Who cares for these children?

An historical analysis of recent documents on provision for those with developmental disabilities

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While family care has many positive attributes, total care by mothers may not always be the optimal care arrangement from the point of view of the children or their mothers. Here we examine the way deinstitutionalisation policies for children with developmental disabilities has swung away from often inadequately funded institutions, substituting 'community care'. 'Community care' is largely tending work carried out by mothers. The public sector again is under funded and provides almost no tending for these children. We examine the way the rhetoric of community care has hidden the labour of tending work carried out by mothers, and examine the discourses used to justify moving this labour from the public to the private sphere.

The documents examined are from the Commonwealth and from NSW. It is acknowledged that while public care provisions of the smaller states are often better than those of the two largest states, similar rhetoric has increased pressures on mothers. Children with developmental disabilities require intensive tending work, whether the disabilities are mental or physical. This tending work may be unpaid work supplied in the private sphere of the family, the bulk of it carried out by mothers, or it may be supplied in the public sphere by teachers, nurses, therapists and other employees of the state. This paper argues for an increase in the care supplied in the public sphere.

In Australia, as in other Western countries, policies of care provision have changed significantly in the past two decades in response to a number of pressures. First, new policies are partly a response to criticism of the adverse effects of provision in under-funded large-scale 'asylum' type institutions, criticism which escalated after Goffman's classic study in the sixties. Second, they respond to the pressure for 'normalisation' a newer ideology of the seventies and eighties which has defined care by mothers as the appropriate response for the needs of dependent children. Third, cost conscious governments and public officials embraced eagerly the chance to substitute unpaid family labour for the government paid labour employed in institutional care. There are discrepancies between demands made on the state and what the state actually delivers. Giving legitimacy to the winding down of services is the economic discourse of the past decade based on ideologies of 'small government'. In liberal democracies which rely heavily on notions of self interest, social programs which deliver benefits to the biggest number of electors are the most secure. The implications of this for families with handicapped children are serious. The ideologies of 'family' and 'small government' may combine against the best interests of these families and the children within them.

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The supply of services for children with disabilities in Australia has taken place in the context of a residual welfare system which has emphasised selectivity in granting benefits (Roe, 1976:224; Mendelsohn, 1979:34; Jones, 1983:310). Such systems imply that the family and the market are the preferred structures of supply for meeting individual needs. The social welfare structure only steps in when these 'normal' mechanisms of the private sphere fail. Primarily their emphasis is that publicly provided services should be supplied in emergency situations, until the normal structures such as the family are able to meet such needs again (Wilensky & Lebeaux, 1965:138-9). Bureaucrats therefore govern the supply of services in a system where normalisation is emphasised and normal life for children is believed to be life where mothers meet their children's dependency needs. One mother interviewed in Western Australia related that she was told that there was no such thing as permanent care when she sought to institutionalise her teenage child. Seeking long term placement, she again was discouraged and told that possible institutions 'were not the kind of place you'd want your son in'. Without persistence and considerable entrepreneurial ability (she was an academic administrator before the birth of the child), she believed it unlikely that she would have succeeded in her quest. She inspected all possible institutions and interviewed the staffs, commenting in the interview that such institutions were not as unpleasant as they had been represented to her, and she found most of the staff dedicated to their work.

Politics of discourse and the public/private divide

The public sphere includes state activity, voluntary sector activities and organisations and market activity. The private sphere refers to the domain of primary, non-institutional, relationships and groups, primarily the family (Edwards, 1988:70). Edgar (1992:45) notes a difference in the terminology used according to whether the labour is provided in the private or the public sphere. 'Caregivers' labour in the private sphere, whilst 'care providers' labour across the divide in the public. Caregivers supply all needs of their dependent charges; care providers are selective in their activities, often keeping the higher status work (Cant, 1994).

The divide between public and private, is seen to parallel approximately the divide between the sphere of activity of men and that of women (Hall, 1982). Thus in modern Western economies, most men's work is firmly anchored in the public domain where it is visible to all. However much women's work, especially tending work, is carried out (unpaid) in the private sphere within the household which many women perceive as a prison or a workhouse (Graham, 1985; Wilson, 1982). Illich (1989:39) refers to this system, where women are identified with the private sphere, as the domestic enclosure of women. Their unpaid work is hidden within the home; 'shadow work' as Illich (1981) terms it. He argues that one of the best measures of discrimination today is the amount of shadow work laid on a person. It is therefore important to examine the boundary between private and public in an analysis of caregiving work since whether this work is paid, indeed whether it is acknowledged at all, rests to a large extent on which side of the divide it is carried out. This in turn depends on the willingness of the state to acknowledge collective responsibility for the work of tending the disabled, and support policies which give expression to such acknowledgment.

The official discourse of community care and its implications in terms of the public/private divide can be traced through a number of policy documents. These policies have found favour in much of the Western world, probably because they seem to offer central governments the opportunities to make significant savings in the area of social service provision. Community care policies imply a move away from care offered in large institutions, which had been delegitimised by Goffman and post-Goffmanian critiques, to care in the community, either in small group homes or in 'normal' households. Such policies, which emphasise unpaid tending work by families rather than tending work paid for by the state, sit well with the discourse of the political right with its emphasis on economic rationalism and smaller government, devolution of governmental functions and re-affirmation of 'traditional' family values and the duties of citizenship (Bryson & Mowbray, 1986; Roche, 1987; George & Wilding, 1988). In the Australian context, Pusey (1990) has found that the present public service affirms the values of the political right and are economic rationalists in their approach to government policy, in contrast with the more generalist views of the service thirty years ago.

Debate is rarely rendered admissible in policy documents emanating from the bureaucracy (Kress, 1985; Yeatman, 1989). Deinstitutionalisation policies are not contested by either political party at either state or federal level, except in the small details of their implementation. One argument put here is that the interests of the target groups of dependent disabled are represented in official documents, but these often conflict with the interests of their carers, which are not rehearsed so carefully in such documents. Carer's voices speaking of their own interests, as distinct from those they care for, are heard more strongly in documents emanating from other sources.

New South Wales policy documents and practices

In the early eighties, a number of policy documents began to question policies which supported the institutionalisation of the dependent members of the population. In New South Wales, de-institutionalisation policies were first clearly enunciated in the Richmond Report in 1983. The terms of reference of the report included the requirement:

> ...to determine the appropriate nature, extent and distribution of services for the psychiatrically ill, psychogeriatric and the developmentally disabled in New South Wales.
>
> (Richmond Report, 1983 Pt.1:4)

Part 2 of this report, *Services for the Developmentally Disabled*, developed new policies for these groups, which have significant implications in terms of whether the care provided is unpaid or paid, and whether it is hidden within the private sphere of family life, or visible in the public sphere. The term 'developmentally disabled' is the favoured term in New South Wales to cover those with physical and/or mental disabilities. The Report proposed reduction and rationalisation of institutional care. Recommendation 2.31 set targets for expansion of community services and the reduction of existing institutional services for the developmentally disabled by 1986.

The objectives laid out in the report were put in place in pursuit of 'normalisation and integration' (Richmond Report, 1983, Pt 2:2). Initial opposition came from the nursing union, who could see the replacement of their members by minimally trained personnel (Mowbray, 1983). They correctly foresaw that institutional places would be closed without the envisaged large expansion of places in group homes. However the opposition was argued on wider grounds. Parental opposition was less well organised. Most existing parent organisations were locked into the position of reforming the care available in big institutions and were not strategically placed to voice doubts about this new solution which was couched in terms which had instant appeal. Beguiling terms such as 'community' and 'care' coupled together have a force which is disarming (Bryson & Mowbray, 1986:183). It took some time for parents to discover that tending work had been pushed over the public/private divide and redefined for most disabled children as parents' 'normal' work, or in the British and American political discourse, parents' 'duty' (Roche, 1987).

Large institutions have been closed and the intellectually disabled residents have been moved into homes in the community. Despite strong opposition from the medical and nursing professions and concern expressed by some parents of people with intellectual disabilities, the government pushed ahead. Hundreds of people learned to live outside institutions. The present Liberal government has stopped implementing the Richmond program and has cut funds to services for people with intellectual disabilities. There are now 700 persons on a waiting list for accommodation.

The Council for Intellectual Disabilities estimates there are 2,000 elderly parents of intellectually disabled persons who care for their adult children at home. The issue of what will happen to these people when the parents die or become too frail to care for them is the cause of great anxiety to these parents. The parents who objected to the Richmond Report when it was made public, predicted and feared just such a scenario. Housing for the intellectually handicapped is a desperate need, and post-Richmond the burden has been pushed across the divide onto ageing parents.

The Barclay Report (1988:21) addressed the public face of the issue of institutional alternatives for the care of those with significant handicaps, without alluding to the new burdens thrust on parents, noting:

> There are another group of parents, relatives and carers for the developmentally disabled who raised their voices in protest. They continue to do so, on the basis that they are not convinced that some, perhaps even many, of the developmentally disabled are necessarily better off in community care than they would be or are in a good hospital for the developmentally disabled.
>
> (Barclay Report, 1988:21)

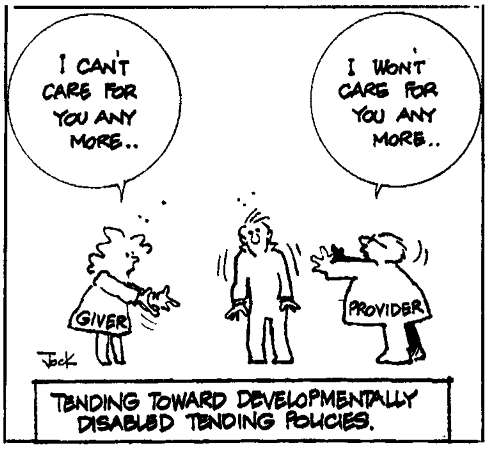
It is instructive to notice which voices are heard in this report and in particular to notice the muted voices of the carers.

The arguments of property owners are presented in a discussion which is extensive, occupying almost seven pages of the document under the rubric 'Community concerns'. By contrast, the doubts of parents were summarised under the heading 'Family concerns' and occupy less than one page. The difficulties experienced by mothers who bear the burden of caring at home are only acknowledged by oblique references and in this section by inference. The fear that, in practice, de-institutionalisation means the State divesting itself of the responsibility of care is canvassed briefly.

Some also expressed concern that the community group home was more subject to the vagaries of Government policy and community attitudes towards the mentally ill and developmentally disabled than Fifth Schedule Hospitals. They feared that if Fifth Schedule Hospitals were closed, persons placed in the community would be at the mercy of Governments who could easily cut back on funds for community services. Such cut backs are more difficult with respect to hospitals (Barclay Report, 1988:66).

What is almost completely missing from this discussion is the issue of the burden of care which has often fallen to mothers and other female relatives. Bryson and Mowbray (1986:185) have commented that discussion of community care in official discourses centres on the target groups rather on those who provide the alternative to institutional care. The Barclay Report conforms to this focus.

An example of the attempt to push care provision across the divide from public to private occurred recently in NSW. Its government decided to tighten guidelines defining transport entitlements for disabled children to and from school. The Department of School Education issued a directive that as many disabled children as possible be trained to use public transport. Under new guidelines the onus was placed on parents to transport children who were incapable of learning how to use public transport. Public assistance was only available in limited circumstances following detailed, written application by parents setting out the full circumstances which prevented them providing the transport themselves.



Three points may be noted. First, the existing policy, involving the provision of individual taxis, was extremely expensive and the revised policy reduced public support to these families significantly. Second, normalisation, in the form of increasing the children's independence, was used to legitimate the change in policy. Third, to avoid assuming this extra burden, parents were required to admit their incapacity in writing. It is a common technique of medical and other personnel involved with these carers to use the carer's reluctance to admit incapacity to obtain compliance with therapists' wishes (cf, Cant, 1993). The public servants drafting the transport policy changes appear to have noticed and copied the technique.

Needless insensitivity was also a feature of the introduction of these rules. Some parents received only 48 hours notice that their children had lost access to taxi transport. In one such case, a child aged 6 years whose parents were unable to transport her because of work commitments, would have been involved in catching three separate buses each day. Media publicity was a major factor in the three week fight it took to restore her transport. This case is instructive as it shows that if parents endure the stress of making public protests, it helps in getting services back. The Department's 'put in writing' demand in relation to parents inability to provide transport, is an added stress, even if they are literate in English (not always the case in multi-cultural Australia). There is a need for advocacy to help parents negotiate new turns in the bureaucratic maze as the welfare state retreats.

A newer initiative in NSW is the appointment of case managers to act as a source of information and to negotiate with services on behalf of the family. The stated aim is 'family centred service' which was interpreted by one official as 'more emphasis on the family's goals and participation and placing more responsibility on the family' (Rosen, 1994). Services, however, have not improved according to a survey carried out by the NSW Council for Intellectual Disabilities. Respite care facilities were reported to be overburdened and there was reported to be a critical shortage of permanent care for those whose parents sought such arrangements (Offner, 1994).

Commonwealth Government's policy documents and practices

In the Coleman Report (1978) *Families and Social Services in Australia*, the choice some parents wish to make not to care for their child with handicaps is acknowledged. During the eighties, either such reports were edited out of documents or parents were more easily persuaded from making the choice not to care. *New Directions* (1985), the Australian federal government report which reviewed handicapped programs, was prepared with the focus on the target groups of those with disabilities. However, of those consulted, 35 per cent were people who themselves had disabilities, and 20 per cent were 'relatives and friends of disabled people', so it might be expected that carers' concerns for their own lives would be apparent in the report. However, as with the

Barclay Report, there is little engagement with such issues. The 'clients or consumers of services' who 'need a strong voice' (*New Directions* 1985), to quote the then minister, do not seem to include the carers.

The Report began with a quotation attributed to a NSW parent:

> I consider it is marvellous to be asked as an individual to present a viewpoint. As a parent at seminars and meetings, I have too often been made to feel inadequate and have been saddened that amidst all the rhetoric both spoken and written by so many advocates, my twenty-four year old Down's syndrome daughter and her needs seemed to be at the very bottom of anyone's list.
>
> (*New Directions*, 1985:4)

There are a number of things of note about this quotation. The first is that it was selected (presumably from many others among the 1000 submissions from individuals) because it mirrors the major discursive field of the report, the rights and needs of the disabled child. The second is that the parent speaks of being made to feel inadequate. The third is that whilst she speaks of being permitted to present a viewpoint 'as an individual', the view she is permitted to present is a parent's view, focused on the needs of the child, not the needs of the parent as an individual in his/her own right.

Parents' voices are given space in *New Directions* not as individuals representing their own interests, but rather as their children's advocates. But the report records that 20 per cent of those consulted:

> ...were relatives and friends of disabled people, usually parents who had particular problems with getting appropriate education and training for their children, or who were worried about their accommodation as they themselves grew older ...(and) therefore could be described as consumers of services.
>
> (*New Directions*, 1985:6)

The focus again is on the child's needs, although the parent is described as a consumer. The only way in which parents can be construed as consumers is if the view is held that the service providers are acting in loco parentis. The implication is that families are responsible; it is not a collective responsibility. The sections which come closest to representing the individual interests of parents are those pertaining to respite care and attendant care and the section on accommodation. The section on respite care notes:

> ...there is a high level of demand for respite care, but there are very few respite care options at present.
>
> (*New Directions*, 1985:30)

Important issues which would lighten the level of burden are addressed. In particular, issues of the need for more readily available respite care are canvassed. The report cites home care service availability at all times and home visits by therapists, along with increased financial support, attendant care and structure of services as 'major areas of concern' highlighted by submissions. Some changes in these areas which would provide significant relief for carers, for example home therapy visits, are not encompassed by the recommendation, although transport to these sessions is a major commitment for many carers, and home visits would provide significant relief.

> *The contrast between the payments for care made to foster families and those to other families underlines the reluctance of the state to acknowledge collective responsibility for all children with significant disabilities.*

An effect of the ideology of familism is clearly reflected in payments granted towards the cost of the care of a handicapped child depending on who provides the care. If the child is cared for by its own family, a Child Disability Allowance of $68.30 per fortnight is paid. If the child is fostered, the rate starts at $194.70 per fortnight for a child up to four years with a minor disability. This increases to a maximum of $580 per fortnight for a very severely handicapped child. For a fostered child, there is an assessment of how much restriction is imposed on the carer, and how much domestic work, physical care and supervision is required. The shadow work of the fostering mother is acknowledged by these payments. In addition where a child is fostered, pocket money is paid and some expenses are met, eg, for travel and surgical equipment. The contrast between the payments for care made to foster families and those to other families underlines the reluctance of the state to acknowledge collective responsibility for all children with significant disabilities.

Conflict between a family and the state over responsibility for care-giving came before the courts in the Pullinger case. This case saw three years of litigation over the interpretation of the words 'acute care'. The child at the centre of the case was 8 years old, blind, with severe cerebral palsy and epilepsy. The Department of Health and a private medical fund agreed that acute care was designed to improve the patient. The Pullinger's case was based on the view that acute care did not need to effect an improvement but could be for the purpose of reducing deterioration or alleviating painful conditions. Without an acute care certificate, the cost to Karen's family of providing the type of care she needed, was prohibitive.

In August 1990 the Federal Court ordered the Department of Community Services and Health to reconsider its 1987 decision that, Karen and two other children, who had already died by 1990, were not entitled to acute care certificates which would oblige their private health funds to pay for the care. But in November 1990 the Department again refused to grant Karen Pullinger an acute care certificate for two separate periods in 1987. The Pullingers feared that if they accepted this decision and paid the $20,000 they owed for acute care, all of the child's current certificates would be cancelled. An alternative was to go back to court again. Within a few days the Federal Minister for Community Services and Health announced that he would intervene to ensure that Karen received acute care.

The Pullinger case is instructive. Only by being prepared to bear the stress of three years of litigation and media exposure did the family get for Karen the needed care. Because the situation was only resolved by direct intervention of the Minister, in future, other families may have to fight the battle again.

In 1992, the Commonwealth published a national policy statement *Commitment to carers* which laid out a number of objectives. These were:

- recognising the work of carers;
- provision of assistance and support to carers;
- improving opportunities and the quality of life for, and maximising the opportunities of carers;

- targeting assistance to carers so that it is fair and equitable;
- improving the range and quality of care options provided in the community.

(Commitment to Carers, 1992)

It reported a $93 million package of measures which 'will add to a range of services and benefits already available'. Benefits have been liberalised at the margins. However, in mid 1993, all 'non-employment' services for those with disabilities were handed over to the states. The Commonwealth no longer provided those services which were seen as duplicating state services, including respite care, recreation and accommodation services. The objective of adding to the range of services was then dropped.

Other policy commentary

While policy documents skirt the difficult issues raised by pushing care from the public paid sphere into the unpaid private sphere, academic research and research from centres such as the Australian Institute of Family Studies and the NSW Policy Research Centre continues to explore them (eg, Bryson & Mowbray, 1986; Rees & Emerson, 1984; d'Abbs, 1991; Graham, Ross & Payne, 1991; NSW Women's Advisory Council, 1993). Although much of this work is focused on elder care, the difficulties for children with disabilities and their carers is also detailed. These difficulties include financial pressures, less consistent therapy for the children, isolation of family members from their peers, and fatigue and ill health of carers. In addition, the abuse of the cared for in the elder care literature suggests that this may also be an issue with other frail dependent groups.

In the nineties, there has been a new turn to the debate on the public /private divide, with the need for more child-care places for women who have entered the workforce becoming an agenda issue for both major political parties. The problems of carers of children with disabilities can be seen as extensions of the more general issue of child-care. The emerging needs of the majority may aid the cause of those whose children are developmentally delayed and have long or indeterminate periods of dependency. Edgar's article (1992), *Sharing the care*, addresses the needs of carers of those with disabilities within this broader context. He details the changes in family structures, women's greater participation in the labour market and other pressure for change. The newer focus on the economic roles of women, and the problems they have with their 'second shifts' of domestic labour in their homes, may bring all shadow work into public view. In this context, a renewed debate on community responsibility for all dependent children, including those with developmental disabilities, may be more lively. The legitimacy of a mother's need to work is now generally accepted in our community. As a result, child care has moved up the political agenda. An extension of the range of child care options, so that handicapped children are catered for, is a logical next step. Mothers of these children are entitled to be able to work just as other mothers are. Indeed, if the 'second shift' Edgar (1992) describes, involves care of a handicapped child, social justice requires such mothers have a range of child care options right up to long day care.

Conclusion

This paper has analysed the rhetoric surrounding policy changes in care provision for children with developmental disabilities. It has considered the way in which the dependency needs of children are divided between the private and public sectors. It suggests that the discourse of community care which assigns the caregiving work needed by these children to mothers, may be beginning to change. The public sphere provision of care for all children is likely to increase.

Congregate care in the public sphere is clearly desired by most parents for some of the time. Some parents may prefer more; some may prefer *none*. The choice should be theirs; it should not be decided for parents by insufficient funding. The discourse of policy makers that has been examined in this document seems to be changing and congregate care, at least in the form of more accessible respite care, is again appearing on the agenda. It has been suggested in this paper, that the extension of such child care options will characterise future policy development. ♦

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