

Dear Carers Australia,

10th August 2010

Thank you for this opportunity to outline to the carers you support our policy platforms to transform the lives of Australias carers if we are elected. This is our second election campaign. Carers Alliance believes that Australia is way behind other first world nations in the way we support carers and in the way we provide supports and services to the person requiring care and to this end our purpose is to change the status quo.

Carers Alliance is fielding Senate candidates in Western Australia, South Australia, Victoria, New South Wales and Queensland.

We have nine key policy platforms to better support carers. As you are aware, Carers Alliance was formed by carers for carers and our interest is to create a better world for carers and the people they support.

- We believe that the 24 hour rule should be axed for all carers not just young carers.
- We believe that the taxation system should allow tax offsets for the costs of care and equipment.
- We fully support a Carers Recognition Act but would like the act to provide carers with the right to an assessment of their own needs. Also we would like the act to give carers a right to services and the right to make choices in their lives. We are concerned that the governments bill offers little that can be considered meaningful and that anything definite will be in the National Carer Strategy. This Strategy sits outside of the legislation - meaning it can be simply ignored by politicians, bureaucrats, service providers and policy makers.

Our key policies are below;

National Disability Insurance Scheme

ALL Australians need a no-fault insurance scheme for everyone who has, or acquires a significant disability. If elected a Carers Alliance Senator will dedicate themselves to ensuring that the ideal of a National Disability Insurance scheme (NDIS) is not relegated to the national dustbin as every other positive outcome from every other inquiry has been.

The NDIS is currently with the productivity commission but as yet neither the Liberals or Labor have committed to its implementation. These failures of delivering positive outcomes have been supported and encouraged by those by those who purport to represent us and together we can change this status quo. If we have a Senator in parliament when the Productivity Inquiry findings are handed down, the Carers Alliance will put before

parliament a private members bill to set up the Scheme. We will also be seeking mandated rights for service for all people with significant disability and for all children with additional needs.

Children:

The Carers Alliance believes society owes every child the best it has to give. It is therefore imperative that each child be given every support necessary to maximize their development – physically, emotionally, intellectually and spiritually.

In order to achieve this outcome, the following changes must be given national priority:

v All children must have a legislated right to age appropriate assessments that ensure their physical and emotional needs are met at all times.

The health system is the first point of entry for all children. To maximize effective service delivery there must be:

- National global assessments of developmental, emotional and physical ability at prescribed stages of infant and early childhood
- Full assessment of the physical (including vision, hearing and dental), emotional and psychological health of the child at prescribed developmental milestones up to the age of 16 years.

These assessments would provide valuable epidemiological data and would ensure the health and well-being of all children. Such a model would be of great benefit to our existing health care system, and is already in place in many comparable western countries. In order to be effect, it is imperative that there be incentives attached to these mandated assessments – these could be linked into existing payments currently offered by the Family Assistance Office.

v All children deserve the right to access programmes and support that will maximise their potential.

A child-centred approach should be central to welfare policy and citizenship. It should be a recognized as a partnership between government and parents.

This investment in Australia's children will offer significant benefits to our society. Independent, confident, well-adjusted children become productive, confident adults who contribute economically, culturally and socially. Investing in our children breaks the cycle of perpetual poverty while establishing pathways to social engagement and community involvement.

Furthermore, once an assessment identifies a child with additional needs, that child must be able to access immediate support such as early intervention services, aids, appliances, modifications, accommodations, technology and needs-based educational assistance to maximise their potential.

The escalating costs associated with protecting children from abuse and neglect indicates the need to implement an all-of-childhood approach as a matter of priority.

Such assessments will also act as a default child protection mechanism – with the capacity to assess not only the viability of the family unit, but also determine whether additional support is required. Timely delivery of needs based parenting assistance and early intervention strategies would be of great assistance to both children and parents, and would ensure the family unit thrives. The security and certainty that comes from being part of a loving family to give our children a good start in life is incalculable.

Supporting children and families in this way would reduce the need for crisis intervention and significantly reduce the number of children that are currently deemed to be at risk of harm.

v All children with special or additional needs must have a legislated right to service and equipment.

Cultural sensitivity regarding disability can delay assessment of need. The mandated assessments of *all* children would give an overall view and would not only target disability but also the social, physical and psychological well-being of *each and every child*.

Regular assessments provide an opportunity to identify children with special or additional needs in a timeframe that is able to maximize the benefits of early intervention. It also enables healthcare and service providers to do projections for future care and equipment needs, based on collected data from similar patient groups.

This ability to generate cost projections is beneficial to everyone involved in the care of the child, as it ensures a *proactive* treatment model can be sustained, where funds are available as required – as opposed to the current *reactive* treatment model, where funds are not sourced until the need is identified with the child being placed on a holding pattern until a vacancy for support becomes available. The current treatment model often results in significant delays during scripting, funding and delivery of necessary equipment – or finds children being placed on waiting lists for therapy or counseling services.

Extended delays to access service and equipment during a child's formative years not only impedes their ability to reach their full potential, but can often result in developmental delays that will have financial ramifications on our society as that child progress's into adulthood.

Education:

Carers Alliance recognises the right of the child to be provided with the tools to learn and become capable and cultivated members of our society.

In regard to the education of children with disabilities and/or learning difficulties we support:

1. Choice in schooling

2. Equitable funding irrespective of the educational setting with funding following the child to ensure flexibility and choice (including home schooling)
3. Universal design for learning

The Shut Out report released in August 2009, authored by the National People with Disabilities and Carer Council, was scathing in its condemnation of the lack of innovation and flexibility in the education of students with disabilities and the prejudicial funding policies across all jurisdictions which discriminates against students with disabilities based on the educational setting.

The Council recommended that the educational needs of students with disabilities should be funded equitably irrespective of the educational setting and that the funding follow the child with disabilities.

Universal design for learning has not been given any consideration in either curriculum development in teacher training courses nor has it been piloted anywhere in Australia. Such innovation would meet the requirements of the much vaunted notion of social inclusion coming from a school setting:

1. Social inclusion means acceptance of diversity
2. Changing an education system that unwittingly creates barriers to diverse learning needs of students (with or without diagnosed disabilities) in the modern classroom.

Our current education system was established last century and probably so too would have been the curricula of teacher training institutions. That means that diversity of learning needs has been accommodated by merely *ad hoc* additions as needs are identified rather than in a way that is planned and inclusive.

In light of this the system needs to be turned on its head basically and while we accept that may be asking too much we think that if we are to have transformative change it should be in all institutions which fundamentally affect how people with disabilities live their lives. Shortcoming in the modern classroom will continue unless something dramatic is done to socially include by providing educational inclusion.

Universal Design for Learning is a natural extension of universal design for architecture and the built environment and universal product design. Some view inclusive learning as: *presence* (the where) *participation* (quality of learning experience) and *achievement* (outcomes of learning).

Universal design for learning looks at 3 things too:

Representation (methods and materials -the what of learning where the content is **not** dumbed down but there is a variety of modes of presentation and access)

Expression (the how of learning – how the student can express understanding of the curricula, eg using electronic formats such as PowerPoint or verbal responses onto an MP3 device. I also see this as using a variety of methods to measure and assessing how a child has learned as well as what the student has learned)

Engagement (the why — which goes to motivation or why a child wants to learn and how to harness that spirit of inquiry into useful learning)

Universal learning design is already naturally practiced within formal childcare and pre-schools.

These facilities also undertake educating and training in a social sense, there is flexibility and a natural guidance by the childcare system which takes into account that the children are at differing developmental stages and have different capacities for expressive and receptive communication- either non-verbal or just developing speech, their level of mobility and physical capacity is also at widely different stages. Early childhood systems accept and makes allowances for all those degrees of skill acquisition.

However, by the time children reach school that fluidity and acceptance of difference seems to evaporate and the system becomes rigid and unable to respond, adapt or even recognise anything other than “the average”.

While education systems follow an outmoded method of allocating funding based on their notion of a students “deficiencies” based on disability, some educators and many parents of students with disabilities believe it is in fact the education system which is disabled, and needs to accommodate the diverse needs of a broad spectrum of learners, rather than blaming the student for being different.

Carers Alliance supports the Universal Design for learning.

Funded carers networks

Carers Alliance as a key policy demands that the federal government fund a network for families who care. The very nature of unpaid family caring means family carers are too often housebound because of their caring role. These families have earned the right to be heard, and a right to develop friendships with families in a similar position.

Families deliver over 92% of all accommodation and support for people with care needs of all ages. Currently families who care are isolated, feeling alone and often desperate. This is a disaster for the mental health of the carer. Families who provide care have no forum in which to discuss their fears, their needs and the needs of the person they support.

The role of caring families in policy and planning is almost entirely absent because they have no funded grassroots voice.

We propose a Regional Disability Family Network as proposed below by the National Carers Coalition (an unfunded parent led group):

Each State and Territory to be provided with a recurrently funded regional service based upon the relevant Department of Human Services regional structure for all disability families caring for a person aged less than 65 years and will actively promote the rights of family carers and the rights of the people that carers support.

- **Regions will nominate a representative to the State Peak Disability Family Advocacy Body.**

The regional Networks and liaise with state Government, agencies, carers councils and disability advocacy groups to ensure that the role, rights and needs of caring families are heard and supported.

- **States will nominate representatives to the National Disability Family Peak Body.**

In a changing civil society, carers do not have the same rights nor the same life possibilities as the broader community, but they do have the expectation that, as providers of 92% of all disability services nationally they are entitled to recognition by government and to be supported to have input to policy, planning and the opportunity to participate in the direction of their own lives.

Special Needs Health

Developmental Disability Health

It is important for primary care physicians to recognize that, in general, adults and older persons with an intellectual disability have the same needs for disease prevention, diagnosis, and treatment as the general population. Those who do need medical attention discover that Australia's hospitals are ill equipped to deal with people with moderate and severe developmental disability with limited communication who are often unable to express pain and discomfort and often serious illness is left undiagnosed.

For this reason Carers Alliance believes there is a place for specialist developmental disability clinics in all major teaching hospitals to provide educational and clinical practice supports for primary care physicians and specialty nurses caring for people with intellectual disabilities. These clinics would enable medical practitioners to gain experience in clinical conditions or other discomforts which are often expressed through challenging behaviour and often result in the patient being sedated without pain relief with the primary condition left undiagnosed.

We also propose travelling developmental specialists who can travel to regional areas which are often poorly served with such specialist services.

Health care providers need to adopt a lifespan approach that recognizes the progression or consequences of specific diseases and therapeutic interventions to assist care for people with intellectual disabilities of all ages. Identifying associated disabilities such as epilepsy, visual disorders and cerebral palsy should be a priority.

People with developmental disabilities should receive the same array of lifespan preventative health practices as those offered to the general population, which needs medical practitioners trained to respond to the often complex abilities of the patient" [Helen Beange healthy aging adults with intellectual disability]

Medicare cards with embedded medical information as well as contact details of the persons responsible to assist health professionals when a patient presents in crisis are already technologically possible. Carers Alliance believes that we should use technology as a means to assist with early diagnosis and urgent admissions.

Developmental Disability Mental Health Care

Undiagnosed mental illness and medical conditions can have atypical presentations in people with limited language capabilities. People with developmental disabilities often need additional assistance to maintain mental health than the wider community. In Australia the importance of this issue is not sufficiently recognised. Currently very little is offered by way of mental health services for this group of people.

The rate of mental illness in the developmentally disabled is much wider than the general population (40%) and yet Australia offers very few services beyond mainstream psychiatry, and that can usually only be accessed in the private sector. Given that people with developmental disability are some of the poorest and marginalised in our society, this is an appalling indictment on all levels of Australian government.

Carers Alliance will continue to highlight to the government of the day the systemic neglect of mental health care for people with complex developmental disability. We will lobby for intensive mental health care to be provided within the public health system with stand alone wards that can offer physical protection and targeted services that assist, not only with responsive mental health outcomes but by providing ongoing support for community living.

It is imperative to train specialists in the promotion of mental health care and to prevent mental illness through a range of therapies and strategies. For people with development disabilities medication is often the therapy of first resort when other strategies can have better outcomes – the focus should be recovery. Incentives should be provided in the study and practice of psychiatry to encourage clinicians to undertake further studies in this field.

Aged Care

Individualised Funding of Aged Care Services – person centred funding

Most people as they age would prefer to remain living in their homes, surrounded by those they know and the comforts of familiarity.

Carers Alliance will fight in the Senate for individualised funding for in home services and community support services.

Intensive EACH packages and Home and Community Care packages should be made available as an alternative for block funded packages designed to assist the elderly stay at home. They should allow flexibility to allow the service user the opportunity to manage their lives and supports around their lifestyle. There is an undeniable nexus between residential aged care, loss of hope and decline in emotional and physical wellbeing. We believe that

individual support to remain at home must be made available to all ageing Australians as required. This is far less intrusive as a way of delivering both supports and health services (preventative health care).

Individualised service packages will allow voice, choice and control by:

1. providing the user of services with the choice of service type,
2. allowing portability of funding allowing choice of service provider or to pay for the care they choose to have in their own home
3. consumer controlled funding, if that is the choice of the person with disabilities or their families/nominated representative

In its simplest form, an individualised funding package is the provision of direct payments to people in order to purchase services they require, which is a transformative idea giving power to the service user. Payments can be made directly to the individual requiring support or an intermediary/broker who offers financial and/or case management. Alternatively, the individual can direct block funding to a chosen service provider who meets the needs of the individual.

Mental Health

Carers Alliance is deeply concerned with the narrow scope of mental health policy from the major parties.

Carers Alliance will work towards ensuring that 12% of the health budget is for mental health services

There seems to be little engagement with multicultural and indigenous services, nor on the relationship between drugs and mental illness. All of the new money that has been provided for mental health has been preventative focused.

While Carers Alliance welcomes preventative measures with the Headspace Centres, little thought and planning has gone into effective access to allied health services, accommodation services nor beds within the Area Health Services for those needing more intensive services and supports.

The consumer has the right to expect that hospital and community mental health services will be part of an integrated network to ensure continuity of care, but access to services is extremely restricted because of the lack of beds within the Area Health Services.

Mental health consumers should have mandated rights to service

This includes;

The right to expect access to specialist medical services

The right to the least restrictive or intrusive effective treatment.

The right to obtain treatment at an early stage of their illness in order to minimise the likelihood of involuntary admission to a treatment program.

The right to having mental health problems or mental disorders assessed, diagnosed, treated and reviewed in accordance with professionally accepted standards.

The right to have age, gender and culturally appropriate mental health services provided in an environment which is conducive to his or her continued participation in community life.

The right to be protected from the threat of sexual harassment and abuse.

The right to a co-ordinated ongoing range of adequately resourced care, treatment and rehabilitation

The right to have treatment appropriate to his or her health and rehabilitation needs

The right to the protection and safety of themselves and others.

Individualised service packages

People living with mental illness will benefit significantly from individual support packages.

These packages will;

1. provide the user of services with the choice of service type
2. allow portability of funding allowing choice of service provider or to pay for the care they choose to have in their own home
3. be consumer controlled funding

In its simplest form, an individualised funding package is the provision of direct payments to people in order to purchase services they require, which is a transformative idea giving power to the service user. Payments can be made directly to the individual requiring support or an intermediary/broker who offers financial and/or case management. Alternatively, the individual can direct block funding to a chosen service provider who meets the needs of the individual.

Person Centred Funding

Carers Alliance is determined to shift the model of services and supports for people living with disability from that of welfare to legislated rights and entitlements.

The consumer should always be at the heart of service provision.

Currently the block funded model sees recipients powerless and at the mercy of the funding body. The provider determines what services a person can have and when they can have them, allowing little autonomy.

Most people living with disability in Australia know where their best interests lie. It is not only reasonable but socially necessary to provide individually tailored services that fit into the lifestyle of the service user.

There is much evidence that state provided services often have little to do with the needs of the individual or the quality of services on offer, but the availability of supply – based on the funding submission and the ‘winning’ of specific contracts.

Not all people will want to self direct their own services but the choice should be available to all. Even those who do not want to self direct their own services should be provided with bank of money that they control so that the individual or their advocate (if a person cannot self direct without assistance) is able to move a person away from a provider if they find the provider is failing them.

Person centred support will see a dramatic change in the quality of services offered. It will change the living standards of people with disability and move them away from being passive recipients of care. Services will become market driven as they should be.

Block funding in the hands of poor service providers is dangerous to the service recipient, they are unable to escape from neglect, abuse or prohibited practices, particularly rife in some group home models with certain questionable service providers.

For too long governments have trusted people with disability or in the case of those dependent on care from family – the family – to provide the services, to pay for equipment and to manage with few supports. When it comes down to these same governments to place the same trust in allocating individuals full control of their funding, they run scared and fall up short (assuming they are the lucky few provided with a reasonable level of services – most are not).

In its simplest form, an individualised funding package is the provision of direct payments to people in order to purchase services they require, which is a transformative idea giving power to the service user. Payments can be made directly to the individual requiring support or an intermediary/broker who offers financial and/or case management. Alternatively, the individual can direct funding to a chosen service provider who meets the needs of the individual.

Carers Alliance believes a universal insurance scheme is the answer to the enormous unmet need. We are determined to ensure that Australia joins other first world nations in providing the supports and services that people need in order to live a reasonable quality of life.

Veterans

The intergenerational Report

The intergenerational health impacts on children resulting from a parent’s military service is an ongoing issue of concern.

Carers Alliance believes that disability and mental health issues of sons and daughters of returned servicemen and women should fall under the veterans packages of both TPI and

goldcard as the health impacts of veterans children are more likely a direct consequence of their parents military service.

These children should not have to wait until the death of the parent to qualify for the services this nation owes to our returned veterans. The Vietnam Veterans Family Study (VVFS) findings are due for release in 2012. If this study shows a dramatic rise in disabling conditions of Vietnam veterans children Carers Alliance will argue for this TPI cover to be extended to their sons and daughters.

We believe our nation owes the best that it can offer to our returned veterans and their families.

Thank you for this opportunity to have input into your valuable

Our Election Platform 2010 - Don't Wait - Our Future is Now! Because together we can create change and together a better world for caring families.

With Regards

Nell Brown

National Convener

Carers Alliance

<http://www.carers.org.au>