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Burden of Caring: Families of the Disabled in Urban India

UPALI CHAKRAVARTI

While most parents adapt well to caring for a disabled child, some do not. The literature on disability, narratives of parents, professionals and disabled activists in India highlight the role of prevailing social conditions in the suffering of the disabled and their families. Many issues germane to their day-to-day lives are made invisible by society, and personal and social suffering are ignored. Families also require a range of support services to be able to successfully care for a disabled member. Using the case study approach, this article examines the experiences of caregiving in families of young people with cerebral palsy. It highlights the individual and social dimensions of disability, and their intersection in the lives of individuals with disabilities and their families.

Introduction

Care is defined with reference to activities and relationships in connection with categories of vulnerable groups such as the very young, the ill and the elderly (Daly and Rake 2003). Care is both a social exigency and a form of interpersonal relations. The authors also point out that although social policy is very important in determining the form and consequences of care, the political economy of care extends beyond public provisions. Even in societies in which the state provides many services, most care is provided informally in families and communities, and has invisible costs attached to it (ibid.).

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It has been estimated that about 10 per cent of children have developmental disorders requiring long-term access to the health care system and extensive care into adulthood (Raina et al. 2004). The cerebral palsies are an example of such a condition that can serve as a prototype of childhood disability. Cerebral palsy (CP) presents in early childhood as a set of functional limitations stemming from disorders of the developing central nervous system. The current estimated incidence of CP is 2.0 to 2.5 per 1,000 live births. Although impaired motor function is the hallmark (manifesting as complex limitations in self-care activities such as feeding, dressing, bathing and mobility), many children also experience sensory and intellectual impairments. These limitations require long-term care far exceeding the usual needs of children and the expectations of their families. This can become burdensome, adversely impacting both the physical and psychological health of caregivers.

A number of factors in the recent past have contributed to assigning a bigger caregiving role to families. For instance, decline in family size and medical advancements (leading to increased survival rates of children with disabilities) have been accompanied by shifts in health care provision from institutional to ambulatory and community-based settings. This combination of factors leaves smaller family units shouldering the responsibility for care, highlighting the need for providing outside support to caregivers. Studies in the West have shown that those following the unexpected 'career of caregiver' for a child with a disability (Boaz and Muller 1992; Hoyert and Seltzer 1992; Keith 1995; Pruchno et al. 1997) experience stressful life situations that can have negative consequences, if the health care and social service systems cannot assist such families. Becoming an informal caregiver is not typically chosen or planned; people do not envision being in a caregiver role when they project themselves into the future. Thus, the preparation for it will often occur after it has already been acquired. In addition, an informal caregiver lacks rights, privileges and prerogatives that come with a formal career status. This is not a career recognised by society as a worthwhile pursuit. The role also differs from occupational careers in that movement along its pathway is

driven not by personal ambition, but rather by the progression of the disorder and the functional dependencies it creates. Finally, a caregiving career cannot be entered into and left at will, especially by women, who shoulder the major burden of caregiving responsibilities in the home. Indeed, we highlight how deeply gendered care for the disabled is within the household.

This article examines experiences of caregiving in families of young people with cerebral palsy through interviews with parents conducted during 2001–2 in Delhi. Informants were accessed through NGOs in the disability sector such as Action for Ability, Development and Inclusion (AADI)¹, formerly the Spastic Society of Northern India. Semi-structured interviews were done around 10 open-ended themes, such as case history, initial reaction at onset of CP, treatment and other services accessed, family support and coping strategies, social interactions, economic adjustments, thoughts on the future of the disabled child, role of the government in the field of disability, and any other issue the interviewees desired to discuss. CP was chosen due to a number of reasons: it is the third highest cause of locomotor disability in India (NSSO 2002). It imposes a range of limitations on the individual, requiring long-term care far exceeding the usual needs of children as they develop, or the expectations of their families as they parent. The amount of physical care required is much greater than in other disabilities, with the level of care being directly proportional to the severity of the condition. Children whose parents were interviewed, were in the 14 to 25 age group, and the families belonged to different socio-economic groups.

Even though the narratives are derived from a small sample of the urban middle and lower middle classes, a range of issues emerge that are relevant to all households having a disabled member, especially in the lower-income groups. This snapshot view of family caregiving and disability leads one to speculate on the scenario in different parts of India, among diverse population groups, such as agricultural workers, daily wagers, manual labourers, domestic workers and migrant populations, who would not have access to the most basic facilities for diagnosis and treatment.

Narrativising Caregiving

Narrative 1: 'Time Seems Endless'

Ramesh² is the mother of two boys with cerebral palsy and mental retardation. Sumit is 21 years old, and also suffers from speech and hearing impairment. He is bedridden. Dheeraj is 15, and in addition to speech impairment, he also gets convulsions. He needs constant monitoring, as he is hyperactive and unsteady on his feet. The family lives in a small room that serves as a tailoring shop and living quarters. Ramesh's husband has poor vision; and he attends mostly to outside work like purchasing threads and beads in connection with the family's tailoring work. Looking after the two boys, doing housework and attending to customers ensure that Ramesh's day is packed from 5 A.M. to midnight. The couple manages to earn Rs. 2,000 to 3,000 per month, of which Rs. 600 is spent on medication for the children. Sumit and Dheeraj had been taken to the AADI and prescribed physical therapy, but due to paucity of finances, absence of familial and social support, and a general feeling of hopelessness, the couple has not been regular with the physical regime.

Reflecting back on her life, Ramesh regrets the loss of her earlier physical vigour and optimism. She said: 'One is growing older, and I am no longer physically fit to deal with the situation. I am also anxious about the future.'

In the recent past her anxiety reached such a peak that she had to consult a doctor, who told her she had to go out of the house for at least half an hour during the day in order to retain her 'mental balance'. Ramesh fought the guilt of leaving her children unattended, as she visited a neighbour or went shopping in compliance with the doctor's advice. After one month, the feelings of being boxed into an existence with no life outside of her two disabled children and a financially troublesome existence diminished. Nonetheless, she still feels resentful of her situation—if only she were more qualified to get a proper job; if she had only known the consequences of getting married within the same family; and if only she could shift out of this cramped space back to her village.

Ramesh is tired of caring for two invalid children, crippled by financial worries, and consumed by anxiety about her own and her children's future. Provision of medical and palliative services by the government would have made a crucial difference in the initial years; and such services could still make a difference. But she has no expectations from the government or from any organisation.

Narrative 2: 'No Miracle Can Happen'

Surinder is a 21-year-old man with profound cerebral palsy. He lives with his parents and a younger brother. He is home-bound and totally dependent on help from others for his daily needs and mobility. Surinder's mother had malaria in the eighth or ninth month of her pregnancy for which she was taken to a nearby government health centre in a village in Haryana. The family attributes Surinder's affliction to the treatment given by the doctor there. Describing their reaction upon learning that their child was disabled, Surinder's father said: 'Initially, we were not depressed, for we didn't realise it would be a lifelong thing.'

When they took him for immunisation, the doctors in a children's hospital informed them that something was seriously wrong with Surinder, and a lot of physiotherapy exercises had to be done with him. Surinder's father said he tried not to waste time being emotionally overwhelmed by the situation, and instead focused on helping his son with the exercises that was the only treatment to enable him to become minimally physically self-reliant. A physiotherapist was hired for this purpose. However, despite the regular regime of exercises, there was no significant improvement in his condition. Surinder's mother had emotional outbursts and spells of crying. Both her natal and marital families provided support in caring for Surinder, as she was employed.

The parents acknowledge the help provided to them by AADI in the initial years. They were counselled not to expect a miracle through which their child would become 'normal'. This counselling made them stop looking for a cure, which does not mean that they stopped hoping for one. They have struggled over the years to get Surinder to walk, talk, eat, dress and use the toilet on his own.

However, now at the age of 21, he can only speak a few words. The regular exercise routine notwithstanding, he cannot walk on his own and needs to be carried. His father can no longer carry him because Surinder is too heavy. Even though he has been toilet-trained, he still needs someone to feed and dress him. Surinder is also on medication for convulsions.

Until a few years ago, Surinder was going to the AADI school. But since he does not have any capacity for the vocational training offered, the school asked his parents to remove him in order to make place for another child. Surinder is left without a daily routine, and, more importantly, there is no interaction with the outside world. This is a great blow for him, because he really enjoyed going to the AADI school. Now, his parents have enrolled him in a nearby crèche, where he goes for a few hours during the day; it is the only source of contact with the outside world, which he eagerly looks forward to.

After years of shifting from one rented accommodation to another, the family has purchased a house of their own. Surinder's father explained the reasons behind this decision. He said:

We had difficulties in finding accommodation with such a child. Initially, the house would be rented on sympathetic grounds, but then we would face humiliating remarks. We have tolerated so many things.... At least here we don't have to bear with that torture.

During the past five years, Surinder's parents have undergone spells of ill health themselves. His father developed severe back pain, rendering him incapable of lifting his son on to his wheelchair. Then, his mother was diagnosed with breast cancer. That was a trying period for the family when his mother had to go for chemotherapy and his father was bedridden for a month. Luckily, there was the support of the extended family to help them tide over this crisis.

When asked how they handle feelings of helplessness and depression, Surinder's mother said:

I can't explain it to you, but at such times God gives us some inner strength, So, with God's grace, and the help of some of

our relatives and some people in my office, we have overcome difficult times.

Similarly, her husband said: 'We are God-fearing people. As difficulties come, solutions or ways to handle them also emerge.'

This is not to say that they are not anxious about the future. Surinder's mother in particular experiences a lot of anxiety regarding the fate of their son after their death. His parents hope that his younger brother, who is very fond of him, will look after him. But they wonder how he will manage his own life if he has to also look after his disabled brother. Furthermore, they are of the opinion that no one can look after a disabled child as well as the parents can.

Surinder's condition has restricted the family's spatial mobility and social life. Physical barriers, the need to take Surinder in a wheelchair, and the absence of disabled-friendly toilets, as also the negative reactions of people to their son, have led the family to lead a more sequestered life.

Narrative 3: 'She Too has the Right to Live'

Living in a big house in one of the lanes of a wholesale market in Delhi is Anjana. She is 25 years old and has four siblings. Madhu, her mother, is a widow who lives in her marital house. Anjana has severe CP. She is dependent on help from others for her daily needs. Her speech is also severely affected. She uses a wheelchair that is wheeled by an attendant. Till a couple of years ago she was going to the AADI school. However, given her highly dependent status and inability to acquire any vocational skills, the school asked her mother to withdraw her. Like Surinder, she now goes to a crèche for disabled children run by the Railway Hospital. This is a way of ensuring she is in a safe environment while her mother goes out to work.

For Madhu life has not been easy bringing up four children, especially after the death of her husband when the family faced a lot of financial hardship. Madhu's parents have helped her in bringing up the children.

Anjana is Madhu's second daughter. As the first child was a girl, her mother-in-law wanted to make sure that the second was a son. She brought Madhu some medicines, claiming they would

ensure the birth of a son. Initially, Madhu resisted taking them, but eventually gave in due to family pressure. Even though she had a normal hospital delivery, Anjana developed a fever for 10 days soon after birth. After treatment by a local doctor, she was taken to Kalawati Saran Children's Hospital.³ Pneumonia was diagnosed and hospitalisation advised. Having heard horror stories about hospitals, combined with superstitious beliefs about children dying there, the family decided to take her to another doctor near their home. When they went to purchase the medicines prescribed by the neighbourhood doctor, the chemist remarked: 'Such a heavy dose for a small baby is not right.' The parents, however, gave her the medicine, and within two days she was much better.

The family noticed that Anjana could not hold her head up even by the fourth month. They took her to yet another local doctor, who told the parents that had they delayed any more, her chances of survival would have been bleak. He was the first person to explain Anjana's condition to them. He said: 'Whatever she does will be delayed and progress is going to be very slow.'

Time went by, but Anjana could neither sit nor walk on her own. Her parents again took her to Kalawati Saran Children's Hospital, where a special chair was made for her. Madhu was taught some exercises to do with her. After seeing an advertisement, Madhu took her daughter to AADI when she was 2 years old. Once Madhu was told the nature of Anjana's disability and her interaction with the AADI staff and parents grew, she found the strength to cope and never visited any other doctor.

She shares her anxiety about Anjana's future with her sister, but never in front of Anjana. Sometimes, she is filled with pity for her daughter and pain at the thought of the future that may await her. However, there have been some events that have helped her develop a new perspective on the situation. For instance, one day soon after her husband's death, when Anjana was sitting in her wheelchair near the front door, a neighbour passed by and said: 'It is not the father who should have gone; it would have been better if something had happened to this girl instead.'

This upset Madhu terribly. Commenting on this event, she said: 'My daughter has also come into the world like everyone else; doesn't she too have the right to live?'

Madhu realises that Anjana's situation is much better than that of many disabled persons. She hopes that her other children will look after their sister after her death. Madhu is a member of an association of parents that plans to set up independent accommodation for disabled persons.⁴ However, she still hopes that her children will take the major responsibility, because she feels it is eventually only the family that can provide the protection and love needed by a disabled person.

According to Madhu, Anjana is a very sensitive and perceptive young woman. She is not demanding or fussy, and she tries to manage things by herself as far as possible. When she was young she used to wave her hands and bang them against the wall, but now she is calmer. Her family has not pampered her—she has been treated at par with her siblings, and scolded and praised on the basis of her behaviour. The family has also never tried to conceal Anjana's condition. They always take her with them wherever they go. She is an integral part of the family and they are proud to have her.

Madhu laments that even 50 years after independence the government has not done anything for the disabled, and she does not expect any substantial improvement in the future. However, she feels that NGOs have a crucial role to play in disseminating information and providing services. Her critique of the NGOs in the disability sector is that their focus is on childhood services, which are essential, but they need to also develop programmes for disabled adults and their families.

Although Madhu has come to accept Anjana as she is, she is plagued by anxiety about her future. Past incidents of sexual harassment and abuse exacerbate her worries. There was a male helper at AADI who would touch Anjana inappropriately. She told her siblings about it, but they thought she was just trying to seek attention and did not believe her. When she told her mother about it, Madhu informed the teachers. Subsequently, the helper was dismissed. Similarly in another incident, a boy in the neighbourhood had misbehaved with Anjana. Whenever this boy came home, Anjana would start yelling and asking him to leave. When Madhu tried to reassure her about his good intentions, she protested violently. Later, she told her mother how he had on one

occasion touched her in a bad way when she was sitting outside in the lane. It is such instances of possible abuse in the future which worry Madhu.

Anjana's case highlights the lack of knowledge about disabilities like CP among lay persons as well as among the different care providers accessed by families a few decades ago. Madhu feels that there is now much more awareness about disability and general childcare. Nowadays, disability campaigns emphasise that it is not something that has to be hidden, be ashamed of or be ostracised for by society. Families are also now aware that they are not alone. For instance, initially Madhu just could not sit through the parents' workshops at AADI. The moment the parents started talking about their problems, she would have tears in her eyes and would want to walk out. She felt helpless and incapable of coping with Anjana's condition. 'But see the situation today,' she remarks. 'Now I go about helping and explaining to other parents, boosting their confidence to handle the situation.'

Narrative 4: 'Dedicating Oneself to Service (*Seva*)'

Manav is a single child in a nuclear family. He was born in Panipat in the state of Haryana in a hospital through a normal delivery. When he was about a year old, the family went to the city of Haridwar in Uttar Pradesh on a pilgrimage. Upon their return to Panipat, Manav had high fever and was unconscious for two days. They took him to a private clinic and then to Delhi after a fortnight. Although the fever subsided, Manav seemed to have forgotten how to sit, stand and walk. The doctors told the family that it might be a case of encephalitis. They were not given any other information, and they returned to Panipat. However, the parents were alarmed when he did not start walking even by the age of 4. They took him to Delhi's Kalawati Saran Children's Hospital. It was there that they were informed that there was no medical treatment or cure for Manav's condition, and that he should be admitted to a special school. So they shifted permanently to Delhi.

Now, at the age of 21, Manav is a tall, lanky young man with a rigid gait, stiff arms and fingers. He has an enlarged tongue due to which his mouth does not close properly, and he drools.

Although he is not learning any vocational skills at the AADI school, he still goes there because his mother wants to ensure a daily routine for him. Otherwise, left at home, he develops behaviour problems.

Describing their initial reaction, his mother says: 'We have left our lifeboat in God's hands, and wherever He wishes to take us with Manav, we are willing to go.'

She says she has 'sacrificed' her ambitions so as to look after him. She had wanted to be a teacher, but she gave that up in order to serve (do *seva* for) her child. In the initial years she felt very frustrated, not only because of the high level of care required, but also due to anxiety about the future. But over time religion has helped her come to terms with the situation. As she put it: 'Now we are in God's hands, so there is nothing to be upset about.'

She adds that even if she has to look after '10 such children', she is willing to do so as she has developed much patience over time.

Her husband also went through great trauma in coping with their situation in the initial years. Manav's mother narrated an incident to illustrate this. When one of his friends took Manav's father to a female seer and she asked him what he wanted, he said: 'I have not come to ask for anything, I have only come to ask for strength to deal with my misfortune [*dukh*].'

This response surprised the priestess, as she was used to addressing people's material wishes, and/or discoursing on the futility of material possessions for salvation. The couple has become very spiritual over time, and they have taken a vow (*diksha*) to serve their child and any such child who comes their way.

Although the extended family has not displayed any negative feelings towards Manav, the couple was pressurised to have another child. They, however, decided against it and have no regrets. They only want to look after Manav. His mother reasoned that if they had a second child who was not disabled, not only would their attention have been divided, but they might have given preferential treatment to the latter, having had greater expectations from him/her. Furthermore, she said that if there are no expectations, there is no cause to be unhappy. She explained: 'From him [Manav] we have no expectations, and he is everything for us, and we are not dissatisfied with life.'

Manav's parents are not disturbed by the pity shown by others. As his mother explains: 'Once the parents have accepted their situation, there is nothing which can hurt them or weaken their determination to look after the child. When parents themselves are disappointed with what they have, it is then that what others say hurts them.'

Manav's parents are of the opinion that the disabled are not the priority of the government. What Manav's mother wants is that the government should ensure that doctors do not neglect episodes of minor illnesses such as colds and sore throats, because they might be manifestations of more serious diseases that could cause lifelong disability. Timely diagnosis and medication can make a world of difference. Before Manav became disabled they thought disability was the result of accidents, if it was not congenital in rare cases. They do not feel angry with the doctors for Manav's condition any more. His mother sums it up tersely: 'What had to happen has happened.'

Even though the parents are resigned to their fate, the anxiety uppermost in their minds is who will look after Manav after their death. They hope and pray that some relative will take on that responsibility. When the anxiety becomes overpowering, it leads the mother to wish that the three of them should die together. She feels that since looking after such a person is considered dirty work (*ganda kaam*) by society, the parents are the best caregivers.

Narrative 5: 'There Was No Choice but to Lock Her Up'

Umul is a 21-year-old woman with cerebral palsy. She now lives and studies in Chennai. Her parents and younger brother live in Bangalore. When Umul was small, her mother (who had a job) used to take her to the hospital for exercises every day. But once she had exhausted all her leave, the exercises had to be discontinued. Since both the parents were employed, her mother had no option but to lock Umul in the house during the day. The enforced immobility resulted in her legs getting locked.

When the parents later took Umul to a unani hospital, the doctor recommended that the mother should quit her job and stay at home to do the exercises if she wanted her daughter's condition to

improve. It was not possible to follow this advice because the family was in debt. The stress due to the family's dire financial situation resulted in Umul's father suffering a heart attack and losing his job. Since then he has not been able to take up any strenuous work. Luckily, Umul's mother continued to hold on to her job as a school-teacher even though the wages were very low. In search of better employment opportunities, her father shifted to Bangalore from Chennai. Even though they barely had any money for basic survival, they managed to procure medicines for their daughter. Umul's mother used to commute regularly between Chennai and Bangalore by train, carrying her 8-year-old daughter in her arms because they could not afford a wheelchair. She came to know of the AADI school in Chennai and admitted Umul there. However, since the expenditure on running two households was so high, her mother resigned from her job within two years without completing the term of service that would render her eligible for a pension, and moved permanently to Bangalore. Umul started attending the vocational training programme at the AADI in Bangalore, where she learnt stitching and embroidery. But she was not satisfied. She had other aspirations. While attending a wedding in Chennai, she managed with great difficulty to meet the Director of the Chennai Spastics Society. She expressed her intense desire to make something of her life and become independent. The Director asked her parents to allow Umul to undergo an independent living programme for three months. Finding that she had an aptitude for academic work, she was admitted to the open school. Her parents said to the functionaries of the society: 'She is your child—do as you like and make her someone worthy. We don't have the resources to do it.'

Since then Umul has been living in the Spastics Society premises in Chennai and pursuing her studies through the open school. She wants to become a lawyer and fight for the rights of the disabled.

Caring and Caregiving

When parents learn that their child has a disability or chronic illness, they begin a journey that is filled with strong emotions,

difficult choices, interactions with many professionals, and an ongoing need for information and services. The narratives show that the burden of caring falls on the family, and within the family, more specifically on the mother. This continuous responsibility, in the absence of any formal support networks, has many negative consequences for caregivers, including the suppression of feelings such as not wanting to do it anymore. For instance, even though Ramesh's husband is supportive, he doesn't actually do the exercises with his two disabled sons because he feels that there is 'no point', as there is no apparent improvement in their condition. While Ramesh also has similar feelings, she still goes ahead with the regime, reasoning that: 'it is our duty to do them'. As a woman and a mother, the option of not doing so does not arise. Similarly, Manav's mother gave up her aspirations to work, since she thought it would result in her disabled child being neglected. She has internalised her commitment to do '*seva*' for her son to the extent that she is willing to look after '10 such children'.

Whenever support from the extended family is available, it has been of tremendous help, especially during difficult times. Again, what is interesting is that it is the mother's mother or mother's sister who get involved in caregiving. It is women who substitute for each other's labour out of affection and a sense of responsibility. In Madhu's case, however, there was no support either from the natal or marital families. Families of interviewees fortunate enough to get ongoing support from AADI highlight the urgent need for outside support services. The model of family support or family-like caring is an aspect of societies and states that have few institutional facilities. As Dalley (1998: 92) writes: 'In societies, which do not have formal segregated care systems, the principal structure of kinship has to provide the basis for caring.'

In India institutional care is almost totally absent. So when the responsibility for providing care falls on 'society', the form of care adopted is either modelled closely on the family or falls upon individual families directly.

In the absence of support services, the hardship families have to undergo is enormous. They are often not in a position to access outside help due to several reasons. First, they face financial constraints. Second, even though it is specialised work, it is difficult

to find persons willing to take on care work, not only because it is underpaid, but it is also considered menial and degrading. Manav's mother put it aptly when she described it as '*ganda kaam*'. Even in families where finances were not a constraint, as in Surinder's case, the service was not reliable and the turnover of helpers very high.

In the absence of support, the mother has to make a difficult choice between working and caring. For instance, Umul's mother had to take up work in order to ensure the basic survival of the family, and she could only do this by locking Umul in the house. This had the adverse effect of Umul's legs getting locked, neutralising the mother's efforts of doing daily exercises with her before going to work. This Hobson's choice situation was not helped by the doctor's callous query: 'Do you want your daughter or your job?' The mother was forced to handle her feelings of guilt and the financial imperative to work on her own. In the absence of familial support, Manav's mother gave up her dream of becoming a teacher because she felt that her child's needs were more important than her own desire for independence and creativity.

Ramesh's situation is even more poignant because she has to look after not one but two disabled children. The parents have to balance the double burden of caregiving with earning a living. Their only support, Ramesh's mother, can help now and then for a limited period because she is aged and requires support herself. She took Ramesh's youngest non-disabled child to the village when he was small, and still comes whenever possible to help her daughter look after the other children. The limited availability of family support to the primary caregivers is heavily tilted in the direction of the natal family, something that cuts across classes. Even in Anjana's case it was the maternal grandmother who provided financial support in the initial years after her daughter became a widow. While concern for the daughter is an important factor, a more important reason for the involvement of the natal kin may be her ongoing stigmatisation in her marital home for bearing a disabled child.

According to Ms. Naidu (Chakravarti 2002),⁵ the disabled child's mother has stronger alliances with her natal family, with her mother or sister offering substantial assistance in caregiving. The husband's family rarely provides any support because they think 'the

problem has come from the mother's side'. Consequently, organisations in the disability sector like AADI end up giving a lot of information to the mother, who undergoes a transformation in personality and behaviour. For example, she learns to come to the institution by bus and to handle people. Through such learning experiences, her world expands. But one does not find the same thing happening with the fathers. Given the nature of male socialisation, they are left with no outlet to give vent to their anger and grief. Therefore, as the woman becomes more capable of managing her disabled child, she becomes more independent, challenging normative constructions of wifehood and motherhood. Such mothers develop good problem-solving skills and demystify disability (*ibid.*). What has to be facilitated is the incorporation of the husband into caregiving in a cultural context in which the husband-wife roles are rigidly structured. So, while the mother is becoming more 'empowered', the question is, will she succeed in educating the husband? Ms. Naidu feels that over time both parents need to restructure the way they look at disability and caregiving.

Another interesting observation emerging from the narratives is that despite the small number of organisations for the disabled in existence two to three decades ago, the services offered, especially emotional support, are perceived to have been tremendous by disabled persons and their families who had the opportunity to access them. Even though the number of such organisations has grown over the years, their services have not diversified. The new organisations also continue to provide the same basic services that AADI and other organisations had done when they started their programme. Even though these organisations now have disabled adults and acknowledge their changing needs, they have not been able to develop support services to address the educational, vocational, psychological and social needs of this group and their families. This is evident from the refrain of parents that children with special needs require opportunities for social interaction and activities to keep them occupied. The parents are caught in a dilemma: they realise that at some point their wards have to make way for other disabled children to avail of the services of the organisations in a situation of resource constraint, but they also want the organisations to recognise that it is not possible

for them to address all the needs of their adult offspring on their own. They are exhausted by the ongoing physical care and apprehensions for the child's future. Since organisations like the AADI have played a critical role in supporting them in the initial difficult years of bringing up the child, they are not only dependent on the organisation for concrete medical and social assistance, they also have high expectations from it. Consequently, there is a sense of betrayal manifested in the lament that: 'the organisation is not doing much for the children now'. Indeed, the question arises whether institutions can cater to the multiple felt needs of disabled persons and their families. Given the meagre facilities in the disability sector, there is a long way to go as far as meeting all the felt needs of this marginalised group is concerned.

Long-term institutional care, especially for severely disabled persons, has not been seriously considered in the Indian context. Consequently, support services provided by institutions mainly focus on prevention and early detection of disability and training of professionals. The Western model of the 'modern' institution, which can take over the caring functions performed by the family, has not been considered. However, the case of Erwadi⁶ and the rural study of 41 villages in Andhra Pradesh (Mander 2002) highlight the need for institutional support for long-term care, especially of severely disabled persons. Mander shows how in rural Andhra Pradesh the disabled are left without food and care for long periods, as families go out to labour. Erwadi brings out the indigenous variant of the institutional solution to care, linking it to faith and traditional healing, a system existing outside of the state structure. This leads us to think about locating such issues as the rights of the disabled, care and caregiving in a broader political economy and cultural context. Neither from the narratives of disabled persons and their families, nor from the secondary writing on disability in India do we get a picture of either the state or alternative traditional structures providing any feasible, humane and acceptable ways of caregiving.

The gendered nature of caregiving is also implicit in the narratives. Although from the parents' responses it appears that both the mother and father are equally involved, in most cases the mother is a housewife, or has sacrificed her professional ambition

to devote herself full time to caregiving. In other instances, financial considerations compel the mother to engage in both earning a livelihood and looking after her disabled child. The mother in the majority of cases is the principal caregiver. Feminists have advocated for a change in social attitudes, drawing attention to the need to recognise that caring is not the duty or the prerogative of women alone.⁷

The narratives also underscore limited family resources and the non-existence of wider support systems for the care of disabled persons. One important issue they highlight is that it is not just medical treatment and physical care that persons with disabilities need, but what is equally imperative is a range of support services to be provided to their families in order to be able to cope. The family burden is not just financial in nature, as shown in the case of Surinder. Money was not a constraining factor, yet reliable help was scarce.

Community, Family and Gender

The organisation of caring in a given society is closely linked to the ways in which it organises the general system of social relations. According to Gillian Dalley (1998), under normal circumstances, the responsibility for caring functions in relation to childrearing and servicing of adult family members falls upon women. They are also expected in 'extra-normal' circumstances to care for the chronically dependent, namely, the disabled and the elderly. In traditional societies with limited division of labour, dependency is managed collectively in a social context in which the public-private dichotomy is blurred. What has been termed as the social construction of dependency is of a different order in capitalist societies. In the latter case those who cannot engage in productive work due to physical or mental impairment, or those who have passed the age limit imposed by society to mark the end of working life, automatically become dependent either on the state or on the family. Dalley argues that their dependency is not intrinsic to their physical or chronological condition; instead, they have been 'socially constructed' as dependent because they are arbitrarily

ruled out from being party to the contract that non-dependent individuals are able, or obliged, to enter into with society. Systems of support and care may vary according to the degree to which the confinement of the disabled is compounded by the social constraints of marginalisation and stigmatisation, or mitigated by the social supports of integration. In societies that do not have formal segregated care systems, the principal structure of kinship provides the basis for caring. In situations where such a society takes on the responsibility for providing formal care, the form of care adopted has tended to be modelled closely on the family.

Analysing the meaning of caring from the perspective of affect, Dalley (*ibid.*) states that a distinction can be made between 'caring for' and 'caring about'. The first is to do with the tasks of tending to another person; the second is to do with the feelings for another person (Parker and Graham, cited in Dalley, *ibid.*: 8). Caring for and caring about are deemed to form a unitary, integral part of a woman's nature. In the 'extra-normal' situation of a child being chronically dependent beyond the definition of dependency dictated by its age—through sickness and handicap—the mother automatically extends, and is expected to extend her 'caring for' function. Just as the affective links that form at birth are tied into the mechanical links of servicing and maintenance in the case of healthy children, the same affective links in the case of disabled and chronically dependent family members get tied to the servicing and maintenance functions. In the public sphere too the same forces are at work; women go into the caring occupations because their 'natures', and their intertwined capacities for caring for and caring about, are thought to suit them well for those types of jobs.

The mixing of the caring dimensions (for and about) has implications for both parties in the caring relationship. Love, in this context, often becomes fractured or distorted by feelings of obligation, burden and frustration. But the prevailing ethos of family-based care suggests that normal tasks are being performed, that roles enacted are straightforward, expected and unproblematic. Evidence suggests that the boundaries of obligation and willingness are indeed carefully delimited; and the willingness to care is highly relational and context-specific. As long as a disabled

daughter or son is a child, caring falls within the normal parameters (even though it may be arduous) and, therefore, is acceptable. Once the child becomes an adult, tensions in the caring relationship may develop—love, obligation, guilt, dislike may all be intermingled.

The ambivalence frequently felt by those involved in caring is further complicated by public discourses that insist that there can be no separation between caring for and caring about. Official and lay perspectives on community care all assert the conjunction of the two, but in reality this conjunction is enacted in gendered ways with particular consequences for women. The gender dimension of caring in which the man is assumed to be the provider and the woman the carer is considered a natural given, but is actually a social fact. Studies have shown that for most women, especially working-class women, the gendered model of caring, drawing upon women's assumed natural propensity to care, results in the triple burden—childrearing, housework and wage labour. Land and Rose (cited in Dalley 1998: 17) have discussed womanhood in the context of altruism. They define the personal servicing that women do—caring for and caring about—as *compulsory altruism*—which encapsulates both the self-sacrifice and selflessness involved, and the prescriptive expectations of society that women shall perform that role. They show how social policies have been built on the same assumptions: to such an extent that the altruism, which women come to see as a natural part of their character, becomes compulsory. These policies could not be implemented if women declined to be altruistic.

Both Feder Kittay (2001) and Williams (2004) see the work of caring for dependants at home as a crucial issue affecting the social inequality of women. Holding that women are often subtly coerced by social norms into shouldering the burden of caring for a dependent, Williams (*ibid.*) argues that any solution to the problem would have to involve two fundamental shifts. One is the reallocation of domestic responsibilities between men and women in the home. The second is a greater role of the state. The state may lighten the burden of people who care for dependants through a wide range of policies.

Conclusion

Disability is socially constructed, but it is largely perceived as an individual problem even by policy makers, medical professionals and disability rights activists. This is largely due to the fact that stigma and charity still continue to structure the way disability is viewed. But as the narratives in this article show, stigma is only one element of the larger political economic context that contributes to the social construction of the experience of disability.

Although people have to deal with disability at an individual level, the suffering is not simply an individual experience: it is intersubjective, largely enacted in the space of families, as Kleinman (1995) has pointed out. The lack of medical knowledge and difficulties in accessing health services, acquiring aids and appliances, developing skills for training (that would enhance self-help skills), combine to diminish the quality of life of disabled persons and their families. In the absence of opportunities for developing social, psychological, educational and employment potential of disabled persons, the need for care in the widest sense of the term creates enormous suffering for those affected.

Even in the case of those disabled persons for whom economic factors are not a major constraint, the political economy determines the way disability is perceived. For example, when a person becomes disabled in old age, especially a man, he is not undervalued because he is judged by the fact that at one time he was a productive individual. The capacity to be productive, or its absence, is a structural factor that configures the understanding of disability. The fact that a man disabled in later years is not marginalised, as a disabled child is from the beginning of life, tells us something about the need to rethink the relationship between the individual and the social, and between disability and society.

To sum up, unlike the women's movement, which has managed to highlight the need for an expanded understanding of work to include housework and care work, the disability movement is still struggling to get recognition for disabled persons as citizens, for caring needs of families, and for formulation of social policies that

respond to their distinctive experiences. Disability continues to be seen as a burden which must be borne by the family with fortitude and patience. It is constructed as a situation where 'suffering' is inevitable. As Anita Ghai, a prominent feminist disability scholar and activist in Delhi (Chakravarti 2002) noted, families are told by counsellors that the way to deal with adversity is to 'tough it out', that if you can avoid showing the pain, then you have been stoic and dealt with the problem 'competently'. The relationship between the state, society and family in the context of disability is also yet to be adequately conceptualised. The political economy affects us all, whether we recognise it or not. And until then:

Across our countryside, shrouded from our collective view and conscience people with disability and their care-givers somehow are living out their lives, surviving, but only just, most often on the precipice of dark despair. It is probably only when they organise into a social and political collective voice that an uncaring state and society will finally be forced to act (Mander 2002).

Notes

1. AADI means the beginning in Sanskrit.
2. Pseudonyms have been used to protect the identities of informants.
3. A government hospital located in central Delhi.
4. AADI has facilitated the formation of a parents' support group. One of its activities is building a respite-cum-residential complex, where disabled adults could live as a community, especially after their parents' death.
5. Ms. Naidu was one of the author's informants. She is an activist in the disability sector, who worked with the Tamil Nadu Spastics Society in its community rehabilitation programme.
6. The reference is to burning to death of 28 inmates in a private mental asylum in Tamil Nadu in 2001. The inmates of the Erwadi Dargah were chained to their beds and could not escape the flames that engulfed their thatched huts. Their cries for help were ignored by the asylum owners mistaking them for the usual outbursts of the mentally ill. The Supreme Court took suo motu cognisance of this horrific incident and called for a nationwide review of treatment facilities for the mentally ill both in the public and private sectors.

7. An interesting observation on the gendered nature of caring was provided by a father of a Down's Syndrome young adult. Presenting the flip side of the father's peripheral role in caring, he felt that through the 'process of daily routine caregiving mothers were able to give vent to their emotional distress and emerged more resilient to crisis situations'. By contrast, fathers, bound by stereotypes of masculinity that excluded them from participating in routine care, ended up suffering from depression because they had no cathartic release for their pent-up emotions in care work.

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