

Record

190

File Number

10162

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Title: Meetings with women with disabilities and carers who are aging

Original source: Australian Disability Review 2-92

Resource type: Written

Publication Date: 01/01/92

Publisher info: DACA

**Abstract**

This paper reports on two meetings held to discuss issues of concern to women who have disabilities and who are aging, and aging women who are carers, organised by ACROD in Sydney and Melbourne in 1990. The future, for both groups, was seen as a major concern, as were day activities for people retiring, nursing home staff training, government subsidies for essential aids and accessible communities. The paper concludes with a variety of recommendations. **Keywords: Aging, Women**

# Meetings with Women with Disabilities and Carers who are Ageing<sup>1</sup>

Two meetings to discuss issues of concern to women with disabilities who are ageing, and ageing women who are carers were organised by ACROD in Sydney and Melbourne in March 1990. The meetings were attended by representatives of most disability groups and women involved in a caring role. The meetings were convened by Robyne Burridge, ACROD's representative on the National Women's Consultative Council.

When opening the Sydney seminar, Ellie Mayhew from the Australian Quadriplegic Association drew attention to the fact that many people with disabilities are now living longer but for many the ageing process begins at an earlier age than it does for non-disabled people. There is little data available on the needs of the emerging group of people in our society except that, as age increases, dependence on the assistance of others for personal care can also increase. It is important that increased dependence resulting from ageing is seen as a need for increased support and not as medical deterioration.

A major concern for ageing carers of people with disabilities is uncertainty and doubt about what the future holds for those they are caring for when they can no longer fulfil this role. Consideration needs to be given also to the increasing band of people with disabilities who themselves care for ageing relatives.

Edith Morgan, from the Older Persons Action Centre Melbourne, opened the seminar in Melbourne by urging people with disabilities and carers to use organisations in both the disability and broader aged-care area to make their needs heard.

Both consultations attracted a diverse group of people whose insight and honest presentation of their concerns highlighted problems being faced by the ageing population of people with disabilities and carers throughout Australia.

While understanding and approving the new directions of the Disability Services Act many ageing parents of people with a disability who were present, expressed fear for the future of their adult children as inevitably they age (the parents). These parents have cared for their sons or daughters in their homes for 30-40 years in some cases and have worked tirelessly for service-providing organisations. These organisations in the past would in turn have been able to assure these parents that quality care would be available for their children when the parents were no longer able to carry out the caring role. Parents at the consultation felt this may no longer be the case and expressed concern about the quality of care their sons and daughters will receive without access to appropriate residential services run by voluntary agencies.

Participants felt consideration must be given to day activities for ageing people with disabilities who wish to retire from vocational services. It was

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<sup>1</sup> A report of two seminars on the issue of ageing and disability convened by ACROD in March, 1990.

recognised this will involve an impact on residential services. A desire for such services may not only result from ageing but from fatigue due to disabling conditions.

For people with disabilities who wish to remain in their homes the vision behind the Home and Community Care (HACC) program was welcomed. However, lack of information about the program, the fact that many of the worthwhile projects funded under HACC come to an untimely end because of a shortage of funds, and the fact that people with disabilities may require more hours of personal care than other ageing people, make accessing the program in a positive way, very difficult.

Extension of the Attendant Care Scheme to include aged people with disabilities was recommended as a means of solving many problems for those people who could take advantage of the scheme. All participants agreed that the cost of disability cannot be ignored, particularly for people with disabilities whose needs increase with age. Participants support the need for the introduction of a disability allowance.

Entry to nursing homes is now administered on a needs basis. Assessment prior to entry to nursing homes classifies people into categories. Ageing people with disabilities are likely to come into the highest category which presumes a need for twenty-seven hours of personal care per week. This is quite clearly insufficient time to provide for the needs of many people with severe disabilities requiring high support needs. There is a pressing need to seek an extension of these hours so that people with disabilities are not disadvantaged when seeking entry to a nursing home.

Participants at both consultations felt that staff training for workers in nursing homes and hostels was an important issue. People who are immobile and who may be experiencing sensory problems, often both hearing and sight impairment, can be very isolated and lonely. This can in some cases lead to withdrawal and perhaps to dementia. With a better understanding of how to communicate effectively with people with disabilities who have communication problems many quality of life issues could be resolved.

In NSW the deaf community is endeavouring to increase the awareness of the problems faced by deaf and hearing impaired people by a series of short talks to staff in nursing homes and this will be reinforced by a video.

Most carers reported difficulties with organising appropriate or regular respite care. This was of particular concern to participants caring for people with head injuries or psychiatric disabilities. Day services for people in these groups seem very inadequate. It was interesting that a mother, whose son has severe multiple disabilities, commented that she had been able to lead her own life unrestricted during the day because of the availability of regular day services. The two women, one caring for a husband with head injuries and one caring for her son with head injuries reported that they had both been forced to give up their professional careers to take on a caring role. Respite care for people with head injuries was often also provided in inappropriate services where the majority of other clients were suffering from dementia. All participants agreed that adequate respite care is essential to ensure a high level of quality of care for people with disabilities.

Inadequacy of income support was also an area of concern. Discussions on the Domiciliary Nursing Care Benefit (DNCB) (currently \$21 per week) centred around the fact that many carers were led to believe they were ineligible, and \$21 per week seems poor compensation for providing twenty-four hour care. The mother of a teenage boy with a head injury requiring twenty-four hour supervision was informed she did not qualify for the DNCB because he did not require nursing or personal care.

The need for Government subsidies for essential aids, accessible public transport systems and generally accessible communities, and Medicare cover of alternative natural therapies, which often provide assistance for people with disabilities, were also raised during the two days, as was the need for pensioners to be able to earn more than forty dollars before the pension was affected. The latter issue was of particular concern to ageing parents seeking to secure their sons and daughters financial future.

Participants were hopeful the Government would consider seriously the recommendation for the introduction of a disability allowance as recommended in the *Social Security Review Issues Paper No. 5, 'Income Support for People with Disabilities - Towards Enabling Policies'*. Particularly welcome in this recommendation was that it be paid to people with disabilities participating in paid employment and other community activity, education, training, job search, household work and child care or care of other relatives.

The issue of the double disadvantage of a person with a disability whose first language is not English was raised briefly at a seminar in Melbourne. It was agreed such issues need to be addressed by all players in the disability field.

## **Recommendations**

The following recommendations emerged from discussions during the two seminars.

### **General Issues**

- . That increased data be collected on the needs of people with disabilities who are ageing and ageing carers of people with disabilities.
- . That it is recognised that support needs for people with disabilities increase as they age and that the increases in support are not health or medically related.
- . That Government consult ageing people with disabilities and ageing carers to develop guidelines for appropriate, affordable and accessible services.
- . That Commonwealth Government fund appropriate services for these two groups.
- . That the needs of people with head injuries or psychiatric illness and their carers are provided for. To date very few services exist or are funded for these two groups.

- . That the different and special needs of people from different cultural and language backgrounds be recognised and catered for in the provision of services.

### **Accommodation**

- . That people with disabilities who are ageing are ensured choice of where and with whom they live.
- . That funds are provided to staff accommodation services to allow people with disabilities who are ageing to retire and spend increasing day-time hours at home.
- . That ageing people with high support needs are not discriminated against when seeking entry to aged nursing homes because of the number of support hours required to provide an adequate level of care.
- . That appropriate leisure activities are funded and provided. It was noted that people with head injuries or psychiatric illness are particularly disadvantaged in these activities.
- . That ageing people with disabilities have improved access to HACC services.
- . That the eligibility criteria for the Attendant Care Scheme be widened to include ageing people with disabilities to enable them to remain in their own homes.

### **Respite Care**

- . That appropriate respite care services are available from the perspective of both people with disabilities and their carers.
- . That specialist respite services for people with head injuries, dementia or mental illness be considered by the Government.

### **Income Security**

- . That a disability allowance be introduced by the Commonwealth Government to cover the extra costs of disability (e.g. aids, transport, personal care, home maintenance etc.).
- . That, until such time as a disability allowance is introduced, the eligibility criteria for the mobility allowance be widened to include people with disabilities not participating in at least twenty hours-a-week employment or vocational training, particularly those involved in community work or caring for other family members and relatives.
- . That the Domiciliary Nursing Care Benefit be immediately increased. The benefit of twenty-one dollars per week has not increased since 1981.
- . That permissible earnings before pensions are affected be increased beyond the current forty dollars per week for individuals and seventy dollars per week for married couples.

- . That sales tax exemptions for aids and appliances for people with disabilities be extended to cover general-purpose goods used for specific purposes by people with disabilities (e.g. air conditioners, computers, low vision aids such as hand magnifiers etc.).
- . That eligibility for assistance with provision of aids and appliances be made consistent across Australia. That information on such assistance be made widely available.

### **Staff Training**

- . That Government assist in the provision of training for staff in generic services to assist them in providing services for people with disabilities. This is important for those caring for people with dementia and communication difficulties (e.g. many people as they age can lose both their sight and hearing).

### **Information**

- . That all information on services be provided in an appropriate form.
- . That special attention be given to providing information for people with disabilities and their carers when:
  - English is their second language; and/or
  - they have sight or hearing loss, or comprehension difficulties.

### **Health**

- . That people with disabilities who are ageing have access to alternative therapies and medicines and where necessary assistance with the cost.

### **Access**

- . That the access needs of people with disabilities who are ageing are considered in all public buildings and community developments.

### **Care of the Carers**

- . That Governments recognise the extent of care being provided by families with members who have disabilities and their need for support. Recognition that most care is provided by women.
- . That services to support full-time carers be available to ensure that burnout and family breakdown does not occur.
- . That it be recognised that an increasing number of women with disabilities are becoming carers of people with disabilities or elderly relatives.

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*Note:* ACROD is presently preparing a position paper on ageing and accommodation issues for people with disabilities. Further information may be obtained from ACROD Ltd, P.O. Box 60, Curtin, ACT 2605, Australia.