Rehabilitation (CBR) project at Sirathu (a village district bordering western Uttar Pradesh, India), a region which was till then unexposed to voluntary initiatives by any formal agency. We came across many opinions in matters related to CBR, which communicated to us the merits and viability of community based approaches in meeting challenges of disability. There were many written reports documenting success of such initiatives. For us, who were stepping out of an academic department into the “real” world for the first time, such informed opinions and narratives of success had a great inspirational import. Driven by the zeal to align psychological knowledge to needs and aspirations of people, we ventured out, made commitments, formalised plans and strategies, made efforts to enter into the community, solicited support and carried out many activities in the name of CBR. We were elated when the programme moved along predicted lines but most of the times remained confused for it would digress in unforeseen trajectories. All through, the programme oscillated between achievements and failures as did our “sense-making” of its outcomes. It is only after the programme has caved in for reasons that this paper would enumerate after a while, that we feel the need to reflect and narrate the story of the programme performance. We are doing it at a cost; there are apprehensions of being seen as initiators of a social action programme who were more enthusiastic than informed, those who made mistakes but did not pause to correct them and now are indulging in the luxury of reflection when threats of either losing face or cessation of funds have become matters of distant past. Yet, the need to tell the story is more compelling than threats associated with misperceptions.

It seems to us that categorizing outcomes of any change effort as either achievement or failure casts outcomes in an evaluative mould and renders any alternative interpretation of the meaning of an outcome, almost impossible. Depending upon how efficiently and at times, strategically, the conflicts and crises inherent in human endeavours are appropriated, outcomes appear to be either achievements or failures. What is deemed as an achievement may have failed in the sense that it may have met the expectations of a select few at the cost of ignoring the aspirations of a large number of stakeholders. Similarly what gets dismissed as a failure may indeed be an achievement for it may affirm the dignity of human effort and furnish insights for improvement. Therefore, while narrating the story of this CBR initiative, it would be our task to critique limits of what we did achieve and present possibilities hidden in our failures. Incidentally, the story that we are about to tell does not have a consistent story line. During the course of this paper readers might experience many shifts, some of which they may not anticipate; the narrative and the sense making will proceed side by side and in no definite order. In reflection, this perhaps is inevitable.

Recently, it has been suggested that among psychologists, the understanding of disability has remained confined to addressing psychological issues which an individual with physical disability might present and therefore psychologists need to “..... demonstrate competency to develop clinically valid intervention strategies and address concerns that fall outside of the realm of psychological issues” (2). No doubt, the core of the disability concept is the individual but the term ‘disability experience’ that has gained currency, implies that disability is not inherent but is experienced at the intersection of person and environment (3). Besides, it is the contention of the first author that only psychologising issues of vital concerns - those that affect human lives and determine the quality of human condition- and not taking any initiative to bring about a positive change, is an act of irresponsibility. Therefore in order that psychologists speak and act responsibly vis-a-vis disability, there is an urgency to grow out of the disciplinary confines and carry forward the task of integration of persons with disability into the societal mainstream by at least recognizing issues which may fall outside the psychological realm. While it may be conceded that psychologists are not trained to address issues at the systemic level, yet there are visible signs to suggest that they would continue to visualise possible utopias and will sustain efforts to realise them (4).

Irrespective of who initiates social action programmes and with what kind of training, the core of almost all such programmes which aspire to intervene in processes with discriminative socio-political underpinnings, is animated with an idealistic vision of creating a better tomorrow for those who are discriminated against. A natural fall-out of this vision is to understand the reality in clear dichotomies such as the perpetrator and the victim, the haves and the have-nots, the deprived and the privileged. Interventions that are designed to bring the underprivileged at par with their privileged counterparts, clearly share this vision. Although noble in their

intent, they seldom address the question of discrimination at a systemic level. Their schemes of evaluation define programme success in terms of the number of underserved who eventually get served through the programme. For example, most CBR programmes subscribe to this 'victim-service' model of intervention because they ascertain the effectiveness of the programme by counting the number of persons who were given aids and appliances, compensatory education, skills or physiotherapy. Even when such remedial projects are undertaken with the help of community's initiatives or expertise, they still reflect the institutional model of rehabilitation which considers compensation for the losses due to physical disability as the only method of restoring independence and freedom.

We recognised right from the beginning that disability is more a socio-political issue than an issue arising out of physical limitation or impairment, and that no CBR programme can ignore the socio - political fabric of the community. We also realised that the means to access and reinforce the lost sense of power and autonomy lies in political action and not in treating persons with disability as a special category of people in need of help and assistance, because such compensatory initiatives only accentuate the dichotomies that must be done away with. What confused us was discovering appropriate strategies that would begin and sustain the political action of this variety.

Why not focus on abilities rather than disabilities? We raised this question hoping that the answer might help us explore capabilities of Persons with Disability for their development and integration into the community's mainstream. This question could also change the reference point : what becomes more important is not what able-bodied are doing or are capable of doing but the unexplored potentials of persons with disability themselves. Implicit in this approach lies the assumption that like any one else, persons with disability too have their unexploited reservoir of creative energies which can be released and utilised for the community's development. In that sense they become equal partners in realising the dreams and aspirations of the community. Related to this, was the possibility of viewing CBR as a project of community development because a CBR programme could sustain if it contributed to the development of the entire community. If persons with disability become more resourceful, then resourcefulness of the entire community is enhanced. Needless to say that placing the enterprise of CBR within the power dynamics and developmental processes of the community can render programme implementation more difficult. What may appear to be a sound ideology may not lend itself easily to concrete action plans. As was true in our case, the problem got further complicated by our lack of expertise in handling such vexed issues.

It may be best to begin with a brief description of the site, the programme ideology and its objectives. This CBR initiative was undertaken in five villages of Sirathu tehsil (an administrative division) of Kaushambi district. These villages had a total population of about sixteen thousand

people. Barring a few high caste families, most inhabitants belonged to scheduled and backward castes and worked either as underpaid agricultural labourers or petty businessmen. There were around three hundred persons with physical disability (we had a list and detailed information of two hundred and twenty persons but we estimated that the list was not exhaustive) due to post-polio residual paralysis (PPRP), tuberculosis, malunion/nonunion of fractures and traumatic amputations due to accidents. Out of these 220 persons 180 belonged to scheduled and backward castes and the rest were either high caste Hindus or Muslims. The number of children with disability was fairly large. The adults had disability since childhood or early adulthood and had not undergone any medical treatment or physiotherapy. Some were educated upto the primary level but the rest were either illiterate or semiliterate. A large number of children with disability did not go to school and the disabled adults usually stayed at home. There were at least one primary school and one adult education centre in each village but the attendance was poor. There was just one Primary Health Centre (PHC) for all the villages of the tehsil. Except for a few government sponsored campaigns for birth control and immunisation, this region was not exposed to any kind of voluntary social action.

Given that the overarching philosophy of CBR is integration of persons with disability in all spheres of community's life, this programme addressed the question of integration within the framework of empowerment of persons with disability and of the community. In that case, perhaps, integration becomes both, the means as well as the indicator of empowerment.

Many community psychologists in the West have used the term empowerment as an individual's sense of mastery and efficiency, without focusing much on the context in which empowerment takes place. Experience tells us that in the world of action where individuals, groups and organisations struggle to control resources to fulfill their competing goals, empowerment for one is loss of power for another and the powerful do not always give up power so easily. One may get embroiled in such debates as long as the implicit linkage between individual empowerment and the empowerment of the community are not appreciated.

Integration of persons with disability into the community's mainstream both as a means and as an indicator of empowerment requires conceptualising empowerment at the levels of a person with disability, a group of persons with disability and at the level of community. At the individual level, the driving force behind empowerment is the critical consciousness of powerlessness due to external forces which are not under personal control. From this vantage point, psychological variables such as personal inefficacy, lack of personal control and learned helplessness come handy in understanding the subjective experience of powerlessness and forwarding strategies that can help the individual become more efficacious and resourceful. This conceptualisation of empowerment dissociates the individual's psyche from his social conditions and ignores the intricate mechanisms through which individual and social environment interact. This conceptual lacunae is overcome when persons with disability are

seen as a pressure group striving to access and create resources and control their allocation. To be able to engage in political activity of this variety, cognitions regarding personal control and self efficacy are perhaps necessary and here in lies the delicate link between the two perspectives. At the level of community however, the notion of empowerment needs to extend beyond its restrictive definitions and popular images. Community empowerment, as we see it, not only refers to the community's greater control over the resources for its development vis-a-vis other communities or the state but also refers to its increased resources which are available by integrating persons with disability into its mainstream. The power struggle between persons with disability and the larger community is at least theoretically resolved when both are seen as the sources and beneficiaries of empowerment. If persons with disability acquire greater power from utilising community's resources, and in the process discover additional sources of power, the community too becomes more powerful by utilising the resources of persons with disability who have now been integrated into its mainstream for its development. Idealistic and to some extent unreal though it may sound, this broadening of the notion of empowerment is necessary for conceiving CBR as a community development project.

This very brief description of the programme ideology can now render the rationale for laying out certain objectives and carrying out certain action plans, more comprehensible. The main thrust of the programme was to integrate persons with disability into the community's mainstream and improve the quality of life of the community as a whole. More specifically, the objectives of the programme were to :

- (a) evaluate the health and rehabilitation needs of the village community and mobilise persons with disability, their families and the community so that they are able to access institutional resources and create new resources to fulfill their health and rehabilitation needs.
- (b) sensitise the community towards special needs and abilities of persons with disability so that it maximally utilises them for its development and
- (c) mobilise the institutional and local resources for promoting economic self reliance among persons with disability.

A significant feature of this programme was that it attempted to anchor attitudes (of persons with disability their families and the larger community) towards disability within the matrix of empowerment and integration. The purpose was to add a psychological perspective to the programme and test the extent to which attitudes (a micro level concept) help in understanding the dynamics of these essentially macro level processes. Intuitively, it appeared to us that the hopes and possibilities which are nurtured despite serious physical limitations are psychological resources to strengthen political actions directed towards securing the desired end states. If

the current psychological state is that of resignation, apathy and withdrawal, initiatives for regaining the lost sense of independence and freedom would be less likely. For such initiatives to surface a more favorable self-perception was perhaps necessary. Positive attitudes towards disability which, from community's perspective refer to a belief that persons with disability can become productive members of the community, could make their special abilities and skills, more evident. The community would get empowered to the extent that it utilises those abilities for its development. Putting it differently, the kind of attitudes which persons with disability and the community hold towards disability would determine the efficacy of political mobilisation, status of persons with disability, their level of integration, and the seriousness with which community would take on the responsibility of their rehabilitation and create necessary conditions for equal participation.

Having said that, now the stage is set to review the CBR activities which we undertook and to critically evaluate their outcomes. Rather than listing the activities which we were able to either initiate or complete, our choice is to consider them as components of various action plans. Looking at the nature of these activities, the action plans which were carried out were creating awareness within the community about community's needs of health and rehabilitation and about the general philosophy of CBR, mobilising the community and persons with disability to get access to rehabilitation facilities which existed but were denied to them, and changing the community's negative attitudes (the data which we collected around that time on disability attitudes, beliefs and behaviour clearly showed that attitudes towards disability and disabled persons were extremely negative) by helping some persons with disability become models of success in terms of being economically self reliant.

The programme took off in early May 92 with a couple of informal meetings at the villages. These meetings were attended by the opinion leaders such as the Gram Pradhans (village heads), Block Development Officers, doctors from PHC, teachers of primary schools and also by persons with disability and their families. In these meetings, issues relating to causes of disability and its prevention, nature of disability in that region and the resources for rehabilitation were discussed. During these meetings, our focus as initiators was to highlight the merits of the CBR approach in addressing these issues. The initial response of the community was very positive. The area for programme implementation was earmarked, people offered their services voluntarily and even suggested concrete steps that could be taken in these directions. Some volunteers took up the responsibility of identifying persons with disability in five villages, the nature of impairment, their needs and special abilities and their expectations from the programme. This survey yielded a detailed record of 220 persons with disability residing in that region.

Building awareness is perhaps the most important and at the same time, most challenging task. Especially when a programme carries a definite ideology, there is an urgent need to arrive at a shared understanding of its essential components. Often in this urgency, the

alternative understanding of the components is silenced and needs other than those which the programme purports to address are marginalised. We still remember an old disabled lady walking up to us and asking what the legitimacy of promoting rehabilitation was when even safe drinking water was a scarce resource. Another young disabled person alleged that CBR was yet another instrument used for denying the benefits of technological expertise in the field of rehabilitation to those who need them the most but cannot afford them.

We did not have ready answers to these questions. These and many more such instances have suggested to us that community's understanding about what is desirable and what the programme should be achieving was at variance from our understanding but, nevertheless, it is this variance which was of critical significance. The act of inflicting a programme on the community with 'stated' goals and objectives closes all avenues for a meaningful dialogue to arrive at a shared understanding about the goals and objectives of the programme. This definitiveness with which a programme is launched militates against the very spirit of empowerment because in this entire exercise, community has no role to play. The goals and objectives if stated as though they are sacrosanct, only reflect the vision of the initiators and not that of the community. Attempts should be made so that they may come to be 'shared' and should remain open to modifications and adjustments as and when required. This we learnt the hard way and tried to recast the programme objectives in the light of community's understanding of CBR. It is another matter that this understanding eluded us because the village community that had competing factions and conflicting interest groups, interpreted CBR in more than one way that were often irreconcilable.

Awareness also increases needs and expectations and when they grow beyond what the programme can afford to fulfil, it becomes difficult to sustain people's motivation. Despite our repeated submissions that it was neither our intent, nor did we have necessary resources to distribute money or other things, people in general and persons with disability in particular perceived the programme as a source that could fulfil their long pending demands for financial help and assistance. We had in our files, a number of such applications and it became increasingly difficult for us to wean people away from those expectations.

These unfulfilled expectations were then manifested at different levels. The promise which the project showed started waning and the enthusiasm with which the programme began started fading at an amazingly rapid pace. The office bearers of the project started abstaining from meetings and other activities. At that stage we came to realise that people were dissatisfied because by then they knew that the programme had no backup of external funding which they could have utilised to strengthen their political base. At the same time, they also saw that the participation of persons with disability and their families in the programme had increased. Since a majority of persons with disability belonged to the scheduled and backward castes,

their increased participation was perhaps being perceived as a threat to the existing socio-political order.

We feel that as long as any social action programme remains at a 'show case stage' in performing essentially a decorative display function such as highlighting the credentials of the initiators and the participants, it evokes great enthusiasm. But when it gets underway and starts striking at the vested interests, threatens to disturb the existing pipeline of resource flow and unsettles political structures, it meets with resistance. Therefore we are tempted to interpret the dissatisfaction of the office bearers of the project both as an achievement and a failure. If some such people were dissatisfied, may be the programme was doing well. The activities directed towards creating awareness had a 'ripple effect' in the sense that many persons with disability belonging to villages other than the selected five, came in large numbers and shared their problems with the group. They even made suggestions about what they could do with or even without external help. We considered it as an achievement because persons with disability and their families who should ultimately own the programme were taking more interest and initiative and the political heavyweights were distancing themselves. It was also a failure because these politically powerful people who could have provided a major impetus to programme planning and implementation were dissatisfied and angry. We made desperate attempts to discover what had led them to feel dissatisfied. Despite our concerted efforts, that remained unknown till the end and we could not devise methods which could have harnessed their political ambitions to use their resources for programme augmentation.

Somewhere during the middle of programme implementation we collected some data from the PHC about the number of inhabitants of the chosen villages who went for immunisation prior to May 93 and between May 93 and December 94. The number had significantly increased both for high caste people, as well as for the scheduled and backward castes though the increase was much higher in case of scheduled and backward castes. It may be unfair to suggest that this was entirely due to the awareness which the programme had brought about. All that can be said is that the programme could have been one of many factors which led to this difference.

Another set of activities that we carried out consisted of mobilising the community to get access to the resources for rehabilitation. The Government of India had instituted many welfare schemes for the rehabilitation of persons with disability, such as loans for self-employment, vocational skills training, concessions in travel and fellowships for education. As our visits became more frequent, we realised that people were either ignorant of such schemes or were unable to avail them for various reasons. This knowledge gave us the first opportunity to take a small step in the direction of community mobilisation for increasing the responsiveness of the bureaucracy towards community's needs. This we thought was not a difficult task and with little effort, the strength of collective action could be readily demonstrated.

In order to avail such facilities, a certification of disability from the Chief Medical Officer or from the head of the orthopaedic department of the local medical college was needed. The community took a major initiative in this direction and organised three such camps where doctors from the city visited the site, made disability assessments and issued disability certificates to more than a hundred persons with disability who were eligible. These certificates were used for various purposes and the local doctors and other officials who were previously denying help came forward to help the persons with disability complete various formalities for obtaining certification. Many persons with disability and their families also contacted the Government and non-government agencies in the nearest city.

However, getting access to community's own resources for rehabilitation continued to remain a distant goal. This happened because many local resources such as surplus land of the villages were managed by people who were politically powerful. They were reluctant to distribute the land to persons with disability because that could have brought about power imbalance and disturbed the existing social structures and relationships. If a village chief extracts political mileage by extending the favour of giving surplus land of Gram Samaj (village community) to one of his allies, would, he give the same land to a person with disability or his family? Therefore as far as using local resources for rehabilitation was concerned, the distancing of the powerful groups from the programme constituted a major set back.

The programme attempted many other activities but they were not followed up very systematically. For example, one volunteer was attached to the orthopaedic department of the medical college for fifteen days to learn physiotherapy but he could not start giving this service at the village level. Similarly, a three-day bee keeping training programme was organised at the PHC of Sirathu with the help of the government's garden at Allahabad city but there was no follow up because it required financial investments in the beginning. With the help of a local NGO, working for the rehabilitation of blind children in the city, we provided small loans to two persons with disability to start pavement shops. Whether or not it created success models is a matter of debate but that definitely created more pressure on us to extend such activities to others.

It was around that time that we thought that the programme was in need of a major change. Instead of feeling desperate and making sporadic attempts to give the programme a new lease of life, we decided to implement plans for the vocational rehabilitation of persons with disability. To achieve this, we arranged to start an integrated school where disabled and able-bodied children could learn together, and a bakery that was to be owned and managed primarily by the disabled members of the village. Little did we realise that attempts at vocational and educational rehabilitation are no magic wands to resurrect a programme that was already sailing in troubled waters.

Within a couple of months of commencement of the integrated school at least two such schools sprang up nearby. This was a great surprise as this was least expected. We were later told that since one of us belonged to a family of erstwhile landlords who had still managed to remain influential in that region, these initiatives were perceived as yet another strategy adopted by the family to increase its power base. The bakery was hijacked by others, marginalising the disabled members of the community. The programme suffered because of yet another reason. In order to ensure a smooth entry into the village community we relied heavily on a couple of key persons. Although it may be a good way to begin with, yet the process of entering into the community must be carried forward, a task we did not engage in. All programme activities centred around these key persons and predictably enough, the programme came to be identified as their programme and not that of the community. Later those key persons got involved in other activities and lost interest. One such key person suffered a major health problem and as a result many ideologically driven activities came to a grinding halt.

Now, in reflection, many images and insights related to programme performance - what we did and what we could not, where we erred and where we succeeded, what could have been done and how - keep coming to us, some of which compel us to ruminate over our success and failures. In retrospect, we find it extremely difficult to flag 'success' or 'failure' as the outcome of our initiative. What seems possible at this stage is to share with the readers, some sense which we have been able to arrive at from this very exciting but unfinished project.

We have come to realise that CBR is a relatively difficult concept to communicate and even more difficult to generate a consensus about what it means. It has been our experience that trying to arrive at a consensus regarding the meaning of CBR, while interacting with diverse groups with varied interests, motivations, background and commitment, is not an easy task. Moreover, the idyllic image which the term 'community' evokes in our minds is more a myth than a reality. It is not as though a vibrant community consisting of people eager to extend help and cooperation to one another already exists and all that is needed is to just plug in the task of rehabilitation. In fact, the community spirit has to be consciously cultivated, maintained and reinforced from time to time. How efficiently this task is handled, determines how smooth becomes the entry and subsequent success of a CBR initiative.

It has often been suggested that in India, most community development programmes did not yield desired results because the programme did not modify the psychological structures of people (5). Our contention is that before one intends to modify the psychological structures of others through any programme, examining one's own motivations is perhaps imperative. If the motivations are only to drive home the point that 'I am holier than thou' or 'I have had a feel of the soil' or to 'add another feather in one's already colourful cap', then one most

likely will become what Miles (1) calls 'a flying expert'. In this case one is not aiming for sustainability of a programme and therefore one will not get it. But if the motivation originates from a deep rooted conviction to change an unjust social order by mobilising people to fulfil their dreams and aspirations, then any intervention to bring about change is not a part-time engagement. Building capacities through social interventions requires fusing of expert knowledge with local knowledge, that which is available in the form of beliefs and perceptions (6). This can happen only when the initiator is willing to become a part of the community and is ready to put other concerns at bay. A successful intervention, after all, is not so much a matter of expertise as it is a matter of commitment.

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