

Food for thought, The carers' movement: DANGERS AHEAD?

Patricia Rock, 1988

Newspaper awards of 'badges of courage' to carers perpetuate an image of them as brave, self-sacrificing martyrs. Patricia Rock detects equally patronising attitudes towards recipients of care within the carers' movement itself. She challenges the language of 'caring' and speaks out for those who receive it. Caring today is big business, not in terms of paid work for carers but in organisational and campaigning terms. Various carers' organisations have raised thousands of pounds for a growing membership and the Informal Caring Programme at the King's Fund Centre is another organisation providing support for carers.

The need for such support is abundantly clear and many disabled people are thankful not to have the sole burden of emotionally supporting the person who is caring for them. Many disabled people still do this and at the same time are expected to be grateful and thankful that someone is mindful of their needs. There is a need to look at what is happening today and unravel some of the confusion and muddle the carers' movement has got itself into.

The word 'carer' is beginning to be synonymous with acts of courage and bravery that is, battling along in a hostile world against uneven odds, with the enemy often, defined as the disabled person for whom she has to care. This is a very distorted and biased view. Such distortion can arise because the disabled person is the silent partner in the relationship.

With such distortions and silences it is no surprise that at a conference on Women and Caring held in the days of the GLC, comments describing disabled recipients as '...lumps of flesh...' were heard. At a more recent conference on carers and caring during the opening speech disabled recipients were described as 'blobs'. This is not talking about caring but a means of relegating the disabled person to the rank of an alien species which only carers have to contend with. At such conferences, frequently organised or supported by carers' organisations, the able-bodied carers speak from the platform. The recipients of their care are dotted about in the audience, listening passively to such humiliating descriptions. Rarely is there any acknowledgement that the disabled recipient may have something to contribute to the relationship, either emotionally or financially.

Such biased contributions epitomise the carers movement which is, a movement of able-bodied (or as the Americans would say, TAB, Temporarily Able-Bodied) people, who see themselves caring for their less able dependant. What is needed is to bring dignity and respect into the caring arena. The need to discuss caring as a form of work with contracts of employment for both parties is well overdue.

While voluntary and unpaid carers have to go on, often alone, the position for the disabled person will remain marginalised and their rights invisible. If a contract of employment was drawn up with the disabled recipients' needs clearly defined, with control over how personal tasks should be completed and by whom, an atmosphere of mutual respect could grow.

Carer, breadwinner, lover...?

At present, the position of the carer is ill-defined (their position is financially unrecognised) which leads to confusion as to what role the assistant is playing: is it carer, breadwinner, lover, partner or friend or a combination of them all? Such blurring confuses the carer so that defining themselves in relation to the dependant becomes confusing, muddling and often devaluing.

For example, I often hear people make remarks such 'I'm her mother, but I care for her'. What does she mean; partly that she is a mother but the role of caring is so interlinked with this that she cannot separate them. This is appropriate when looking after a child perhaps, but not a 32-year-disabled woman.

So what is Caring? In the public mind caring may be associated simply with looking after sick people or children but today it also includes disabled people who need personal assistance to live their lives. But they are neither sick nor children. Many are of voting age and the word 'caring' infantilises them because people think that if you care for someone it must be in the same way as for a child (as children need to be washed and dressed)

and if this is done for an adult then that adult must be like a child with a child's needs. This is not so. Confusion abounds.

The confusion is partly attributable to a lack of voice by disabled people in how and who assists them. Their personal assistants are often a parent or relative, who has seen them grow up yet because they still need tasks undertaken on their behalf, continue to address and treat them like children. If they could choose who attends to their needs, they may well choose someone else who is not emotionally involved with them and thus determine a different relationship to the carer/assistant.

Today, their wishes are unexpressed and there is no support (no recipients' association or organisation) to demand their rights, and help them to determine choice or, control over their lives. Other people, usually the assistant, unelected, and sometimes unwilling, makes decisions about them, often without their consent. All too frequently this is because there is no-one else to give constant and permanent unpaid assistance.

No choice has been exercised by either side and a relationship occurs often by default.

In the process dignity and respect for each other can often get lost. The disabled person has no support structure, and no means of voicing their wishes.

They can be isolated in that relationship and within their home without any other disabled people to share in the burden of being a recipient and having to ask hundreds of times a week for the same task to be undertaken.

With any luck, change is on the way, with government policy committed to placing disabled people in the community. But as yet there has been little commitment to provide facilities or services to make that a reality for many disabled people. Long-term hospitals for people with learning disabilities (once called mentally handicapped people) and those with mental illness are closing and the carers movement will have to assist greater numbers of unpaid assistants (commonly called informal carers). Respite care for carers is being organised in some areas and the Griffiths Report has stressed case management with decision-making being made in conjunction with the disabled person.

But action is piecemeal. The Disabled Persons (Services, Consultation and Representation) Act 1987 gives disabled people the right to an advocate under the law which should encourage every organisation to ensure that disabled people are properly consulted about their needs ~ requirements. This is another hopeful signpost and shortly a conference on caring, being organised by the London Borough of Hounslow, bringing carers and dependants together to discuss the issues around care and care packages may break vital new ground and end the syndrome of the 'brave and courageous carer' battling alone day in and day out.

This is an archaic and degrading image. The days of feudalism are over in this country where one person is tied to another without pay for work, yet the practice seems to, remain and be perpetuated in the present arena of 'caring'. Let's hope that Hounslow can take the lead and bring in a breath of fresh air of mutual trust, respect and dignity. We can already learn from the independent living centres growing up around the country where disabled people who need personal assistance are initiating contracts of employment and taking control over their lives. The carers' organisations could build on these initiatives and encourage assistants to value their disabled recipients and help members to realise that the dependant can contribute effectively in the relationship.

At present, when an assistant can cope no longer, the last resort is institutional care. But this is no longer going to be an option, thank goodness, and other alternatives must be constructed. Rarely is such a placement discussed with the recipient, with demoralising consequences for everyone involved as feelings of failure and hopelessness set in. There are a number of factors which can lead to breakdown of the relationship and there must be a choice available to personal assistants and dependants alike, otherwise the devaluing of people will grow, with the possible consequence of physical and/or mental cruelty to the dependant.

Children take the brunt

Social workers are constantly reminded of the consequences of families under emotional, physical, mental or financial strain where children can take the brunt of the family tensions and conflicts. There have been articles published on such abuse to handicapped and elderly people resulting from similar strains and tensions. The carers movement needs to fight for the rights of its members. The right to have personal assistance recognised as paid work with contracts of employment between assistants and recipients.

Without this basic right, assistants will continue to receive 'badges of courage' from national newspapers while disabled recipients are implicitly regarded as the silent 'enemy'. It just does not have to be like that and the time for action is now. Money is not the barrier but attitudes.

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