# Chapter 1 (In 'Help', Tom Shakespeare (2000) Venture Press, pp. 1-20)

## HELPLESS

This chapter explores cultural representations of disability and dependency. We are used to thinking of disability in individual and medical terms. But our understandings of what it means to be disabled, or to receive care, draw on broader social constructions: they are not 'natural' or inevitable. Just as 'the family' or 'a homosexual' are concepts which can only be understood in specific historical situations, so terms such as 'child', 'disabled person' and 'the elderly' do not label distinct biological processes, but emerge in cultural contexts and mean different things in different times and places. Understanding the dominance of particular stereotypes of disability and discourses of dependency in modem thinking can demonstrate how these experiences can best be understood in terms of structures of meaning and collective values.

A particular theme in the following discussion is the way that people who are physically or mentally different are seen as 'Other'. This notion conveys the idea that disabled people are seen as abnormal and alien. The notion of otherness is explored through images of disability in novels. Next, there is an outline of the processes involved in the metaphor of disability and otherness. There follows a discussion of discourses of care and dependency within social policy, to show how these also reinforce the otherness of care-recipients. The chapter ends with an exploration of alternative approaches to disability and dependency.

## Disability and dependency in culture

Representations of disability can be found in a wide range of cultural sources, ranging from mythology and folklore to contemporary Hollywood films. In Greek and Roman plays, the villains had red hair and we might remember that 'sinister' is Latin for 'left'" connecting left-handed people with evil. But there are also more complex uses of impairment, for example in the plays of Sophocles. The tragic hero Oedipus, after his crimes of patricide and incest, ends up blinded at Colonnus. But his status as a disabled character predates this fate. Oedipus' father, having heard the prophecy of his fate, deliberately wounds his young son, who is crippled as a result ('Oedipus' means swollen foot). Disability here seems to symbolise the tragic flaw. Philoctetes has a similar impairment. He is an important fighter in the army that goes to Troy, particularly because of his magic bow. The Greeks go to make a sacrifice, which is interrupted because one of the temple snakes bites Philoctetes on the foot. The wound becomes infected and nauseatingly smelly. His companions abandon him on an island, where he is marooned for ten years, while they attempt unsuccessfully to defeat the Trojans. Finally, they realize that they have to return to fetch Philoctetes: he and his magic bow are essential to their victory. Sophocles' play

symbolizes the idea that disabled people have qualities which make up for their lack, but it is also a commentary on the prejudice, isolation and exploitation which a disabled person might experience.

As the contrasting tales of Oedipus and Philoctetes demonstrate, stereotypes of disability can be used in different ways: sometimes a minor character has an impairment to heighten an atmosphere of exoticism or difference; sometimes a major character has an impairment to illustrate a particular personality trait; sometimes the impairment may be a necessary aspect of the plot. Disabled people may be represented a sinister and twisted (Shakespeare's Richard III or Robert Louis Stevenson's Blind Pew), or as pathetic innocents, and sometimes as superhuman and possessing compensatory abilities. Whether superficially positive or negative, these images are usually exploitative and one-dimensional, reinforcing popular prejudices about disability rather than creating rounded and realistic characters. As Rosemarie Garland Thomson (1997) argues, they are stylised and overdetermined: impairment dominates over other character attributes. Yet images and constructions of disability and dependency are never coherent, and are usually drawing on contradictory ideas. So, for example, people with learning difficulties can be seen as simultaneously helpless and threatening, and both asexual and sexually dangerous and polluting. The rest of this section draws on various novels of the nineteenth and early twentieth centuries, in order to explore how disability is represented. These books, of course, are not about gods or heroes, but are about ordinary people. Modern ideas about normality and abnormality were shaped in this period and influenced by these discourses.

Charles Dickens was particularly fond of giving a character an impairment, often to heighten a sense of pathos, or make them seem more ridiculous or evil. For example, several characters in *Our Mutual Friend* (1864-5) are distinguished in this way. Silas Wegg is a self-important and ultimately treacherous minor character, whose main role is to exploit his benefactor.

*'Wegg was a knotty man, and a close-grained, with a face carved out of very hard material, that had just as much play of expression as a watchman' s rattle. When he laughed, certain jerks occurred in it, and the rattle sprung. Sooth to say, he was so wooden a man that he seemed to have taken his wooden leg naturally, and rather suggested to the fanciful observer that he might be expected - if his development received no untimely check -to be completely set up with a pair of wooden legs in about six months. '* (Dickens, 1985a, 89)

Wegg's impairment defines his personality. One might even imagine that the name, 'Wegg', was just a contraction of the identifier, 'wooden leg'. By giving him a wooden leg, Dickens makes him distinctive and more ridiculous and perhaps even more sinister. One remembers Long John Silver and Captain Ahab, other obsessed and revengeful characters of nineteenth-century fiction: although while they are dark and tragic, Silas Wegg remains in the realm of farce (along with Captain Hook). A more central character in the same book is Bradley Headstone, the schoolteacher: the story of his self-destructive and obsessive passion for Lizzie Hexham is a key part of

the narrative. In order to contribute to our view of the man as driven and passionate and dangerous, Dickens describes him as having an epileptic seizure on discovering that Lizzie is to marry his bitter rival, Eugene Wraybum. While Wegg is comically conniving, and Headstone is passionately brutal, Dickens's darkest disabled character is Quilp, in *The Old Curiosity Shop* (1840-1):

*'The child was closely followed by an elderly man of remarkably hard features and forbidding aspect, and so low in stature as to be quite a dwarf, though his head and face were large enough for the body of a giant. His black eyes were restless, sly and cunning, his mouth and chin, bristly with the stubble of coarse hard beard, and his complexion was one of that kind which never looks clean or wholesome. But what added most to the grotesque expression of his face, was a ghastly smile, which, appearing to be the mere result of habit and to have no connection with any mirthful or complacent feeling, constantly revealed the few discoloured fangs that were yet scattered in his mouth, and gave him the aspect of a panting dog. '* (Dickens, 1985b, 65)

Unsurprisingly, these physical characteristics are accompanied by negative personality traits: Quilp is lecherous, avaricious and malign. He represents all the malevolent aspects of the mythological dwarf.

A competing stereotype is of the tragic innocent, most often a disabled child. Looking again at the work of Charles Dickens, the character of Tiny Tim in *A Christmas Carol* (1843) is an obvious example of this highly sentimental use of disability. So is Little Nell, in *The Old Curiosity Shop.* Another such use comes with the pauper child Johnny in *Our Mutual Friend,* whose only role in the book is to fall ill and die, while in the process being generally loving and loveable and pathetic. In Charlotte Bronte's novel, *Jane Eyre* (1847), the consumptive schoolfriend Helen Burns plays a similar role: although increasingly affected by tuberculosis, she is always brave and noble, and an ally to Jane at the dreadful orphan school. On her deathbed she displays all the Christian virtues of faith and goodness, bravely welcoming death at the age of 14 because it will mean she avoids further suffering and is united with her Maker.

The character of Smike, in Dicken's *Nicholas Nickleby,* is an older variant of the innocent disabled person, although he seems to have learning difficulties rather than a physical impairment:

*'The poor soul was poring! hard over a tattered book, with the traces of recent tears still upon his face, vainly endeavouring to master some task which a child of nine years bid, possessed of ordinary powers, could have conquered with ease, but which, to the addled brain of the crushed boy of nineteen, was a sealed and hopeless mystery. '* (Dickens, 1978, 143-4)

His appearance is ridiculous: an emaciated teenager, he is dressed in the clothes of a child. Dickens's descriptions reinforce the picture of Smike as a tragic disabled person: he is 'timid, broken-spirited', a 'poor, half-witted creature' who is 'wretched'

and 'careworn'. The simple, pathetic Smike is devoted to Nicholas, who is the only person who stands up for him against the wicked Mr Squeers, and he follows Nicholas around until finally and inevitably he dies - although, like Helen Burns, he welcomes death because it takes him away from suffering to a glorious Heavenly existence.

Characters like Helen Burns and Smike exist to point up the horrors of social conditions in the orphan schools and institutions of Victorian England: they are tragic but brave disabled people who are designed to arouse indignation and pity in the reader. Yet, the political critique is achieved at the cost of reinforcing a negative image of disability. Such characters can also provide an object lesson to the novel's hero or heroine, or else the opportunity for the lead character to prove their own merit and kindness. Rosemarie Garland Thomson, in discussing American social reform novels such as *Uncle Tom's Cabin,* suggests that these types of disabled character define and legitimate the role of maternal benefactress for middle-class women, who were at that time socially excluded from other roles in society. Perhaps Dickens is satirising this tendency when the newly enriched Mrs Boffin, in *Our Mutual Friend,* chooses the pauper child Johnny to adopt and look after.

*Jane Eyre* exploits disability as a plot device. The heroine comes to work for Mr Rochester as governess to his adopted child. The secret presence in the house of Mr Rochester's first wife creates dramatic tension. First the only evidence of her presence are sounds that Jane hears in the night: 'It was a curious laugh; distinct, formal, mirthless.' (Bronte, 1977, 131). She also hears eccentric murmurs, gurgling and moaning, and is woken by a 'demoniac laugh -low, suppressed and deep' (1977, 175) and later by a scream which is compared with that of a wild bird of prey. Later, the mysterious woman bites and sucks the blood of her victims. Jane compares her to a vampire, and is shocked at the sight of her: *'I never saw a face like it! It was a discoloured face -it was a savage face. I wish I could forget the roll of the red eyes and the fearful blackened inflation of the lineaments!'* (1977,322). The first Mrs Rochester fulfils the evil stereotype; as her husband later acknowledges: *'Bertha Mason is mad. and she came of a mad family, idiots and maniacs through three generations! Her mother; the Creole, was both a mad woman and a drunkard!'* (1977, 331).

Here, notions of racial exoticism add to the sense of otherness and threat: the Caribbean woman who had first seemed dark and exotic turns out to be mad, bad and dangerous too. Bertha Rochester heightens the melodrama and mystery; she also operates as a stereotyped disabled character; finally, her role is central to the plot. The revelation of her existence leads to the critical denouement halfway through the novel, following which Jane Eyre has to leave Mr Rochester. Later, Bertha destroys Rochester's home in the fire which leads to his own disabling injuries and her death, but also ultimately to the novel's happy conclusion.

In *Lady Chatterley's Lover,* by D.H. Lawrence (1960), the war injury of Sir Clifford Chatterley sets up the entire plot, in which his wife is transformed by the sexual relationship she develops with Mellors, the gamekeeper, but it is also central to the

metaphorical life of the story. The novel is primarily about sexuality and about class: disability is the catalyst for the affair, rather than of interest in its own right. However, Sir Clifford's impairment symbolises his general incapacity to love, or to understand women, or to be a real man. Throughout the book he is infantilised. For example, while he has manual and powered wheelchairs, *'Yet he was absolutely dependent on her; he needed her every moment. Big and strong as he was, he was helpless...But alone he was like a lost thing'* (1960,17). 'He is described as a 'child man', his impotence contrasted with the passionate sexual energy of the working man. Moreover, he is unable to have authentic feelings: he has the 'slight vacancy of the cripple.' (1960,6). All of his negative character traits are connected, we are led to understand, with his injury. In a powerful scene, Sir Clifford's motor chair cannot ascend an incline on his estate, and he has to ask Mellors to push: the discussion of the broken motor and its rods and gears is clearly a direct metaphor for the disabled man's physical lack, not just of legs but also of functioning penis.

The notion of disability robbing a man of his masculinity is a common trope, particularly in postwar Hollywood films -for example, *The Men, Born on the Fourth of July,* and even *Forrest Gump.* But in this novel, D.H. Lawrence uses Chatterley's impairment highly specifically, to symbolise his own hatred of what industrial capital was doing to Britain, and the failure of the bourgeois man to respect or understand the 'real men' of the working class.

Dickens, Bronte and Lawrence were not interested in disability as such. Instead, their disabled characters function metaphorically: either to manipulate the emotions of the reader, or to enable the author to develop plot or convey a deeper symbolism. For this reason, although often vivid and memorable, such characters can be rather shallow and two-dimensional. Usually, the disabled character is defined by their impairment, and remains an object, rather than a subject exercising agency in their own right: things are done to them, rather than them doing things. It is also important to draw attention to the way in which normality is constructed in opposition to these images of dependency and impairment. From his analyses, Lennard Davis concludes that disability is a key element of the novel as a artistic form:

*'In thinking through the issue of disability, I have come to see that almost any literary work will have some reference to the abnormal, to disability, and so on. I would explain this phenomenon as a result of the hegemony of normalcy. This normalcy must be constantly enforced in public venues (like the novel), must always be creating and bolstering its image by processing, comparing, constructing, deconstructing images of normalcy and the abnormal.'* (Davis, 1997,23)

## The meaning of the disability metaphor

We have discovered that images of disability are relatively common (they are as ubiquitous in Hollywood cinema as they are in Victorian novels), and that while they encompass a range of stereotypes, they are centrally about metaphor, rather than about the realistic experience of impairment itself.  Cultural texts can both reflect and influence our ideas about real life. Stereotypes of disability work for the reader

because we can fill in the gaps: they reproduce ideas or preconceptions with which we are familiar. As children grow up, they learn about disabled people partly through the books and films and legends which they encounter, and so real disabled people are understood in terms of fictional stereotypes. Consider the 'triumph over tragedy' stories which dominate the media, or re 'supercrip' image which accounts for our fascination with Helen Keller or Stephen Hawking or Evelyn Glennie. Professionals or the public do not learn how to treat disabled people from Shakespeare's plays or James Bond films, but the discourses of disability which we have identified contribute to a cultural undertow of prejudice, which contributes towards policy and practice.

The American historian Paul Longmore argues that it is fear of disability which underlies media stereotypes:

*'What we fear; we often stigmatise and shun and sometimes seek to destroy. Popular entertainments depicting disabled characters allude to these fears and prejudices or address them obliquely or fragmentarily, seeking to reassure us about ourselves. '* (Longmore, 1987, 66)

This insight highlights the way that representations of disability may often be more about reinforcing normality than an interest in disability itself. Impairment becomes something which other people have, and which is not part of ordinary embodiment. As Jenny Morris has argued,

*'Surely, the representation and exploration of human experience is incomplete as long as disability is either missing from or misrepresented in all the forms that cultural representation takes. It is fear and denial of the frailty, vulnerability, mortality and arbitrariness of human experience that deters us from confronting such realities. Fear and denial prompts the isolation of those who are disabled, ill, or old as "Other", as "not like us".'*(emphasis original) (Morris, 1991,85)

Morris and Longmore are suggesting that cultural representations reinforce or speak to a tendency for non-disabled people to exclude people with impairment, and to define themselves in opposition to them. One group -those with 'normal' bodies -is legitimated, while another group - those with 'in-valid' or deviant bodies -is seen as inferior and abnormal. This process is called 'Othering', and can be demonstrated to occur between men and women, heterosexuals and homosexuals, and between members of dominant ethnic groups and minority ethnic groups.

My analysis of disabled people, children, older people and other groups as helpless and excluded builds on a tradition of theorising the Other. Simone de Beauvoir (1976), writing about the way men define themselves in opposition to women, and Albert Memmi (1990), writing about colonised peoples, have shown how relations of domination construct the Other as object, but also as lack and void and mystery, not individualised but anonymous and generalised (Hartsock, 1990, 160). The critic Edward Said (1994) has shown how the nineteenth- and early twentieth-century literature constructs and reinforces colonialism, even when it appears to be talking

about something else, producing the Orient as the phobic projection of a western imaginary. Disabled critics have argued that the same process is happening in terms of disability. Ludmilla Jordanova has summarised what Othering involves:

*'The idea of Otherness is complicated, but certain themes are common: the treatment of the Other as more like an object, something to be managed and possessed, and as dangerous, wild, threatening. At the same time, the Other becomes an entity whose very separateness inspires curiosity, invites enquiring knowledge. The Other is to be veiled and unveiled.'* (Jordanova, 1989, 110)

The dominant group both separates itself from the Other, but also depends on the Other for the sense of its own identity. To be a man is to avoid effeminacy or dependency, or woman-identified behaviours and activities. The definition of able-bodied is non-disabled. Frantz Fanon (1986) explores the ways in which this uneasy relationship involves resentment, envy and aggression. Domination leads the Other to have feelings of inferiority and neuroses as a result of traumatising contact with the dominant world. The white gaze annihilates body and individuality as the black person becomes no more than their skin colour and may end up wanting to become white, and, in the same way, some disabled people long for a cure. Able-bodiedness (whiteness) is the criterion for beauty and acceptability.

The separation into able-bodied and disabled is an artificial process, one which is policed and reinforced by the imagery of Othering. In fact, everyone is impaired: everyone has a body which is imperfect and flawed, susceptible to illness and disease, subject to ageing and inevitably mortal. The idea that the world neatly divides into people with physical limitations and 'normal' people who have perfect bodies is an illusion. Only by projecting their frailty and vulnerability onto the Other -old people, disabled people -can non-disabled people maintain the illusion of their own strength and wholeness. To be able-bodied is to be in denial. This suggests the truth of Jenny Morris's claim:

*Our disability frightens people. They don't want to think that this is something which could happen to them. So we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity.'* (Morris, 1991, 192)

The cultural stereotypes of disability discussed earlier serve to amplify and mark out disabled people as different, as outside the normal run of things, as alien. Disabled people are scapegoats for the fears and vulnerabilities of non- disabled people -what David Hevey has called 'dustbins for disavowal' (Hevey, 1992,34). I

This discussion has begun to uncover the origins of disabling imagery, and to account for the vast range of stereotypical characters found in western culture. It is my claim that these representations show the importance of disability for non-disabled artists and audiences, and reveal the processes of Othering and anomaly

which enable the 'normal' population to maintain a sense of themselves and also deal with the existence of minority groups such as older people, disabled people, and people with mental illness or learning difficulties. Fundamentally, representations present such 'helpless' people as the outcome of natural processes, not social exclusion. These images are central to culture and the media, and contribute to the environment in which children learn about the world. It would be surprising if they did not also influence discourses on health and welfare.

## Disability and dependency in social policy

In this section, I trace four dimensions of the academic and policy literature on social care which could be said to continue the processes introduced above. In the images and analyses which we have encountered, disabled people have been firmly marked out as different from non-disabled people; they have been objectified; they have been represented as tragic but brave, or sinister and evil, or as possessing compensatory abilities, but never as ordinary and normal. Unfortunately, variants of these tendencies can be uncovered in the professional literature. Those who become reliant on professional' help become viewed as dependent:

*'Because neediness is conceived as a threat to autonomy, those who have more needs than us appear to be less autonomous, and hence less powerful and less capable. The result is that one way in which we socially construct those who need care is to think of them as pitiful because they require help.'* (Tronto, 1993, 120)

The following discussion explores these tendencies in the social policy literature on disabled people, older people, and children.

1. *Polarisation*

Discourses on disability reflect and reinforce the opposition between normality and abnormality. But this is an artificial distinction and an exaggeration. There are not two 'natural' categories of dependent and independent. Everyone is impaired, and all people have areas of vulnerability. No one is more than 'temporarily able-bodied'. Independence is a myth. Moreover, disabled people can be successful and high-achieving and powerful, despite our habits of thought.- The life of            F.D. Roosevelt is an example of the way that disability is seen as incompatible with power. He had contracted polio in 1921, and ever afterwards used a wheelchair to get about. He could not stand without support. Yet as President of the United States of America, he had to represent the idea of a strong and independent nation: he could not be seen to be weak or dependent. In the popular imagination, you cannot be disabled and dominant. There are approximately 35,000 photographs of the President in existence. Only two unpublished photographs show him in his wheelchair (Gallagher, 1985).

Yet no one is really independent. The human being has evolved over millennia to be more dependent. For example, of all animals, humans have the longest period of infancy and the most extreme infant dependency. Yet this period of social and

intellectual learning is essential for humans to achieve advanced culture, language and civilisation. Human dependency in childhood is a direct evolutionary outcome of success in adulthood (O'Hear, 1997). Moreover, no adult is really independent. Everyone depends on others, whether to drive the bus or deliver milk, or perform any number of basic personal and systemic maintenance roles. We are all service users. Mike Oliver suggests:

*'No one in a modem industrial society is completely independent, for we live in a state of mutual interdependence. The dependence of disabled people, therefore, is not a feature which marks them out as different in kind from the rest of the population but as different in degree. '* (Oliver, 1993,50)

In fact, it has been a tradition that the more dependent you are, in some circumstances, the higher status you have. For example, if you describe a family who live in segregated accommodation, are looked after and have their meals cooked for them, go to special schools, do not look after their own money, have people to drive them around, and are likely to be stared at wherever they go, it might be imagined you were talking about a very dependent type of person. Yet you could be describing the British Royal Family.

The implication is that the usual way of defining dependent people as having 'special needs' might also be prejudice, rather than reality. Why do disabled people have special needs? Disabled people need the same things as everyone else: they need housing, education, employment, information and services. In fact, disabled people have ordinary needs, which are not normally met. The result is that they have to rely on particular kinds of helping services which are seen as rendering them abnormal and inferior. The problem lies not in the individual, but in the services and environments which render the disabled person excluded and needy.

2. *The burden of dependants*

People who receive care may become conceptualised as dependent. Warnes (1993) argues, with reference to the treatment of older people, that there is a tendency to objectify those people who receive welfare services. Making a comparison with Jonathan Swift's notorious Modest Proposal, Warnes counsels against the mindset of burden becoming or remaining a characteristic of social policy or political analysis, even by those with progressive intentions:

*'What happens is that the agents carrying the burdens are misidentified: the more graphic the portrayal of the wearisomeness of old age, poverty or sickness, the greater the sense of grievous load upon others. Sometimes the distortion is so great that, following Swift's modest proposal, it turns out that those who experience the burden are of so little concern that they become disposable.'* (Warnes, 1993, 329)

In the case of older people, the experience of old age is essentialised and problematised, as if older people were invariably incapable and physically dependent (Phillipson *et al.,* 1986). This pathology model of old age ignores the many older

people who continue to be successful and non-needy. Images of older people focus either on a jolly grandparent stereotype or on a desolate and frail person. During the nineteenth century, the word 'senile' changed its meaning, from merely 'old' to 'deteriorated and incapable'. Doctors in the twentieth century have medicalised old age by defining it as pathological. In social policy, emotive words about the' demographic timebomb' and the burden of an ageing population serve to undermine the individuality and agency of older people:

*'Phrases such as "the growing burden of elderly people" or "the rising tide of elderly mentally frail people" have themselves entered into the theory and practice of social work, distorting both the nature of the social work response and the worker's relationship with older people.'*
(Phillipson, 1989, 193)

Such references are used both to justify restrictions in social expenditure and to suggest that an ageing population is both unnatural and undesirable.

Jens Qvortrup (1990) has criticised the exclusion of children from most statistics and social accounting: young people are invisible in the way in which married women used to be. He suggests that there is an unquestioned child dependency within this documentation, a protective exclusion from public life.

In fact, often children are conceived of in terms of a cost. This may be a financial cost on their parents, or as an item on 'time-budget' studies. Having parenting or caring commitments, then, is represented in terms of the burden of children. The social policy debate on provision of childcare and the possibilities of women entering the workforce similarly regards children as a burden, or a problem to be solved.

The discourse of burden also applies to disabled people who are placed in situations where their children have to take up a caring role. The literature on young carers, exploring situations where children take on caring roles in relation to parents with impairments, tends to objectify disabled parents as 'dependants', and to characterise the situation as a 'plight' or 'curse'. A positive attempt to challenge the social exclusion of child carers slips all too easily into a tendency to pathologise people with impairments who choose to have children (Olsen, 1996; Olsen and Parker, 1997, 127). The children of disabled people are seen as victims: *'This carries the danger of implicit and explicit criticism of disabled parents, their values, their choices, and even their right to have children at all'* (Olsen, 1996,42). By focusing on the single issue of young carers, this research can obscure other issues: for example, it may ignore the fact that disabled people can be carers. In problematising families with a disabled parent, there is a danger of ignoring the ways in which all families involve interdependence: for example, older children looking after younger children, and other age-appropriate responsibilities for children (Keith and Morris, 1994, 53). In general, the accounts of families with a disabled person as mother or father are guilty of essentialising and pathologising disability, and suggesting that disabled people cannot make good parents and that their children become the victims of this incompetence and selfishness, all on the basis of very scant research.

The literature on disabled children similarly has tended to rely on the assumption that having a child with impairment is to experience inevitable burden, for example in the titles of older books on the subject such as *A Constant Burden.* Emotive and offensive terms like 'severely disabled' implicitly blame the victim for their situation. The literature tends to make a range of normative assumptions about the effects of having a child with impairment on the parental relationship or the family dynamics: for example, a suggestion that having a disabled child means that relationships break down, or that siblings suffer. There tends to be a suggestion that, in the case of a child with impairment, the typical loving parental relationships are replaced by a relationship of caring and physical support based around performance of certain tasks.

Services provided for families with disabled children reflect this assumption of burden: there is a considerable stress on the need for respite care, for example, on the basis that the heavy responsibilities of having a child with impairment typically necessitate a break, or a rest. The same 'intolerable burden' model of respite care is evident in policies relating to adults with learning difficulties (Cotterill *et al.,* 1997) which tend to stress the benefits to the carer, rather than any positive outcomes for the service user. Yet parents themselves may be most anxious about the desires and experiences of the cared-for person. Again, practice literature on fostering and adoption stresses the special qualities needed to look after disabled children, and the particular problems which carers of disabled children have to deal with, in ways which sometimes make disabled children sound like sacks of potatoes, or exotic zoo animals. The emphasis of many policies is ion the needs and wishes of parents and siblings: it is rare that disabled children themselves are asked what they think about them.

Broader debates in the area of social policy also reflect the tendency to view disabled people as an inevitable burden on their families, and to biologise and individualise the problem of disablement. The carer movement has redefined care in a way which enshrines this notion of burden, as I will argue in the next chapter. Again, Morris (1991) has drawn attention to the work of feminists such as Finch, Groves and Dalley, whose critique of the ways in which women perform the majority of care in the community led to their demand for more residential care, a view which ignores the views and rights of disabled people and other recipients of care.   The irony of the literature focusing on women as carers is that it fails to notice that women are also disabled people.

Another area of literature which constructs an argument of disabled people (especially children) as burdens is the discussion of pre-natal screening and termination of foetuses affected by congenital impairment. This discourse rests on a number of assumptions: that being a disabled person involves a life of suffering; that disabled people are inevitably dependent on others; that the state will ultimately have to bear the cost of supporting disabled people. Public health writers such as Nicholas Wald make explicit the ways in which screening programmes are evaluated on the

basis of cost-benefit analysis regarding the avoidance of the burden of disabled children (Wald *et al.,* 1992).

3. *Lack of a voice*

Also evident in the literature is the way in which people who receive care are denied a voice: whether the discussion is about older people, disabled people, children or people with HIV/AIDS, it is not common for first-hand accounts to be available. We therefore rely for our information on the projections of policy-makers and academics or professionals, or sometimes the testimonies of non- disabled relatives and carers. For example, it is very rare to hear directly from the disabled child in literature on disabled childhood (Shakespeare and Watson, 1998). Baldwin and Carlisle, in their review of the literature, tell us *'We lack children's accounts of pain, discomfort, dependence on Other for feeding, bathing and toileting. We do not know how they feel about the way doctors, social workers, therapists and other children treat them.'* (1994, 35).

People with learning difficulties have traditionally been assumed to be unable to speak for themselves, and their voices have been eclipsed by those of family members or professionals. The rise of the self-advocacy movement, in the form of groups which are often called 'Speaking up. ..' or 'Speaking for ourselves', challenges this silencing. Research has shown the ways in which case histories of people with learning difficulties tend to silence them. The notes do not give family details, or record the achievements of people with learning difficulties. They contain clinical information, or details of value to the professional, not to the person themselves:

*'Lack of personal history material within official records appears to create a vacuum all too easily filled by a "professional" version, namely a "case history". The privileging of professional histories maintains the membership of people with learning difficulties within a marginalised and stigmatised group and confirms their identity as "cases", rather than individuals.'* (Gillman *et al,* 1997, 683)

This approach can be contrasted with a life history approach, which enables people to be seen as active agents, as normal members of society, as people who have a life.

As other analysts have shown, we do not hear from the person who is cared for in the literature on caring, whether it is the feminist literature on community care, or the new literature on children a carers. Thus Jenny Morris criticises Gillian Dalley's models of collective residential care for failing to let disabled people's voices be heard (1991, 157). There has been criticism of researchers using terms which respondents are unwilling to use themselves, for example, where the 'young carers' researchers are accused of imposing their own definitions and perceptions on the subjects of their research (Keith and Morris, 1994, 39). In fact, the rise of carer literature displaces the voices of the cared-for even further (Keith and Morris, 1994, 37), just as in the political and policy arena the development of a carers' movement challenges the gains of disabled people's organisations.

Warnes argues that the construction of the debate itself implies the submergence of the service-recipient's voice: *'the focus on care-giver burden by definition gives a primary position to the provider of care'* (1993 326).

The failure to hear the voices of those who receive care means that the problematic aspects of the experience for them are sometimes neglected. For example, the family may be the site of oppression for disabled people (Morris, 1991, 143). This may be to do with the paternalism or over protectiveness of parents towards children with impairments. Alternatively, it is clear that there is a high prevalence of abuse of disabled children, and also of older people, which is attributable to the role of care within the family, as well as to the behaviour of people outside the family. These issues will be highlighted in the next chapter. I am not suggesting that we should not listen to or research the experiences of carers. However, it is a priority to consider and research the voices of people placed into a situation of dependency or having impairments, rather than to use carers, parents or professionals as proxies. Of course, we must consider the civil rights of parents and carers, but this can only happen on the basis of the full and prior consideration of the civil rights of disabled people and older people.

4. *lnfantilisation*

We have seen the polarity between normal and abnormal people; the tendency to view the latter as a burden; and the failure to hear the voices of care-receivers. Some people have suggested that a broader process is occurring, whereby recipients of care are regarded as if they were children, just as, in the colonial era, the colonised were seen as childlike and immature, in need of civilising discipline. The sociologist Jens Qvortrup argues that the distinction between adults and children is an organising principle of modern societies. A polarity between dependent, vulnerable, innocent, asexual children and competent, powerful, sexual, adult citizens is central to our ways of thinking.

At first sight, adults who are disabled or mentally ill or old or have learning difficulties seem to challenge this polarity. Yet often a major part of the stigma experienced by these different adults is to be treated as if they were children: they are to be protected, they are incompetent, they are to be 'seen and not heard', they require others to make decisions for them, they cannot work or live independently, or be sexual. In short, they are not normal adult citizens.

Jenny Hockey and Allison James discuss the humiliating effects of this kind of discourse in what they call 'the metaphoric role of childhood' in framing dependency. Older people may be particularly subject to this infantilisation. We are familiar with terms like 'second childhood', and affectionate but patronising phrases such as 'little old: lady' and 'old boy' and 'old girl'. They argue that related processes occur in the treatment of disabled and chronically sick people. Hockey and James conclude:

*'lnfantilisation processes can have a powerful and potent role in shaping many dependent people's everyday experiences, engendering feelings of social marginalization, personal humiliation and emotional vulnerability.'* (Hockey and James, 1994, 10)

Most non-disabled adults do not experience these processes. However, women have traditionally been treated as childlike, as Shulamith Firestone argued (1979). Although this has mainly changed with the advent of a more sexually egalitarian society, women attending antenatal clinics still enter into a curious process of infantilisation:

*'The passivity required of a mother in medicalised childbirth is a microcosm of the passivity associated with femininity. For example, the advice and instruction given by midwives, nurses and health visitors can undermine the mothers status as an adult.'* (Hugman, 1991, 193)

This suggests that the perceived need for medical care and supervision can temporarily displace the usual adult role. It also points to the particular dynamics of the doctor/patient relationship which win be explored further in the next chapter.

The cultural models of dependency which have been considered here also relate to material and economic processes. It is no coincidence that most of the groups under discussion have been non-productive, in a market sense, since the early industrial revolution. Many disabled people, most older people and children do not work. In our society, paid work is a major marker of status. Those groups which are excluded from the market are consequently devalued. The changing status of women, since the early 1970s, can perhaps be linked to the fact that women are entering paid work more than ever before. Where people are not allowed to make an economic and social contribution, or where their contribution is not recognised, then their position in a capitalist society is likely to remain marginal.

**Redefining the problem**

We have seen how cultural representations and social policy analysis can fall into the same errors. These stem from a tendency to take dependency for granted, and see it as a natural outcome of having an impairment, or growing old. Added to these assumptions are tendencies to treat people who receive care as abnormal, as alien, as burdens, and as childlike. This book is an attempt to challenge these approaches, and to reconfigure our understandings of disability and dependency. Prevailing approaches to dependency are flawed because they rest on a model which both individualises and medicalises the experience of disability or ageing. It is as seen as automatic that older people or disabled people or people with HIV/AIDS need care. The problem of disability is located in the deficits of an individual who does not operate in the usual way, whether because of physical or mental incapacity. Yet many commentators and campaigners have suggested that it is more helpful to locate these problems in a collective and social and structural context. Dependency is a production of particular social relations.

One dimension of the traditional model is that the wider environment and the role it plays in creating social dependency is ignored. For example, if a house is inaccessible, or is located far from public transport, or on the top of a hill, there will be consequences for a 'person with impairment or physical limitation. These disabling factors could be avoided if the person was housed in a barrier- free setting. If someone lives in a city with inaccessible transport, they will be dependent on an ambulance or a taxi or a volunteer to a greater extent than if they lived in an accessible city.  Equally, if a disabled person did not face physical and attitudinal barriers to employment, they would be more likely to get a job and therefore escape dependency on benefits.

People are disabled by society, as well as by their bodies. It is the social and environmental barriers, prejudicial attitudes and other exclusionary processes which often make living with an impairment so hard for disabled people and their families. Cultural representations of disability, and professional discourses of welfare dependency, are another way in which people are disabled. This approach, known as the social model, emerged from the campaigns of the disabled people's movement. It can enable us to look at care debates in a new light. However, it can be applied more broadly to explore the processes of oppression and marginalisation which apply to members of other help-receiving groups.

*'It is not physical impairment which is the barrier to asserting choice and control. Rather,  it is the obstacles which society constructs: the over-protectiveness of professionals and parents, the undermining of self-esteem, the failure of non-disabled people to develop appropriate communication skills.'* (Morris, 1993, 173)

Keith and Morris (1994, p.45ff.) focus attention on the factors which make a disabled parent reliant on the personal assistance of a young carer. These include poverty, disabling professional attitudes, disabling services. disabling environments and the broader problems of disabling experiences and disabling communities. Disabled parents rely on their children as carers not because they wish to, but because society has failed to provide them with adequate social support. A social model of disability relocates the problem of dependency from being a corollary of impairment to being a product of a disabling society. Rather than putting resources into support for young carers, it would be appropriate to put resources into integrated living schemes and personal assistance, which would render dependence on child carers unnecessary.

When Keith and Morris made the following comment about child carers, it is equally relevant to the debate about disabled children: *'The choice both parent and child have in these circumstances is often dependent on access to external support, accessible housing and appropriate aids and equipment'* (1994, 54). Rather than seeing the problems of disabled childhood as a result of the child's impairment, it is beneficial to look at the wider context of support and services extended to different families. This point is made by parents in Bryony Beresford's research on *Positively Parents* (1994): there were many responses suggesting that it was not the impairment itself which was the main problem for the family, but poverty and the reactions of

others. Many of the experiences of families with disabled children did not differ qualitatively from those of families with non-disabled children, many of which are also isolated and impoverished. As Beresford concludes:

*'We should not forget, therefore, that a parent caring for a disabled child may also be facing other stresses which, to them, may be far more problematic than those associated with the disabled child.'* (Beresford, 1994, 111)

The social model parallels the work within social gerontology on the structured dependency of old age (Townsend, 1981). This approach attributes the problems of ageing not to individual or medical deficits, but to the decline in financial resources of older people in the postwar period; to compulsory retirement; to passivity-inducing community care; and to the way that the expansion in residential provision has led to a reduction in support for people in their own homes. Estes argues:

*'The needs of older persons are reconceptualised as deficiencies by the professionals charged with treating them, regardless of whether the origins of these needs lie in social conditions over which the individual has little or no control, in the failings of the individual, or in some policy- maker's decision that a need exists. '* (Estes, 1979, 235)

The social focus of research and policy is on individual adjustment to ageing, not the social arrangements which disempower and marginalize older people.

Even old people themselves are made to feel incapable and limited. Moreover there is a lack of priority and prestige given to working with older people within social work, health and social research itself.

Since the early 1980s, the social sciences have deconstructed discourses on gender and race and sexuality to demonstrate that what was always thought to be 'natural' are actually the products of social and cultural processes. The positions of disabled people, older people and children are now at last being reconsidered along similar lines. The implications for helping will be considerable.

**Conclusion**

In challenging the images of dependency which are communicated in literature or within contemporary care practices, it is necessary to develop an appreciation of the ordinariness and agency of disabled people and older people. Rather than treating those who receive care as alien beings, imprisoned in failed bodies, the role of society in creating and constructing the problem of helplessness has to be acknowledged.  This may also be important for those who are on the receiving end of help, who may have internalised their idea of their own incapacity, and may expect no better than the treatment and attitudes which they experience. As Paolo Freire has written:

*'Self-depreciation is another characteristic of the oppressed, which derives from their 'internalisation of the opinion the oppressors hold of them. So often do they hear that they are good for nothing, know nothing, and are incapable of learning anything - that they are sick, lazy and unproductive - that in the end they become convinced of their own unfitness. '* (Freire, 1972, 38)

Just as colonialism has historically led to the corruption and degradation of indigenous cultures, so the impact of colonial care may be to undermine the self-respect and positivity of those rendered dependent, and to create constituencies who are to an extent psychically damaged by the treatment they have received. This is the subject which Fanon has illuminated: there is an urgent task, beyond the current discussion, to explore the healing which is essential amongst those at the margins of the caring society.

Since the early 1970s, the constituency of those made dependent on medical and welfare services has begun to move from this position of resignation and passivity to a radicalism based on an understanding of the processes of oppression. Sometimes, people have been regarded as ungrateful, or bitter, or unable to come to terms with their bodily problems, as my colleague Pam Carter wrote, during her period as a cancer survivor:

*'I have little difficulty in understanding why the voices of disabled women and others often sound so angry and "difficult". It is terrible to feel real anger; especially when the cause is unjust treatment which is unlikely to be put right. So part of being the helped and not the helper is to be flooded with this kind of anger over and over again. Of course, the cancer literature deals with anger: It is one of the stages of grief, and so on. But it is psychologised and individualised, not analysed in terms of the social relations that it involves. It is the fact that these relations are of inequality that creates the angel; not only the emotional effects of the illness. '*

When the helpless become angry, then perhaps it is a sign that things are going to change in the world of welfare. Crucial to this change is the establishment of a sense of self and agency in the face of exclusion and generality. The construction of the Other through the discourses of care and dependency effaces the particularity of Otherness. There is a need for disabled people and Other help- recipients to establish themselves as subjects, each with a voice and rights which are rich enough to respect their individuality while recognising them as a member of the community.