SUBMISSION FROM:
NSW LEGACY PEOPLE WITH A DISABILITY ADVISORYCOMMITTEE

Submitted by: New South Wales Legacy People with a Disability Advisory Committee

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Introduction

For 87 years Legacy has been committed to the support of wives and children of servicemen and women killed during war, whilst training for war, in peacekeeping or other hazardous service, or who have died subsequent to their service.

In this role Legacy supports a significant number of people with a disability who are deceased World War 2 veterans' children**.** These persons with a disability are often in their fifties and sixties. Parents have cared for them all their life within the family unit and they have not been identified until a crisis has arisen. Some parents have never advised anyone that they have a child with a disability. They are sometimes only identified when the carer dies or is put into a nursing home or hospital. The ageing carers, who care for a disabled person in their fifties or sixties, face many difficulties.

As the widows whom Legacy cares for age they, themselves, also develop disabilities. These are often not recorded as such but it is considered part of the process of ageing. Their disabilities can range from mental problems such as Alzheimer's, loss of mental acuity, anxiety depression or stress, mobility problems, health and caring issues due to eyesight and hearing disabilities. Widows with a disability are not reflected in the numbers of persons with a disability in the figures below. Added to this are the injuries suffered by widows due to prolonged lifting, injuries from manual handling or injuries sustained when dealing with a PWD with challenging behaviour.

Legacy NSW cares for 38313 widows and 566 disabled dependants. Australia wide Legacy cares for 109308 widows and 1309 disabled dependants. Our involvement in care for disabled dependants and aged widows with a disability is significant.

Legacy NSW Initiatives

When Legacy found an increasing number of disabled dependants as widows aged it was realised that something had to be done to recognise and care for disabled widows and persons with a disability. In some cases there is a role reversal which is detrimental to both parties where the person with a disability tries to care for the aged parent. The following initiatives have been developed and adopted.

Legacy NSW "Persons with a Disability Advisory Committee" was set up. The committee wrote a constitution to guide Legacy's approach to the care of persons with a disability. Guidelines were set in place for the care of persons with a disability. As well the committee developed an aide memoire to guide legatees (members of Legacy). See Annex B for this guide.

The aide memoire was to help form a "portrait" of a person with a disability on enrolment in Legacy. Again this can not be developed if a widow choses not to disclose information about a child with a disability.

Legacy employs **community service workers (CSW's),** where appropriate and financially

…../2

possible, to assist in the carrying out of care for our dependents. CSW's help bring skills and knowledge which may not be possessed by the members of our organisation. The CSW's have been instrumental in searching for and gaining supported accommodation for some of our dependants.

Legacy advisors offer advocacy services for our dependants. This may comprise support in seeking housing, respite, negotiations with government departments, day programs for persons with a disability, care for the carer, holidays and activities.

Legacy can offer financial support if it is deemed necessary on a short term basis but Legacy seeks to obtain support from government agencies and service providers.

The Advisory Committee has helped in the provision of information to the twenty NSW Legacy Clubs. Two forums have been held in Sydney and advisory visits have been made to clubs to provide information and help raise awareness of people with a disability. The information has been provided to help find aid/assistance for our dependants.

Although Legacy has been limited by its resources a number of Clubs have initiated planned activity days for our persons with a disability and provided transport to these. These activities often depend on the number of persons with a disability in certain areas. Persons with a disability support groups are active in Sydney and on the NSW Central Coast.

Legacy has worked with Professor Cartwright of Southern Cross University Coffs Harbour Campus, on the development of "personal portraits" for our widows and persons with a disability. Information processing forms a vital part of planning for our dependants.

Desired Outcomes

Legacy sees a number of desired outcomes for persons with a disability.

- Advice needs to be readily available to carers, to persons with a disability and to support people and organisations. It can be extremely difficult to locate relevant advice and information.
- Persons with a disability and carers need to get the right counselling to help them handle their situation. This can vary from very little to the need for substantial intervention. Legacy feels that both the need of the person with a disability and the carer need to be addressed.
- Persons with a disability and carers need to feel happy and contented. They need to feel comfortable. Their health and well being is extremely important and they need to feel safe.
- Organisations such as Legacy and the general public need to be aware of day placements and funding available. Suitable activities and day programs need to be widely available to increase the interaction of a person with a disability and to build their social and physical skills. Not only do they need to be available but persons with a disability need to be able to access these programs as they are needed. These programs also give some respite to carers. In Legacy's case the carers are often aged.
- Where it is appropriate persons with a disability should have some form of employment available. One of our persons with a disability has shown the benefit of employment in a sheltered workshop. Bob (*name changed*) has worked for many years in a sheltered workshop; has used his money to pay off two cars; has driven for 25 years without incident. With minimal support he is living independently.

…./3

- Persons with a disability need to be able to access services. This can be looked from two angles. Firstly the services need to be identified and be available. Secondly physical access needs to be assured. Legacy can relate the story of a widow who arranged transport though Department of Veterans' Affairs for a doctor's visit for her husband who was suffering from Alzheimer's and restricted mobility. She also had severe mobility problems. After she had picked her husband up from the nursing home and travelled to the doctor's, she found that both she and her husband were unable to negotiate the steps into the building. They then had to get the hire car to return them firstly to the nursing home and then to her home. Further investigation was then done to find a specialist where physical access was not an issue.
- Daily living skills and daily functioning skills need to be addressed. This can help decrease the dependence on carers. These skills need to be taught. This also includes access to knowledge and equipment.
- Social networking and support for both carers and persons with a disability needs to be in place. Legacy is approaching this need by trying to arrange, where possible, social outings for persons with a disability and carers. The availability of respite is important for the support of carers. A carers' support network should be in place to assist them to care for a person with a disability.
- The problem of isolation needs to be overcome. This refers to both carers and the person with a disability. Programs that suit the needs of the person with a disability need to be in place and transport to get them there needs to be available. Some of our wards have access to such programs and they are extremely beneficial socially, for the development of skills and the maintenance of well being. Carers also need access to support and to services to overcome isolation. Legacy actively tries to overcome the problems of isolation but it is a difficult and challenging task. Sydney Legacy runs a "Wattle Group" which provides separate monthly outings for persons with a disability who need full care and those who operate independently. Similar programs are operated by Brisbane Water Legacy on the NSW Central Coast. Moves are afoot to initiate a program in the Newcastle area. These programs are more difficult to organise in smaller areas with fewer persons with a disability.

Problems

The detection of persons with a disability can pose a problem. It is often not until a crisis situation has been reached that anything is done. Even then it can be a battle to secure appropriate services. A further problem for Legacy is that the widows did not readily disclose a person with a disability in the family or seek any specific assistance.

Where do you go to source aids and equipment? This centres on gaining access to suitable funding and care. Who has the funding and the appropriate programs? How do you gain access to suitable programs? It is often difficult to weave your way to locate suitable options. We need to know what is on offer and we often feel kept in the dark.

Legacy offers support as an advocate should the carer need one. Our legatees at times find it difficult to work their way through the processes of seeking aid. To carers, particularly aged carers the process is overwhelming. This is relevant to both physical access to buildings and services.

Gaining accommodation for a person with a disability can be a minefield. Different accommodation types need to be available. These could be short term or respite, long term or

…./4

supported living. The provision of long term accommodation can present real problems. It has been suggested that a possible solution could be a demountable structure on available unused council or allied land. This could be rented at a "peppercorn rent." Unfortunately accommodation which appears to be temporary can also have a negative effect on a person with a disability. At any rate there needs to be some certainty about funding for longer term programs and accommodation.

It is necessary to know where to go to find out how to source aids and equipment for a person with a disability. This also applies to the carers and the widows with a disability who are in our care.

Because of the age of our carers they do need respite from time to time. Legacy is in a position to offer them a brief holiday but this is usually accessed once every couple of years on a case by case basis. There needs to be respite which can be accessed on a regular basis.

Great programs don't necessarily get the funding. It is disappointing when good programs struggle because of funding. The programs involving Daniel (see Annex A) met his needs but struggled because of the availability of funding. Consistent funding is needed to keep good programs going.

People, both within our organisation and outside of it, who have the skills to support persons with a disability need to be identified. There are times when Legacy is unable to provide the people with the skills to support our persons with a disability. If the person with a disability lives in an isolated area access to support persons (i.e. community service workers) can be difficult. Overcoming the problems of isolation of carers and a person with a disability is an issue that concerns Legacy.

Access to care and support can depend on an ACAT assessment. Sometimes widows with disabilities, after the assessment, have to wait for up to six months before receiving support. The following serves as an example. A husband and wife were receiving home support from Department of Veterans' Affairs. The husband died. The wife suffered from macular degeneration and mobility problems. Following an ACAT assessment the wife became eligible for home health but she was placed on a waiting list for six months before she could receive services.

Recommendations

The following are recommended as focus areas for any future government action.

- Awareness of disabled people and their problems. This involves the detection of disabled people in the community and their problems and needs.
- Once disabled persons are identified there needs to be continuity in the services provided to them. At present the approach is more piecemeal and depends on funding to various groups.
- Programs are designed to meet the needs of the disabled but knowledge of programs, eligibility and access are different matters. A unique "one-stop shop" concept for information along the lines of the Commonwealth Care Link system is essential.
- A website, along the lines of the location of public toilets, could be developed listing the services (eg government departments, service providers, doctors and dentists) not

…/5

compatible with the needs of persons with a disability.

- Despite the efforts and improvements in recent years, physical access to buildings can still be improved.
- Funding is needed to help drive change for the disabled. Good programs can falter with the reduction or removal of guaranteed funding.
- The percentage of PWD’s that Legacy cares for needs to be recognised and information and funding should be provided where necessary.