

Submission on Disability Services Office Draft Disability Framework 2004-2007



Carers
Association
of SA Inc.

PO Box 410 Unley SA 5061: Telephone 8271 6288: Fax 8271 6388:
Email info@Carers-sa.asn.au: Website: www.Carers-sa.asn.au

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This submission was prepared in consultation with a Carers Focus Group.

Excerpts from the DSO Disability Framework 2004 – 2007 are in italics, with comments and recommendations from the Carers Association in normal type.

Layout Recommendation:

- That dot points be numbered for easy identification.

This submission should be read in the context of the Carer Association's support for, and involvement in, the development of State Carers Policy. The Carers Association has called for the State Carers Policy to provide an across government context in which individual agency policies involving Carers can be themselves developed.

Glossary

The Disability Framework requires the addition of a Glossary defining the following terms:

- Carer.
- Community.
- Community Care.
- Consumer.
- Client Group.
- Family Carers.
- Foster Carers.
- Host Family.
- Personal Support Service.
- Respite:
 - Emergency Respite.
 - Usual Respite.
- Shared Care.

Recommendation:

- That the terms 'Carer/s' and 'consumer/s' be used consistently throughout the document.
- That the term 'consumer/s' is not used to also refer to 'Carer/s'.

The New Vision of Disability Services

No comment.

Underlying Needs

Underlying Needs dot point four: The need to establish a single system of Options Coordination to promote equity and access across disability groups.

Whilst the Association acknowledges that one system has the potential to cut across what is perceived in practice as a 'maze' nevertheless this point requires further clarification:

- Does streamlining of disability services into one system mean that the access bar is lifted and that, for example, 50% of people can't access it?
- Does this mean streamlining to save money and if so, what are the safeguards for consumers?

Examples of current unmet need include young persons with Attention Deficit Disorder or Attention Deficit and Hyperactivity Disorder unable to access disability services due to not meeting definitional requirements. There is a perception that due to limited funds IDSC "raised the bar" to prevent their access to service.

Recommendation:

- That the Framework clarify the DSO client base.

Foundation Principles

Foundation Principles dot point three: People with disabilities, carers and siblings should feel confident that each required service is accessible and responsive to the needs of their family member with a disability.

Recommendation:

- That 'should' be replaced with 'can' in Foundation Principles dot point three so that it reads: 'People with disabilities, Carers and siblings can feel confident that each required service is accessible and responsive to the needs of their family member with a disability.'

Due to the nature of the caring role Carers continue to place their health and well-being at risk with many suffering from 'burn out'.

Recommendation:

- That another dot point is inserted in Foundation Principles, as follows: 'Carers recognised and supported in their caring role in order that they may have quality of life.'

Foundation Principles dot point ten: Disability services should always be centred upon non-territorial, quality, cost-efficient outcomes, used in concert with the goodwill of the whole community.

Disability services, whether based in a single or multilayered system, should *always* be centred on the client and their Carer.

With reference to community goodwill the question arises as to the extent to which the community at large 'wants to know' about disability. One perception is that they do not. Unless an awareness/education campaign is carried out any goodwill that

might exist for the full inclusion of people with disabilities in 'mainstream' community will remain tenuous.

Recommendation:

- That an education campaign on raising the awareness of the social value of people with disabilities and the impact of the care-giving role on those who are Carers be developed and undertaken.

Planning for Disability Services

How are needs prioritised? Who does the prioritisation? Is the current IDSC system of high financial input to a low number of clients going to carry over into the proposed state-wide Disability Services SA? A more equitable system of providing eligible consumers, families and Carers with services is needed. Currently there are consumers and their families, who have been assessed as eligible, but who are not receiving services.

Also the current reported practice of including into client numbers for a two year period after their last call, those people who ring DSO Options for a service, is misleading. This practice gives an inaccurate picture of the services delivered by the bigger disability organisations to those most in need.

Recommendation:

- That a baseline of minimum service provision for those assessed as eligible be established.

Disability Services Office Goals

Disability Services Office Goals first paragraph: To promote citizenship and valued participation in the community by people with a disability, including their access to mainstream services available to all members of the South Australian community.

Carers report the perception that 'access to mainstream' in practice results in "You are on your own". If the facilities to support access to the 'mainstream' are not there to help people with disabilities participate they cannot be included. The resultant exclusion transfers costs and delivery of care onto family Carers. How are such facilities to be provided?

Key Result Area 1.1 Improve Responsiveness and Quality of Services

In dealing with complaints a timely and sincere apology can often defuse a situation early.

Recommendation:

- That the Disability Framework develop practices and protocols that encourage and enable service providers to apologise where appropriate.

Key Result Area Key Outcomes dot point one: National Standards for Disability Services are implemented and monitored through service agreements and an external validation process.

The Association supports the proposed requirement for services to implement the National Standards for Disability Services.

Key Result Area Key Outcomes dot point three: There is consumer education regarding the service standards and clear consumer grievance processes are in place.

Recommendation:

- That service providers be required to:
 - Develop and implement clear consumer grievance processes.
 - Clearly define access paths for services.
 - Publicly advertise access paths for services.
 - Clearly define service denial appeals processes.
 - Develop Care Plans in partnership with consumers and Carers including the maintenance of adequate levels of service provision

Recommendation:

- That legislation be introduced, or relevant amendments made to appropriate legislation, to enable consumers and Carers to complain about the DSO and government and non government service providers.

Key Result Area Key Outcomes dot point eight: The DSO undertakes regular service reviews and program evaluation based specifically upon the measures set out in service agreements with agencies.

Recommendation:

- That rigorous and regular independent service reviews organised by DSO be undertaken with Carer and consumer input.

Where is the evaluation of DSO processes as well as services provided through DSO funds? Who audits the DSO?

Recommendation:

- That Community Visitors be part of the audit process.

Key Result Area 1.2 Ensure Legislation Supports Rights

Key Outcomes

- *The Disability Services Act is amended to bind the Crown in relation to services provided specifically for people with disabilities.*
- *The Act is amended to specify formal complaints mechanisms for consumers and Carers.*
- *The Act is amended to clearly state expectations of funded services, together with mechanisms to deal effectively with funded agencies that fail to deliver quality services.*
- *The Act states that supported accommodation in community settings is the standard for all new accommodation services.*

- *The Act provides a mechanism for funding of Government disability services (as well as non-Government services).*

There are concerns that the current *Disability Services Act 1993* only recognises Carers within a context of caring for family members and that it does not guarantee any service provision.

Recommendation:

- That *the Disability Services Act 1993* be amended:
 - To bind the Crown in relation to service provision.
 - To specify mechanisms to deal with agencies that fail to deliver quality services.
 - To make provision for the funding of Government disability services as well as non-Government services.
 - Such that any choice by Carers and care recipients of a public or private health sector service is not removed.
 - To incorporate the International Classification of Functioning, Disability and Health as endorsed by the World Health Assembly (WHO 2001 - Appendix A) as a definition by which service provision is allocated. This means disability service eligibility will be based on functional loss, not diagnosis.
 - To incorporate recognition of the rights of Carers, in particular the rights of Young Carers aged 18 years and under.
 - To incorporate a requirement for the provision of services to Carers in their own right.
 - To acknowledge that Australia has ratified *The United Nations: Declaration on the Right of Disabled Persons, 9 December 1975.*
 - To acknowledge that Australia has ratified the *UN Convention on the Rights of the Child (1989).*
 - Such that it conforms with best practice as outlined in Acts in other Australian jurisdictions.

Key Result Area 2.1 Moving Towards Community Living

Key Outcomes

- *More community accommodation places, with a concomitant reduction in the number of residential places in institutions.*
- *A state-wide assessment framework, for people requiring support in a range of settings. The development and evaluation of systems to assess consumer needs and service costs is researched by the Disability Research Unit of the University of Adelaide. All assessments are undertaken in accordance with the "Principles of Assessment for Disability Services".*
- *Planned entry and exit processes for institutional care through Options Coordination are in place with encouragement of community alternatives, wherever possible.*
- *Service Activity Agreements specify the number of places in institutions. Over time the number of places in institutions is expected to decrease.*
- *The credentialing model of health care is implemented and funded with appropriate standards.*

- *People living in congregate care who wish to remain in congregate care are able to do so.*
- *A variety of innovative accommodation models for community living will be encouraged and supported.*

Families are not mentioned at all in this Key Result Area, although it is acknowledged that they are central to Key Result Area 2.2. There is reference to community living but nothing about people living with families. Families need transparency on all issues relating to integration and accommodation. The primary aim should be to keep families together in the community by working with them and supporting them.

For many people with disabilities their family is their community. But what is meant by the term 'community care' in terms of this document? There needs to be clarification. Is it services delivered by families, formally or informally? Many families assume it means that they are providing the service, whilst many service providers would regard it as meaning that they, the service provider, are providing the service. So, community care can mean care by community services by one group of people or care by family members by another group of people. We cannot make assumptions as to the meaning people might prescribe. National networks emphasise the care carried out by family members in this respect. Refer to previous comment about provision of a Glossary.

There appears to be a presumption that the members of the community agree with this Key Result Area, but what community consultation has occurred? The community in general needs to be made more aware about disabilities otherwise the Carers and care recipients bear the stigma of their misunderstanding.

Young Carers

There is no reference to the paediatric sector in this Key Result Area. Of particular concern are those children and young people who are becoming Carers of parents and/or siblings with high care needs. Given that the *Convention on the Rights of the Child* (1989), which has now been ratified by 191 countries, holds 'respect for the best interests of the child as a primary consideration', the Disability Act needs to reflect compliance with this statement by prioritising the provision of support services to Carers who are aged under 18 years of age.

Recommendation:

- That the *Disability Services Act 1993* be amended to provide mandatory service support to Carers under the age of 18 years.

Modelling

As stated above, there is a lack of clarity as to the meaning of 'community'.

Recommendation:

- *That the Disability Services Act 1993* be amended to include a definition of the word 'community'.

As previously stated, the definition of community care needs to be clearly articulated as a mix of funded services, residential programs and support by family and friends, and that services will be funded to support families in their contribution.

A variety of innovative community living models needs to be encouraged with more community accommodation places with accompanying reduction in institutions being only one available option. A key area to enable effective and supportive community living is for the disability support services to work with and support families in the community. It is extremely rare that a person with a disability who is living in the community is unsupported by a family member or friend acting in a Carer role. These Carers need support and adequate resourcing.

Recommendation:

- That changes be made to Key Result Area 2.1 Key Outcomes dot points 5 – 7 so that they read:
 - The credentialing model of health care is implemented and funded to appropriate standards.
 - People living in congregate care who wish to remain in congregate care are able to do so with clear delegation of care roles instituted.
 - A variety of innovative accommodation models for community living will be encouraged and appropriately funded.

Credentialling

The disability sector has developed a model of credentialling but failure to adopt this model in the aged care sector raises real concern and questions about how the disability and aged care services integrate in the delivery of appropriate quality services.

Demographics

The ageing of people with a disability and their interface with aged care is of concern. If the number of places in institutions established specifically for people with a disability, is to decrease, (Key Result Area 2.1 Key Outcomes dot point four) what are the implications for the increasing number of ageing people (the 'baby boomers') who may need a service and those that care for them? What is the nexus between disability and ageing, particularly in relation to conditions such as MS and motor neuron disease? Is this a realistic outcome given the nexus between planning and demographics?

Recommendation:

- That there be an additional dot point in Key Result Area 2.1 Key Outcomes.

Recommendation:

- That services will be based upon demographic statistics, with sufficient disability services being implemented to meet the needs of the 'Baby Boomers' who are now entering high risk groups.

Key Result Area 2.2 Assisting People With Disabilities and Their Families

The Association supports the inclusion of this key areas but is concerned at the lack of comment on psychiatric disability.

The focus of the Framework appears to be the expectation that the Carer will provide the care regardless. We have spoken, above, about the perception by the Carer of a lack of choice in taking on the caring role. It is vital that the Carer and care recipient are seen as an important caring unit, which should not be fragmented between service delivery systems.

Key Result Area 2.2 paragraph one: sentence 1: While the needs of people with disabilities are the primary concern of service providers, DHS recognises that carers are essential to services since they provide much of the day-to-day support and advocacy for people with disabilities.

The Association has called for legislative recognition of Carers that would underpin policies such as the Framework. As stated above, Carers should be recognised as having needs of their own which are related to, but different from, the needs of consumers.

Carers are too often viewed only as advocates for consumers or as a resource for service providers and consumers, rather than as customers in their own right with their own emotional and other support needs. It is desirable to look at the whole person rather than see that person as just a Carer. Carers often experience difficulty in articulating their own needs when faced with the paramount importance of securing adequate and appropriate care for a loved one.

Key Result Area 2.2, paragraph 1, sentence two. Most Carers are family members – the parent, partner, child, or relative of the person with a disability "

The Association supports a definition of 'Carer' based on relationships. The Association currently uses the following definition of a Carer:

- A Carer is someone who provides care and support for their parent, partner, child or friend who has a disability, is frail aged, or who has a chronic mental or physical illness.

When discussing family/caring responsibilities reference can be made with regard to:

- Kate Reynolds' Equal Opportunity Amendment Bill section 5 (3) (a) (b) currently before the Legislative Council citing a person's responsibilities as a Carer, that is, if the person accepts the caring role.
- The wider community's perception of a person undertaking the responsibilities of the caring role.

Recommendation:

- That 'siblings' and 'close friends' be included in Key Result Area 2.2, paragraph 1, sentence two, so that it reads; 'Most Carers are family members – the parent, partner, child, sibling, relative or close friend of the person with a disability "

Key Result Area 2.2, paragraph 3, sentence one: The need for services that support the carer and reduce the pressure on families will be developed.

The need already exists.

Recommendation:

- That Key Result Area 2.2, paragraph 3, sentence one read: That services that support the carer and reduce the pressure on families will be developed.

Key Result Area 2.2, paragraph 3, sentence three: The provision of flexible respite options is seen as a vital way of providing support to carers.

Refer to comment, above, on the addition of a glossary: the term 'respite' needs clarification: who is it for? The Association supports the provision of flexible respite, which gives the Carer choices and certainty.

Key Result Area 2.2, paragraph 3, sentence four: A number of initiatives will improve services for families.

Recommendation:

- That Key Result Area 2.2, paragraph 3, sentence four read: A number of initiatives under this Framework will provide measurably improved services for families.

Recommendation:

- That there be further clarification as to the initiatives proposed that will provide measurably improved services for families.

Key Result Area 2.2, paragraph 3 states that "services that support the Carer and reduce the pressure on families will be developed." However the framework's intent is more aptly described on page 23 as disability service funds to be used to access (mainstream) services.

Recommendation:

- That the Framework clarify exactly what support services are to be maintained or established to achieve the ends of the Framework.

Key Result Area 2.2 Key Outcomes dot point one: A service focus for Aboriginal children and adults with a disability across South Australia is created both in Options Coordination and local services.

Association supports this outcome.

Key Result Area 2.2 Key Outcomes dot point two: Sibling support services are developed for people who provide a support role for their brother or sister with a disability.

Sibling support services need to be developed and delivered within time-lines and quality audits. Under *The United Nations Convention on the Rights of the Child 1989*, a child has the right to survival and development. Young Carers, those aged 18 years and under, should have top priority for disability support services.

Key Result Area 2.2 Key Outcomes dot point three: A priority focus on Carers who are ageing is maintained.

Whilst supporting the continuation of the priority focus on supporting Carers who are ageing, given their very real needs in supporting ageing people with disabilities or adult children with disabilities, the Association nevertheless points to the pressing need to develop a 'caring for the Carer' culture within the disability support services, including transparent care planning with adequately resourced care plans, enabling the continuance of long-term low-cost care provision.

The DSO needs to continue to speak with and learn of the needs of Carers of all ages and to seriously take their needs into account. Support for the Carers includes enabling the maintenance of their well-being and health, otherwise there would be two individuals requiring system intervention.

Recommendation:

- That an additional key outcome for Key Result Area 2.2 be the promotion, support for, and training of, family Carers of all ages.

Key Result Area 2.2 Key Outcomes dot point four: The DSO promotes assistance for families regarding costs of equipment and health items, including continence aids.

How will this happen?

Key Result Area 2.2 Key Outcomes dot point five: Non-government agencies are encouraged to participate in a voluntary vehicle purchase scheme, whereby people with a disability and their families can purchase accessible agency vehicles at trade-in prices as they become due for replacement.

Whilst supporting the intent of this outcome the Association is concerned that it could become a 'fill-in' response, and that any enforcement strategy may well be overly onerous on participating agencies and unworkable.

Recommendation:

- That a campaign to develop greater awareness of similar scheme within government be undertaken.

Recommendation:

- That consideration be given to the establishment of a state-wide fleet system of accessible vehicles.

Key Result Area 2.2 Key Outcomes dot point seven: A special focus on meeting the needs of parents with a disability.

This special focus needs to include the family in which children are often providing care-giving from a very early age and in which there may well be children with familial disorders inherited from their parent.

Key Result Area 2.2 Key Outcomes dot point eight: Challenging behaviour services are improved to give children and adults requiring such a service greater opportunities for better educational and social outcomes.

Feedback to the Association indicates that children with ADHD and Autism are receiving insufficient funding and other resources and focus that would enable their development. The impact on families becomes long term dependencies. These two groups should become a priority focus. This may include how greater support, information and services are provided to families so that they can better manage the care.

Recommendation:

- That the needs of children with ADHD and Autism be addressed within the DSO Framework.

Key Result Area 2.2 Key Outcomes dot point ten: In each region, "disability inclusion committees" are established, consisting of people with a disability and their families, as well as other community members in a position to raise community awareness of disability and citizenship rights.

Whilst recognising the need for societal inclusion of people with disabilities the Association is concerned that unless significant education has occurred previously, this may only serve to reinforce existing negative community views. It is vital that during the establishment of the Regional Disability Inclusion Committees education, training and promotion strategies to reduce bias and stigma still being felt by people with disabilities be undertaken. This will raise the awareness of the social value of people with disabilities and the impact of the care-giving role on those who are Carers.

When the time is right for the development of the Regional "Disability Inclusion Committees" it is vital that the government sector responsible for the funding of disability services does not view these bodies as able to offer supplementary funding in supporting an ailing government support program.

There is concern that the Disability Inclusion Committees will establish their own registers of people with disabilities. DSO needs to guard against the setting up of such registers. Standards around consumer and Carer participation must be established that are transparent and inclusive of the wider disability community. A number of frameworks are currently being developed at a Commonwealth level for consumer and Carer participation.

Recommendation:

- That a widespread education campaign on raising the awareness of the social value of people with disabilities and the impact of the care-giving role on those who are Carers be developed and undertaken.

Key Result Area 2.2 Key Outcomes dot point eleven: Upon request, an advocate is provided for any family (and their child) who becomes involved with the justice system, either as a victim or through being charged with an offence.

Recommendation:

- That the financial cost of disability support for people with disabilities involved with the Justice System should be partially met by the Justice System.

Key Result Area 2.3 Defining a Disability Service – Personal Support

Personal Support Services for Carers need to be developed. Care planning needs to be done in a timely, and on a non emergency, basis. Service provision should be viewed as Personal & Carer Support Services to reflect that not only is access a key issue but the provision of actual disability services and Carer support are both equally important key issues.

Recommendation:

- That an additional sub-program to be underpinned by the Personal Support Services be 'Personal Support Services for Carers'.

Key Outcomes

- *The DSO is the funder of personal support services in accommodation, respite and community access for people disabled before the age of 65.*
- *Clear eligibility criteria with Domiciliary Care Services ensure clients who become disabled or frail after age 65 receive personal support from Domiciliary Care Services.*
- *The DSO does not fund such activities as housing, health and education services, nor does it fund goods and services that all citizens use on a fee-for-service basis.*
- *The DSO negotiates with appropriate mainstream providers to transfer to them current funding and services in the disability program, other than for personal support.*
- *All funds currently expended through Options Coordination brokerage come under these arrangements, ie the only permissible service that can be purchased is personal support*

The Association is concerned that the items as listed in this section as Key Outcomes are rather, descriptors, not outcomes. Outcomes are achievements to be aimed for. What will be the outcomes that result from the personal support services listed: this requires further clarification; ie clear understanding of personal support: Family Carers provide personal support and require personal support. What is the personal support currently being offered and what changes to that support are being proposed?

Given that the DSO is not to fund such activities as 'housing, health and education services, nor does it fund goods and services that all citizens use on a fee-for-service basis' (dot point 3) and will 'negotiate with appropriate mainstream providers to transfer to them current funding and services in the disability program' (dot point four) what arrangements are being proposed for involvement in appropriate across government initiatives for Carers, such as those proposed by the Carers Association submissions to the State Carers Policy?

Key Result Area 3.1 Improving Accommodation, Respite and Community Access.

Key Outcomes

- *Increased emphasis on long-term host family arrangements for some adults with a disability.*
- *Weekend and holiday stays with a host family have a high priority for children with a disability.*
- *A housing standards of not more than 5 people in a group home applies.*
- *Flexible accommodation support, including tenancy support and attendant care, depending on the support needs of the individuals, is the preferred model of support.*
- *The DSO negotiates with the housing authorities for funded housing stock to be offered to residents for purchase with a consequent reduction in rental payments.*
- *The DSO works closely with the South Australian Department of Education and Children's Services in order to provide a smooth transition from school to post-school options.*
- *The DSO ascertains the number of people with a disability, living in a supported residential facility or boarding house or who are homeless, and establishes a project to assist them to access appropriate accommodation and supports.*

Recommendation:

- That Key Result Area 3.1 Key Outcomes dot point two be changed to read: 'Weekend and holiday stays with a credentialed host family.'

Recommendation:

- That Key Result Area 3.1 Key Outcomes dot point three be changed to read: 'Application of housing standards by only purchasing services that comply with the standard.'

Recommendation:

- That Key Result Area 3.1 Key Outcomes dot point four be changed to read: 'Flexible accommodation support, as determined by the Care recipient and Carer.'

How does one reduce ones rental payment when one is purchasing and making mortgage payments?

Recommendation:

- That there be clarification of Key Result Area 3.1 Key Outcomes dot point five:

Recommendation:

- That Key Result Area 3.1 Key Outcomes dot point seven be changed to read: 'The DSO ascertains the number of people with a disability and their Carers, living in a supported residential facility or boarding house or who are homeless, and establishes a project to assist them to access appropriate accommodation and supports.'

Recommendation:

- That additional dot points be included in Key Results Area 3.1 Key Outcomes:
 - The DSO offers funded family day care to siblings of children with high needs.
 - The DSO offers funded family day care to the pre-school age children of parents with a disabled.
 - The DSO offers funded family day care to children with disabilities.

There is a critical need to provide services for children with disabilities that enable overnight stays so that families can have a break. Such breaks to include community housing and community respite housing, family day care and credentialed host families.

There is concern at the appropriateness of funding host families and the implications for loss of opportunity for Carers and the care recipients if they do not fit in with the host family. there would need to be a very good matching process as well as protective measures in place. What about the Care recipient whose needs are too high? Extra dot points are required in Key Result Area 3.1 to cover:

- Young Carers.
- Day Care.
- Respite Houses.
- People with high needs.

The Association is concerned at the current trend where the number of respite hours being provided to Carers is reduced, that is taken out of the Carer's allocation, when administrative costs increase. Carers regard this to be 'cribbing' of essential respite, and that such a practice should cease. This negatively impacts on the Carers well being. Carers entitlements need to be safeguarded. Whenever administrative costs increase or priorities change the result is a reduction of services invariably the Carer carries the load.

Recommendation:

- That levels of respite provision be tagged such that increases in administrative costs will not be taken from Carers' hours of service.

The importance of respite cannot be overstated; nor the need for clarification as to what is understood by 'regular' respite and 'emergency' respite. Carers do not consider regular and emergency respite to be the same thing. Flexibility means Carer choice, including who the agency is that delivers the service and the choice of care worker.

Key Result Area 3.2 Role Clarity for Government Agencies

Key Outcomes

- *Disability Services SA provides a system of service coordination across the State.*
- *Current separate Government Options Coordination agencies become one regionalised service, Disability Services SA.*
- *The special needs of different client groups continue to be acknowledged and specialist expertise exists within the one management structure for Disability Services SA.*
- *Disability Services SA works with individual clients within a single regional structure, assisting them to use mainstream services in their community and to gain access to specialist disability services.*
- *Clients have choice of service provider, with portability between providers.*

Recommendation:

- That Key Result Area 3.2 Key Outcomes dot point three be changed to read: 'The specialist needs of different client groups continue to be acknowledged and provided for and specialist expertise exists within the one management structure for Disability Services SA.'

Recommendation:

- That clients have clearly identified and easy to access service entry points.

Recommendation:

- That clients have clearly identified and easy to access complaints and appeals procedures.

Recommendation:

- That clients have all decisions on service provision, including denials, in writing.

Carers have expressed concern at the efficacy of the current case management system, seeing it in some instances as a 'team process' where any number of people on a team can provide the case management role, resulting in a lack of coordinated service. It belies what is generally understood as 'case management'. What evaluation processes are to be put in place, within DSO and to ensure across government service provision and effective case management?

Recommendation:

- That appropriate evaluation processes be established to ensure the effectiveness of case management under the proposed Disability Services SA.

Key Result Area 3.3 Equitable and Transparent Resource Allocation

Key Result Area 3.3 Key Outcomes dot point two: Shared corporate services are introduced for the government sector and made available to the non government sector.

The Association would welcome sharing of corporate services where it would enhance the delivery of services and not result in loss of the independence of the non government sector.

Key Result Area 3.3 Key Outcomes dot point five: Information is better managed, more accessible and drives decision-making and outcomes.

Information provided at the various phases of policy and program development needs to be reliable, up to date, easily accessible and transparent to all stakeholders.

The Association supports measures that create efficiencies which ensure better planning and transparency in planning, delivery and evaluation of services.

Key Result Area 4.1 Prevention and Early Intervention

Key Result Area 4.1 paragraph one, sentence three: Supporting families who are caring for a son or daughter with a disability is a priority.

The Association supports this priority, in particular reiterates the needs of young Carer siblings who take on caring roles for a brother or sister.

Key Result Area 4.1 Key Outcomes dot point one: There is an investment in prevention and early intervention where it yields proven benefits.

There is concern as to how the investment might be 'proven' and that it might work to exclude a number of people if not based on valid, evidence based benefits.

Recommendation:

- That Key Result Area 4.1 Key Outcomes dot point one be changed to read: 'There is an investment in prevention and early intervention based on evidence based benefits.

Key Result Area 4.1 Key Outcomes dot point three: An emphasis on flexible ways of supporting families through respite and post school options which do not solely rely on paid places but can also encompass community development and volunteer activity.

There are a number of issues that need to be clarified with respect to the proposed use of volunteers:

- Skilling.
- Safety.
- Screening.
- Availability and reliability of attendance.

- Volunteer coordination across regions.
- Development of strategies for utilisation of volunteers based on proven effectiveness.
- The danger of inadvertently 'crowding out' family members from caring roles as a result of the management of volunteers.

Key Result Area 4.2 Community Development Practices

Key Result Area 4.2 paragraph three: there should be an emphasis on finding ways to support and empower people, groups and communities to better manage their own health and well-being, to build community capacity and to ensure sustainability for the longer term.

Recommendation:

- That Key Result Area 4.2 paragraph three be changed, replacing the word 'people' with 'individuals' so that it reads: 'There should be an emphasis on finding ways to support and empower individuals, groups and communities to better manage their own health and well-being, to build community capacity and to ensure sustainability for the longer term.'

The Association is supportive of the intent to build community capacity, empowerment of individuals, and long term sustainability of programs that assist people with disabilities and their Carers. This is the cornerstone of the Association's work. The Mission of the Association is to promote, assist, empower and enhance the lives of family Carers.

Key Result Area 4.2 Key Outcomes dot point three: Funding and service partnerships with Local government and other generic service networks are expanded.

There is concern at the implications of transferring services to Local Government without an appropriate funding re-allocation.

Recommendation:

- That Key Result Area 4.2 Key Outcomes dot point three be further clarified with the addition of 'government and non government' so that it reads: 'Funding and service partnerships with Local government and other government and non government generic service networks are expanded.'

Key Result Area 4.2 Key Outcomes dot point eight: Services are not funded on the basis of diagnosis as the primary consideration – a client's service needs underpin assessment.

In assessing needs through functional disability there needs to be care that gaps are not created; for example in cases where the person with a disability is perceived to have low level physical functional loss but has challenging behaviour creating a high level social interaction loss. Determination of functional loss needs to be clarified. In any event individual packages are required to maintain effective service delivery that meets individual needs.

Carer assessment is an important component of service provision providing for adequate care for the consumer, a collaborative approach and quality of life for the

Carer. It is critical that, in assessing consumers, agencies also assess the impact of the caring situation on Carers. This should cover the Carer's time commitment, financial impact, training needs, respite needs, social impact, health impact and emotional impact.

The Carer not only has the right to be assessed but also the right to have the results of the assessment taken into account when services are provided. This will offer a protection to Carers when services are provided as their needs will also have to be taken into account. Carers can also ask for a re-assessment when circumstances change, meaning they may be able to call for greater assistance.

Recommendation:

- That Carer needs are assessed at the same time as those of the person with a disability and that appropriate services are put in place to meet those needs.

Key Result Area 5.1 Across Government Service Support

The Association supports the intent of developing across government support strategies to meet the outcomes proposed in the Framework.

Recommendation:

- That DSO works with the Carers Association and networks of Carers to ensure Carer need are represented and heard in the development and implementation of service delivery programs.

Key Result Area 5.2 Transport: A Crucial Road To Citizenship

Key Result Area 5.2 Key Outcomes dot point one: DSO works with the services sectors, the Local Government Association, the Ageing and community Care branch of DHS and Transport SA to transform current uncoordinated transport services into an efficient, accessible community transport service for people with access restrictions in South Australia.

The Association welcomes the recognition given to the importance of transport provision. The provision of low cost transport options, provided by either government or non government agencies for those unable to drive due to disabilities, chronic illness or frail age, or unable to access private transport, assumes vital importance for the access of services and in the reduction of social isolation. It is also important in providing relief for family Carers who otherwise are responsible for the provision of transport for those they care for.

The Association supports the intent to secure coordinated and streamlined, low cost, sufficient, accessible transport options for people with disabilities and their Carers, and in the provision of information to its citizens regarding available options.

Recommendation:

- That the development of a coordinated accessible transport system be accompanied by effective communication strategies to inform people about transport options available for them.

Key Result Area 5.2 Key Outcomes dot point five: With the Ageing and Community Care Branch, work with Transport SA and the Passenger Transport Board, to initiate a Companion Card scheme.

The Association supports the development of Companion/Carer Card schemes.

Summary

Summary paragraph three: Simply put, when all service sectors understand that disability services funds are used to access, but not provide, the communities services, the whole services system is better placed to meet the needs of people with a disability and their families.

There is a need for clarification of the difference between 'personal support services' and 'community services'. What assistance will be provided by DSO that enables people with disabilities to access 'mainstream' services? What assistance will be provided by DSO so that 'mainstream services' can offer accessible services? What guarantees will be forthcoming in terms of resource allocation that will prevent a loss of services during and after the transition period from the current system to the new system. Success will depend on the implementation plan and the timeframe of that plan.

There is a concern that it will be harder for the Carer and the care recipient to negotiate the new system with its multi-entry points. This would create considerable additional stress and anxiety on the Carer. The establishment of cross-departmental committees briefed to ensure ease of access would work to lessen carer concerns.

Recommendation:

- That strategies be developed to ensure appropriate and adequate support for people with disabilities and their Carers during and after the transition period to the new system.

Recommendation:

- That strategies be put in place to provide for cross departmental coordination of entry points into service provision across health, education, transport etc.

Recommendation:

- That a cross government working group be established to oversee the integration of personal support services and community services.

In association with integrated service pathways the development of comprehensive Care Plans, adopted by everyone with a standard protocol including diagnosis and carer assessment, that 'travel' with the care recipient and Carer would ensure that both care recipient and carer needs are met. In addition, there would be recognition that the Carer has a responsibility to see that the Care Plan is carried out, and be given the authority to do so. The issue of legal authority of the Carer is particularly important where the care recipient has a mental illness, is aged, or is an adult child with a disability.

Recommendation:

- That Care Plans be developed through the personal support system that include an assessment of, and strategies to meet, Carer needs.

Appendix 1: Legislative and Policy Context: Disability Services Policy Statement

The Association welcomes the policies and underlying principles expressed in this section, particularly noting the intent to 'have the unique needs of (their) carers and family members recognised and taken account of' associated with the underlying principle that people with disabilities have the right to 'services and supports which recognise and are supportive of the unique needs of carers and families of people with disabilities, which strengthen their families and which minimise the impact of disability on families and carers.'

The Carers Association is hearing from an increasing number of Carers seeking advocacy assistance in their dealings with a wide range of service providers. Carers, in representing themselves and or the persons they care for, are finding it increasingly difficult to do so without appropriate and adequate support. People acting alone are finding themselves disempowered within complaints process systems that can be long, complex and bewildering. The end result is that their rights are not being protected.

There are also cases where the Carer and the care recipient should not have the same advocate because of a conflict of 'best interests'.

There is a need for an independent state-wide Advocate for Carers, to whom family Carers can go in their own right to seek redress. There are a number of agencies that provide free or low cost support for complainants such as the aged and those with disabilities, however they have a number of limitations associated with the parameters of funding and focus and more often than not are overstretched. They are thus not in a position to provide the services that Carers require.

The establishment of an specific state-wide Advocate for Carers will serve to underpin the proposed changes to the Equal Opportunity Act that seek to include Carers within the anti-discriminatory ambit and that seek to provide for adequate and appropriate resourcing of complainants.

Recommendation

- That provision be made for an independent state-wide Advocate for Carers.

Appendix 2: People with Disabilities in South Australia: An Overview

One in ten young people aged 15 – 25 is in a caring role. This represents 17% of all Carers. There are 13,300 Carers under 18 years of age in south Australia. an estimated 5% of these young Carers are primary Carers, providing the main source of unpaid informal support for the care recipient. They are most likely to be providing care to their mother, often in a single parent household.

Recommendation:

- That a separate section on Young Carers be added to Appendix 2.

There is concern that statistics on disability and Carers are not being gathered often enough to ensure reliability of figures.

Recommendation:

- That DSO urges the Australian Bureau of Statistics to collect statistics on disability and Carers more frequently.

Further Comments

Definition of Disability

The Association notes that the World Health Organisation functional loss definition of disability is under consideration by the DSO.

Recommendation:

- That a wide definition of functional loss which incorporates all types of disabilities and disorders be used.

Recommendation:

- That there is transparency on the services which can be provided within the new definition.

Recommendation:

- That there is transparency on the complaints and appeals processes for services denied.

Funding Separation: service gap impact on Carers and care recipient

There are currently people being served by the Disability Sector that have high (medical) health needs. The Association notes that consideration is being given to the notion of separating funding provided to children with high (medical) health needs from DSO funds. If such a funding separation is driven forward by the DSO and a gap in services eventuates for children with high (medical) health needs the result would be:

- A lack of recognition of the needs of families.
- A lack of recognition of the issues and needs of Carers.
- A lack of a suitable funding framework for services.
- That Carers of people with high health needs will become extremely stressed trying to locate non-existent services.
- An access and equity issue in which seeking of non-existent services results in frustration and destruction of trust.

- That Carers left caring under these circumstances would be better served by transparency as to the availability of services so that their expectations are realistic.

The end result for the person with the high health need would be:

- Their community based health needs are unmet.
- They are likely to suffer serious medical consequences, such as strokes and heart attacks.
- As a consequence they are at greater risk of becoming dysfunctional and a greater burden on the disability budget.
- They are at greater risk of an early death.

There is concern that the devolution of funding may result only in short term gains, but result over the longer term in an expansion of the DSO high dependency client base. These needs could be addressed through the DSO and the Health Commission forming a combined pool of funds for people with high health needs that is separate from the DSO budget for disability.

Recommendation:

- That DSO and the Health Commission provide a combined pool of funds for people with high health needs that would be separate from the DSO budget for disability.

Family Options - Paediatrics

In New Zealand the process of funding devolution occurred between the disability and high health need sector approximately five years ago. The end result of the funding devolution was the high needs health consumer sector were without Carer respite. In particular, the high health needs paediatric sector aged 0-16 years were left with no respite program funding.

At this time a mother of a daughter with a high needs autistic spectrum disorder killed her child. The investigation of the girl's death indicated that lack of respite for her Carer played a significant role in the Carer's loss of reasoning abilities.

Accordingly the Ministry of Health worked with Carers to identify this sector's respite needs. Funding of the health budget (note, not disability funding) was then dedicated to the development of a paediatric high needs respite service, called "Family Options" (see Appendix A).

This service has been expanded since inception and now accommodates the respite needs of 100 children with high needs in the northern part of New Zealand.

Recommendation:

- In the situation that funding for the respite needs of the high health needs sector would be devolved from the disability budget that it be a social imperative to ensure an alternative program is developed **prior** to the occurrence of devolution.