

family

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Abstract

The article describes an attendant care scheme based on individualised consumer control and worker participation. The author, an attendant of the Disability Attendant Study Incorporated in Victoria, maintains that attendant care is the key to de-institutionalisation and gives people with disabilities greater control over their lives and time. It allows people to live independently and contribute to the broader community, and for greater flexibility in service delivery. **Keyword: Individualisation**

FULL MARKS FOR ATTENDANTS

PHILLIP RIPPER

This article describes an attendant care service based on consumer and worker control. The service has opened new doors for people with disabilities, their 'carers' and relatives who are living richer, fuller lives in the community. The author maintains that attendant care is the key to deinstitutionalisation.

The Disability Attendant Study Incorporated (DASI) - now in its sixth year - is a project designed and managed by people with disabilities; it allows them to live active and productive lives in the wider community. The Study's twin aims are to develop a consumer controlled, community-based attendant care service for people with disabilities in and around Northcote, and from that experience, to influence the development of a 'National Attendant Care Programme'.

Attendant Care is broadly defined by DASI as "assisting the disabled person with everyday tasks which a person without a disability could perform for her/him self". Tasks can include: personal assistance such as helping with toileting, bathing, getting into and out of bed, grooming, eating and drinking; assisting with general household tasks including meal preparation, cleaning and bedmaking; or assisting with personal administration tasks such as banking, bill paying, maintaining aids and appliances or charging batteries. Consumers may also use attendant care to assist them in their recreational activities or holidays.

DASI was formed in February 1984, after Alan, a victim of cerebral palsy, found that he required more assistance with his personal care, than his ageing parents were able to provide.

After securing an accessible unit from the Ministry of Housing, Alan approached his local council seeking some kind of attendant care. The council could only provide temporary home-help, thus highlighting a gap in local service provision. As a result, Alan and several other people with similar needs, joined with the council and the Australian Quadriplegic Association (AQA) to formulate a submission for federal government funding for one year under the Commonwealth Employment Programme (CEP). This funding established DASI, and

provided long-term jobless people with job opportunities and training in attendant care.

When CEP funding expired, additional funding was granted under the Department of Labour's Affirmative Action Programme. More recently, the Study has been funded under the Department of Community Service's Home and Community Care (HACC) Programme, a joint State and Federal Government body.

THE PHILOSOPHY

Individuality and Human Rights

DASI's guiding philosophy includes recognition of the rights of people with disabilities to: live independently and contribute to the broader community; have access to attendant care; choose their own lifestyles, make choices, take chances and share those human rights which are enjoyed by all other members of the community.

Consumer Control and Worker Participation

DASI's membership is comprised of consumers and workers. We acknowledge and cherish individual differences within the membership and we recognise the benefits which flow from worker participation in management. Participation in DASI is achieved by using an 'action research' method which allows for maximum participation by the membership in planning, design, implementation and evaluation of the project. Regular evaluation allows new directions to emerge, and these are then implemented and reviewed. As a result, a co-operative model of service delivery and management which relies on consumer-control, worker participation, negotiation and accountability has been established.

Consumer-control and worker participation is enshrined in all aspects of DASI's decision-making processes; our constitution ensures that consumers hold a majority on all committees and that attendants are represented at each level of management.

DASI is run by a Management Committee of five consumers of attendant care (all of whom have disabilities) and two attendants.

Consumers and attendants on the Committee are elected by their respective peers. Sub committees composed of consumers and attendants have also been established to work on various issues including: training, occupational health and safety, rostering, industrial issues, funding, future planning and administration. All meetings formulate recommendations which are then presented to the Management Committee for decision.

"Attendants ... are selected on the basis of their personal qualities..."

DASI currently provides attendant care to seventeen people with disabilities in and around the Northcote area. We employ about nineteen full and part-time attendants, as well as casuals who work in emergencies. We also employ two support staff in the form of a co-ordinator and a support worker. The co-ordinator is responsible for daily management tasks and the overall implementation of Management Committee policy. He is largely responsible for maintaining and cultivating new funding strategies and for providing support and advice to other organisations interested in attendant care. The support worker organises weekly attendant care rosters and trains and recruits new care staff. The support staff and Management Committee offer support to all members of DASI, and workers meet regularly for team support, information exchange and to discuss general issues.

QUALITIES RATHER THAN QUALIFICATIONS

Attendants are not expected to hold any formal qualifications, rather, they are selected on the basis of their personal qualities and their understanding and commitment to DASI's philosophy. To further highlight the philosophy of consumer control, DASI attendants are trained 'on the job' by the consumers with whom they work. This consumer-controlled 'on the job' training recognises that consumers best understand their own needs, and

how they can best be met. This approach starkly contrasts with the philosophy which may exist in some institutions - that of 'the doctor/ nurse knows best'.

"The use of attendant care removes the burden of gratitude which people with disabilities often feel they owe."

Additional training in areas such as communication, hygiene, and occupational health and safety including backcare, are organised by the support staff. In organising training, staff utilise the many resources and skills which exist within the organisation and within other community-based organisations such as community health and neighbourhood mediation centres, and community legal services.

THE ADVANTAGES

The use of attendant care removes the burden of gratitude which people with disabilities often feel they owe to their 'helpers' and replaces it with an employer/employee relationship. There are relatively few rules about how this working relationship operates, and so tasks and expectations can be negotiated between attendant and consumer on a case by case basis. This allows for greater flexibility in service delivery and ensures that the needs of attendants and consumers are satisfactorily met.

The case for attendant care can be argued on many fronts. Firstly, it provides an inexpensive alternative to nursing home accommodation, the cost of which can range from \$38,000 to \$110,000 per person per year. By contrast, attendant care as provided by DASI, costs on average \$23,000 per person per year. This expenditure has enabled many consumers to move out of residential institutions, and in other cases, to remain in their homes in the community.

From a broader economic standpoint, attendant care has additional benefits. It has for example, enabled some family members (who have largely cared for disabled relatives) to re-enter the workforce, and it has provided jobs for previously unemployed people. At the same time, the flexible nature of DASI's model of attendant care - with its emphasis on fitting the service to the people rather than the people to the service - has given people with disabilities greater control over their own lives

and time. As a result, many have been able to enter part-time and full-time employment. Thus, three people - the relative/friend of the disabled person, the attendant, and the disabled person themselves - have all been able to work, pay taxes and consume, and have reduced their reliance on pensions and unemployment benefits.

As you can imagine, the reliance on a loved one to carry out all of your personal care needs, can put a relationship under enormous stress. Other benefits of attendant care, such as vastly improved quality of life for the consumer and their relatives, are not measurable in monetary terms. For instance, Lee - the wife of a young disabled man wanted to study dance in order to teach ballet, however, attending to Grant's needs made this almost impossible to achieve. Likewise, Grant's reliance on Lee for his personal care needs, made his tertiary study extremely difficult.

Since joining the Study, Lee has completed her course and is currently employed teaching dance. Similarly, Grant has completed a degree and is now employed as a computer scientist. The provision of attendant care has thus enabled Grant and Lee to achieve some of their ambitions; it has provided additional freedom to each, and has improved their quality of life immeasurably.

"Rob requires a relatively high level of care, without which, he would face the possibility of living in an institution."

Rob and Cathy have also benefitted from the use of attendant care. Rob requires a relatively high level of care, without which, he would face the possibility of living in an institution or hospital. Attendant care has relieved some of the pressure on Cathy, so that now she has been able to secure full-time employment, and it has expanded the options for Rob. Rob now not only works, but he also attends football games, social occasions and the like.

Consumers and their families are not the only people benefitting from the attendant care project. Many attendants who were previously unemployed, have gained meaningful employment; the Study encourages attendants to view their work as a 'career' rather than 'just a casual job'. DASI provides permanent employment with all of its

benefits, including a livable wage, holiday pay and leave-loading, and Workcare cover.

PROMOTING THE BENEFITS

Many community groups, such as the Attendant Care Coalition, are promoting the benefits of attendant care. The Coalition is a lobby group whose aims include developing attendant care for people with disabilities, so that they can achieve independence and control over their lives. The Coalition is campaigning for attendant care to be enacted in federal legislation as an income security measure for people with disabilities; it also promotes the attendant care system as a means of providing a flexible range of support options for those who need care. The Attendant Care Coalition also aims to ensure that any system of attendant care, takes account of the industrial rights and responsibilities of all of the parties who are directly involved.

Attendant care is the key to deinstitutionalisation because it enables people with disabilities to live independently of institutional constraints and exercise their fundamental human rights and choice of lifestyle. As such, it should be viewed as a basic right for people with disabilities. Without attendant care, many disabled people would be forced to live in, or return to, institutions.

Whilst there are many barriers to deinstitutionalisation - such as inappropriate housing, lack of access to transport, support and income - these problems must be tackled in conjunction with the fight for attendant care services. Without attendant care, the dreams of deinstitutionalisation will remain just that, dreams!

Postscript

DASI is one kind of service model for people requiring attendant care. It is however, fairly unique, as Commonwealth and State Governments do not yet recognise attendant care as a fundamental right and service need of a large number of people with disabilities.



References

1. The Learning Package - A Model of Co-operative Learning and Training in Attendant Care.
Suitable for all people interested in attendant care: consumers, attendants, significant others and service providers. The package is also valuable reading for people interested in community-based, consumer-controlled co-operative models of service delivery, and for human service organisation interested in developing co-operative learning and teaching methods.
2. Gianni, Steven (1989) 'What's This Attendant Care' produced by the Attendant Care Coalition.
An easy to read introduction to attendant care.

For further information on the attendant care movement, or copies of the above reference material, contact:

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After a long interest in community work, Phillip Ripper joined DASI as an attendant because he was attracted to serving those in the community with special needs, in a practical way. He later became a Consumer Attendant Support Worker for DASI, a position he currently holds.