

The Leaking Pot & the Wise Water Carrier

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Once upon a time, a young man worked as a water-carrier at the palace. He had two clay pots, which he hung on the two ends of a pole held across his shoulders. He walked from the stream to the palace and back along the same path all day long. One of his pots had a crack and hence water leaked out of it. Yet, he loved both of them and cheerfully went about his work.

The leaking pot, though, was quite unhappy. A nagging feeling that its inability to hold water was causing hardship to the water-carrier chewed at its heart. One day, unable to bear its dejection any longer, the leaking pot burst into tears. The puzzled water-carrier tenderly asked what the matter was.

Upon finding out the reason for the pot's unhappiness, he asked the pot to look at the path they took every day. On the side where the leaking pot hung, the path had beautiful flowers blooming. There were flowers of all possible colours: colours which one could only dream of. The other side was completely barren.

The wise water-carrier explained that he had planted all those beautiful flowering plants on the side where the leaking pot hung. The pot's unique ability had made the path beautiful and had made the water-carrier's walks back and forth extremely pleasant.

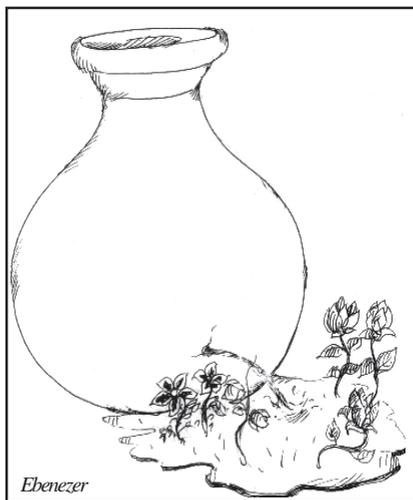
Moral of the story: Each one of us, with our abilities and disabilities, can be constructive members of society if society takes the trouble to nurture us.

I read this story in a newsletter of an agency, which provides services for people with mental disabilities in a mid-western state of the USA. Incidentally, the newsletter claimed that the above story was an Indian folk-tale.

I volunteered in that agency for a year and would like to share my observations. I am aware that this level of care and competence is not typical of the vast majority of agencies providing special care in the US, but its example vividly demonstrates how, in some societies, important initiatives have been taken to bring a measure of normalcy into the lives of the handicapped.

This agency is government-funded and also receives small private donations. It caters to a rural population and has a very modest budget in comparison to many private agencies.

This professionally run agency has close to one hundred full-time and part-time paid employees as well as volunteers and caters to around three hundred people with mental disabilities.



One of the most remarkable features of this place is the effort to use language to re-mould out-moded and unproductive thought habits. For instance, the people served by the agency are not termed "patients", but "clients". Negative sentence constructions are discouraged. (For example, instead of saying "... Don't do this...", employees here will say "... Do this instead...")

Most employees work in direct contact with the clients. The management includes a social worker, licensed nurses, trainers, consultants and speech- and physio-therapists. Every member of the management has years of experience working directly with people with mental disabilities. Social workers ensure the agency is humane. Chemical and physical restraints are absolutely banned.

Performing hysterectomies and vasectomies on clients for reasons other than medical needs are considered barbaric.

Direct contact employees and volunteers are required to have at least a high school degree. This guarantees basic literacy since they administer medicines and document daily happenings. Direct contact employees receive at least two weeks (or 80 hours) of paid training each year. Training involves first aid, behaviour management, crisis prevention, crisis management, documentation and use of appropriate language.

Interestingly, most of the direct contact employees in this agency are college students who are happy with the flexible working hours and use their earnings to finance part of their education.

Employment procedures are fairly streamlined, complete with interviews, personal contact addresses and checking of police-records. A typical employee works no more than forty hours a week to ensure high quality work.

The agency provides services that can be broadly classified into two categories: respite-care services and group-home services.

Compassion and Dedication

Respite-care services include assistance with personal hygiene, going for walks, movies, sports and other pleasurable activities as well as assistance with commuting to schools or work places. These clients typically live with their families and the agency merely provides assistance in day-to-day activities.

Group-home services are long-term and extremely well managed. Each group-home has anywhere from four to six clients living together. Clients with greater behavioural problems live in smaller group-homes of four clients each to receive maximum assistance. Clients with similar abilities are placed in the same home.

Each home has a manager and an assistant manager who also do their share of what we may consider menial work like cooking, cleaning bathrooms and so on. The managers also take over the duties of absent employees. Apart from these two managers, there are two to three employees, including those for overnight duties.

The homes are extremely clean and functional, if not decorative. Each client has a room (or space boarded off) of at least 6 by 10 feet. This room has a bed, a drawer or cabinet for clothes and other essentials and a small music system.

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The common area includes a kitchen, a living room with a couch, television and phone, bathrooms, a medicine cabinet area and a documentation table.

Each client is slowly conditioned towards self-help skills like eating and personal grooming and hygiene to the best of his/her abilities. The agency also helps find a job for each client. More able clients work in integrated environments like libraries or catering services. Others work in a sheltered packing factory contracted from a local company. Here, again, there are employees of the agency to train clients to do their work in a patient and consistent manner. Certain clients make as much as five hundred dollars a month and certain others make as

little as five cents a month at this factory. Yet the agency makes sure that each client has a place to go from eight in the morning to four in the afternoon on weekdays. The agency also organises parties and social gatherings at regular intervals.

A lot of effort is put into making the lives of those with mental disabilities as normal as possible, instead of treating them as adult children.

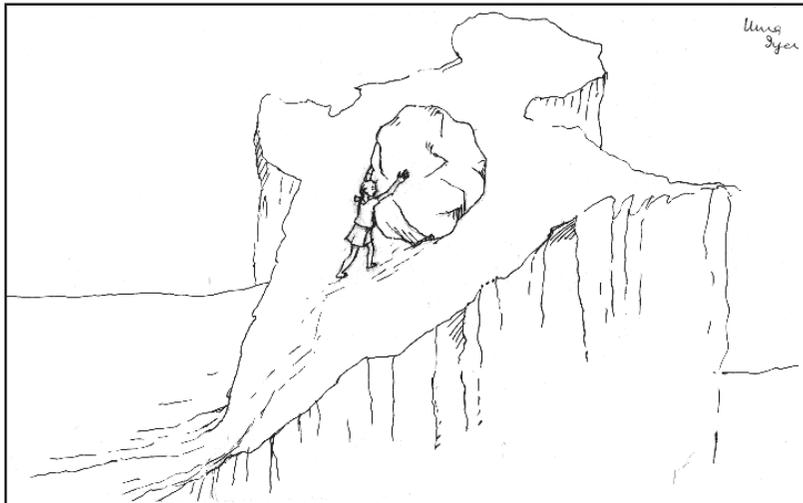
Parents of clients typically live in the same town and are consulted regarding medication or behavioural problems. Every client's behavioural problems are discussed with professional counselors and, with consistent and patient behaviour management, the problems are minimised if not completely erased.

I am told that privately funded agencies function even better, although I do not have any first-hand information. Overall, I was very impressed by the compassion and dedication of the agency. It was extremely touching to see a society, supposedly obsessed with individualism, care so deeply for fellow human beings. They work hard but have large enough hearts to take inspiration from an old Indian folk-tale.

Contrast with India

Contrast this with what I saw this summer when I visited my family in Hyderabad, India. A relative of mine (whom I shall call Smita, to protect the family's identity) has a profound mental disability. It was sad to see that though Indians take great pride in community living, Smita and her family got no help or community support in helping her live a dignified life.

The family's greatest frustration is its isolation in the crowded city. The family gives society its dues and pays the government its taxes. Yet there is not one agency, public or private, which would take Smita to a movie or a sports meet. Respite-care services or year-long programmes are non-existent even in a city like Hyderabad, which is home to the prestigious National Institute for the Mentally Handicapped (NIMH).



The only available options are permanent residential institutions that are either exorbitant and/or pathetic, barring a few exceptions. Governmental agencies are notoriously insensitive in their attitudes. Hysterectomies are routinely performed on women, even by private agencies, with or without family consent. Once a child is put in such an agency, parents are discouraged from participating in the care of the child and are viewed as a nuisance. So parents do not trust these facilities and end up caring for the child at home as long as they can. There are a few institutions, privately run, which provide good and humane care. Most however are segregated and unsupervised.

Around 10 per cent of the Indian population has some form of disability. For every person with a disability, an entire family is impacted. Yet the concerns of the disabled have no representation in politics, governance or the media. There is no move to give the disabled their rights. To the best of my knowledge, they cannot own property, hold bank accounts or vote. If our society were only to go one step forward and declare them animals, maybe activists like Maneka Gandhi would show interest.

Social isolation, with no means to vent pent-up energy, leads to behavioural problems in people with disabilities, even to the point of violence towards family members. Families that can afford it

employ live-in help to provide care twenty-four hours a day, seven days a week – and it is sometimes less than a week before these care-givers tire, feel exploited and begin to provide sub-standard services.

Well-wishers and even professionals in the mental disability field advise Smita's parents to start an agency themselves in collaboration with other families in a similar situation. What, then, is the point

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of well-funded institutes and research positions for the study of mental disabilities if the burden of setting up agencies falls on parents themselves?

Those who have idyllic images of Indian households caring for family members with mental disabilities do not consider the fact that people in these families also have other “normal” responsibilities – aged parents, young children and possibly their own mental and physical health issues. Does society

not owe anything to these families who contribute to society and pay taxes for facilities like schools, roads and playgrounds, to all of which their children have little access?

In fact, since these families have special needs, the mother typically gives up her job to assist her disabled child. In some cases, highly qualified professionals have quit jobs, since they have no social support. This is a huge loss of productive capability for our society. The poor have it much worse, since they need as many earning members as possible to subsist.

This will not do. We Indians cannot persist in this sin of treating some of our people as less than animals. What these families need is not pity or charity, but social participation. This makes good economic sense and is an important social investment.

It is incorrectly believed that the concerns of the mentally disabled can be addressed only after a society becomes prosperous. Agencies such as those I described above can provide much needed employment and, at the same time, relieve the pressure on affected families, so that they can pursue productive lives. Government funds may be lacking, but private agencies can step in. Many private schools, of national and international parentage, are mushrooming to meet the demand for quality education in India. Likewise, there is a big demand for agencies which provide respite-care and long-term services in India for special populations. Such agencies are important social investments for the long-term security of every one of us. Tomorrow any of us could have an accident, and lose our vital faculties. Our families and we ourselves should still be able to continue functioning productively.

It is not just Smita and her family but millions of others like them who are waiting for this turn-around to take place.

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