

family

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Abstract

Dina Bowman is the senior researcher at Eco Systems in Victoria. Her paper focuses on women as mothers in UK, USA and Australia, who are unpaid carers of people with disabilities. She argues that while not ignoring the rights and needs of people with disabilities, these should not be gained at the expense of the women who care for them. **Keyword: Families**

DISABILITY & GENDER

COMMUNITY CARE

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This paper grows out of work that I have been doing on the impact of community care policies on the lives of women. This work is funded by the Victorian Women's Consultative Council through the Victorian Women's Study Grant.

Over the past six months or so, I have been looking at community care policy and practices in the UK, USA and Australia, particularly Victoria. My specific focus has been on women as carers. My aim has been to see what strategies can be developed to avoid some of the pitfalls and to adopt some of the good practice and policy from these countries.

This paper is both broader and more specific than the work out of which it grows. In this paper I look specifically at women as unpaid carers of people with intellectual disabilities - by this I am predominantly talking about women as mothers of people with intellectual disabilities.

I use the term intellectual disability rather than mental retardation or people with learning difficulties. While I think labels can be stigmatising, I think that the debate over which term is politically correct or non-stigmatising obscures the reality of the stigma and what should be the real focus of the debate. However, it is

important to define terms, especially at an international conference where so many of us share a common language but invest words with very different meanings.

I must stress that while this paper focuses on women as mothers of people with intellectual disability, I do not ignore the rights and needs of people with intellectual disability. I understand and acknowledge that carers' interests and the interests of those they care for, may not necessarily coincide. While it is important to focus on the rights of people with intellectual disabilities this should not, and I stress this, not be at the expense of the women who care for them. A feminist analysis of community care should also take account of the position of women with intellectual disabilities - I raise this briefly in my discussion of 'family', 'community' and 'normalisation'. I also acknowledge that some men are unpaid carers of people with intellectual disabilities but I leave any analysis and discussion of men's situation to men.

I focus on women because:

1. My personal experience as a mother of a child with intellectual disability informs my analysis and underpins my commitment to people with intellectual disability and the women who care for them;
2. Women are overwhelmingly over represented as carers - both 'informal' (unpaid) carers and paid (often very badly) workers;
3. I want to explore and articulate the assumptions made by policy makers and service providers about the role of women and about unpaid work.

Mimi Abramowitz said that we need to apply a 'gender lens' to any discussion of welfare. I hope this paper serves to correct some of the prevailing masculine myopia.

I focus on women because I'm a woman, and as a mother of a child with intellectual disability I experienced an exaggeration and exacerbation of the responsibilities of motherhood. There is a tendency to either paint a picture of total gloom and doom - that caring for a child/person with intellectual disability destroys your life - or alternatively, to paint a rosy and bright picture of joy, unselfish caring and sharing and personal growth. Of course mostly, it's not black or pink - but somewhere in the middle.

I want to focus on the structural issues which work to make our lives better or worse. There is a tendency in discussing community care to focus on the individual and while it is important not to lose sight of the individual, this focus can cloud the real nature of the problems that confront us. While the real problems are universal, the way in which societies respond to disability are not. I think it is important to acknowledge the reality of impairment - which is not a social construct. My daughter had multiple impairments but these impairments served to handicap her and her family because of society's response to those impairments. The way in which societies choose to respond to disability is not universal and is often a reflection of the general social, cultural and political traditions combined with prevailing economic circumstances.

In the past decade or so there has been a wide acceptance of a number of philosophies which have been 'translated' into policy and practice which reflect the societies which have adopted/adapted them. I want to explore some of these prevailing philosophies, especially in terms of the assumptions they make about women and our roles and responsibilities.

Normalisation

Robinson (1989) is quoted, in a very important book, "Normalisation the 90s - A Reader for the Nineties" as complaining about the 'morally based rhetoric' of normalisation. He calls for 'an acceptance of open debate in which people can

question aspects of normalisation without being treated as unprincipled fools or moral lepers' (Robinson, 1989: 248). I hope my comments will be accepted in the spirit of open debate.

Normalisation has been an extremely influential policy in the UK, USA and Australia. Eric Emerson, in the "Normalisation Reader" gives an extremely insightful and detailed account of the history of the normalisation concept from its Danish origins in the 1950s through its American 'translation' and UK formulations. He identifies a number of important issues around the development of the concept. The early Scandinavian formulations were reasonably straightforward in that they advocated a more 'normal lifestyle' for service users. Normalisation was a

'statement about how services can reflect the basic rights of people with learning difficulties in an egalitarian society'
(Emerson 1992: 3).

Emerson notes that normalisation reflected the trends of many Western societies in responding to the demands for equal rights for a number of disadvantaged groups. The development of normalisation paralleled the development of liberation and 'rights-based' movements such as the women's movement and reflected a concern for disadvantaged peoples.

Wolfensberger changed normalisation from an egalitarian imperative to a modification of the social status of deviant groups.

Wolfensberger's reformulation of normalisation changed its nature from an egalitarian imperative to a theory regarding the modification of the social status of deviant groups. This reformulation has profound implications for women as it totally ignores any analysis of gender or race. The most recent work of Wolfensberger, in particular,

shows little understanding or concern about women's rights or gender issues.

Community and Family

One of the underlying assumptions of normalisation and community care is the existence of 'community'. 'Community' is one of those catch-all phrases which can mean all things to all people.

Wolfensberger (1987) has argued that paid care has served to oppress people with intellectual disabilities and has argued for the abolition of human services on the assumption that the community will care. This is an eminently attractive idea for policy makers and bureaucrats, especially in tight economic times. But it ignores the reality that there is no such thing as 'the community'. There are communities made up of people who may or may not be able to care.

Mostly, women do care, particularly for their children, often in the face of enormous obstacles and at great personal cost. When people talk about community care they are really talking about 'family care' yet there is no agreed definition or manifestation of 'family'. A very small percentage of families in the USA, UK and Australia consist of a bread winning father, stay at home mother and children. However, policies are developed with this mythical family as the premise.

Much of the debate about community care ignores the fact that people with intellectual disabilities have mostly lived in the community with their families. While the philosophies and the policies have changed, for many the reality of family based care hasn't changed at all.

The changing rhetoric can mask a number of real changes. In Victoria, for example, Home and Community Care Services (HACC) are provided through local government to support people with disabilities in the community. Specific Home Help is targeted to assist parents of children with intellectual disabilities.

This service was established in the early 1970s and while it has never been adequate, the increasing debate and rhetoric on HACC has seen an ever widening gap between practice and policy. For example, in the early 1980s I had access to specific home help on a weekly basis, albeit for only three hours. Now the specific home help service is no longer available in that municipality. Partly this is due to the fact that HACC predominantly targets the needs of frail elderly people who are in need of support to stay out of institutions. The HACC guidelines are specific in saying that services are available according to need and specifically comparative need. While your real need may be acknowledged, if there is someone in greater need, your need will remain unmet.

The Australian experience is similar to that of UK and USA where the adoption of rhetoric dovetails neatly with the need for cutting costs. In the UK there is an immense amount of change under way. The introduction of the new Community Care Act requires local government to develop community care plans in response to local community needs. The ideas behind the act are:

1. that local governments can more easily and effectively respond to the local community;
2. the roles of purchaser/provider of services are split, so that local government workers become assessors of need and then purchasers of services on behalf of that individual;
3. that there be a 'mixed economy of care' and a 'contract culture'.

Public services are being radically restructured and the notion of universal provision of services is being systematically eroded. Current discussions about community care ignore the fact that organised social services provided by government are a concrete example of community care - where every one in the community contributes to provide assistance for those in need.

Community care which relies on the individual family is a reversion to a charity based model without the underpinnings of duty and obligation which may have tied families together, in earlier times. Families mostly do work to protect those in need of nurture and support, however, many do not, as evidenced by the high incidence of child abuse, incest, divorce, etc. As many feminists have argued, families based on patriarchy can be very dangerous places for women and children.

I sometimes think that policy makers live in a soap opera land where everyone is caring and sharing and all problems are solved in half an hour. I have a friend who has many problems and she once said to me 'I want to live on Ramsey St' for those of you who don't watch "Neighbours", Ramsey St is a mythical street where everyone is white, well off and has easy to solve problems. All the neighbours know one another and are caring and sharing. I don't know about you but the street where I live is certainly not Ramsey St. I live in a neighbourhood where there is a great mix of cultures, where there is a high number of people who are unemployed or living in poverty and where many people do not know, and perhaps don't want to know, their neighbours.

organised social services provided by government are of community care - where everyone in the community contributes

Policies of community care must be seen within social and political contexts. The UK has a parliamentary system of government, with national government and local authorities (local government). The prevailing political philosophies of conservatism emphasise small government, 'subsidiarisation' (responsibility devolving to the lowest level of government), minimal government

intervention, 'choice', 'mixed economy of service provision' and a great belief in the power of the 'family'. On the face of it these words seems to increase an individual's power and choice.

People can 'choose' to purchase services. However, the social reality of Britain, for example, is such that there are around two million unemployed people, many people live in poverty, in inadequate housing, are single parents, etc. The numbers differ but the problems of unemployment, poverty, etc are the same in the US and Australia. If the basis of choice resides in capacity to pay, there is no real choice. If you are unemployed you do not have the capacity to 'choose' private services. To choose there must be a market, if you require services that don't exist, you won't be able to choose them, regardless of how much money you may have.

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In the USA the political system and political traditions are such that there is less reliance on government and a mixed economy of care exists. Most public services are provided by private agencies which may be subsidised by federal or state funding. Funding programs exist by category and it is a very skilled process to unpick what funding exists for which program. The provision of services, unless you are extremely disadvantaged and fit into a specific category, is based on the capacity to pay. The system means that there is a lot of diversity and some very innovative programs but there is no basic framework of services and no universal service system.

The tendency in Australia is to look at the 'best practice' in the USA and UK or Canada and attempt to adopt the model without any understanding of the context in which the program developed. Sharing the same language can mislead us into believing that we share the same cultural,

political and economic traditions. Australians tend to adopt a 'biopsy' or 'applecore' approach examining policies and practice without reference to context. Our 'cultural cringe' means anything from overseas is considered better than locally developed practice. It is of great concern that we appear to be following the Americans and the British down the road of privatisation and fragmentation of community services.

Both Britain and the US are undergoing a crisis of community evidenced by recent riots in Bristol and Los Angeles. Social change comes from political and economic factors, not from theories. While much of the rhetoric has changed, and some of the reality, with closures of large institutions, much has not changed. USA, UK and Australia are all suffering from economic crises. For many people basic issues such as access to good quality (even basic) housing, schooling, income support and health care block any hope for a decent life.

Community care policy responses are tinkering at the edge of the problem. It's no good icing a cake if the cake is mouldy.

Fundamental assumptions about the role and responsibilities of women and men must be challenged and reformulated. We must seek to make structural changes to paid work so that paid work is available more equitably to both women and men and to people with intellectual disabilities. The work of caring must be recognised and paid for. At the same time there must be a maintenance (in UK or Australia) and in the US, a development - of services to support both women as carers, and people with intellectual disabilities, so that we all have a more equitable share of rights and responsibilities.

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Note:

Women interested in forming an international network on feminism and intellectual disability issues please contact me at the address above.