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(Inq into better support for carers)
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"Inquiry into Better Support For Carers" Submission

Submission By:

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PREFACE

I would like to commend the Hon Jenny Macklin MP and the House of Representatives for conducting this inquiry into better support for carers.

I am one of the 2.6 million Australian Carers[1] of a person with a disability and one of the 7500 WA Carers of WA CHILDREN who cannot walk, talk, sit, stand, move or perform some aspect of self-care without assistance[2]. My daughter cannot sit, stand, move, walk, talk, bathe, toilet, eat without a carer. I am her 24-hour a day carer.

An understanding of the carer role and contribution in/to society, the barriers to social, economic and employment participation and the impact of these on the carer, person/s they care for and the community at large is vital to seeing clear and practical measures and strategies to better support carers.

In my submission, the reader will gain an insight into the four terms of reference (through the eyes of a carer, with discussion on the impact to the carer, person cared for and the community):

- The role of carers; The contribution of carers in society; How the role and contribution of carers can be recognised.
- Barriers to social participation for carers, Barriers to economic participation for carers, Barriers to employment opportunities for carers.
- Practical measures required to better support carers, including practical ways of determining carer numbers, carer needs and key priorities for action.
- Strategies to assist carers to access the same range of opportunities and choices as the wider community; Strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring; Strategies to assist carers effectively plan for the future.

It is essential to determine carer needs in the development of practical measures and strategies to better support carers.

Some key strategies and priorities identified in this submission to best support carers include:

1. Determine Carer Needs
2. Inform Carers of Their Support Options
3. Address Lack of Access to Equipment
4. Address Carer Remuneration
5. Address Lack of Access to Respite
6. Review Carer Access to Childcare
7. Address Carer Career Options
8. Address Carer Future Planning Options
9. Review Guidelines & Reporting of Disability Trusts
10. Address Future Planning for Carers of Children with Profound Disabilities
11. Address Impact of Carer Role on Carer Health

If all of these key priorities are addressed, and suggested strategies explored and adopted Carers would be better supported, and there would be a positive impact on the social and economic future of our communities.

There are currently over 2.6 million carers in Australia[1]. Many of these carers have not been informed of this inquiry, some have and are already time poor and unable to make a submission. It would be a mistake to assume that these carers needs are being met, simply because they have not made a submission.

TERMS OF REFERENCE

1) The Role & Contribution of Carers in Society (Pages 3-5)

- Carers save taxpayers an estimated $30.5 billion annually (the cost of replacing carers providing informal care with paid care workers),[3] more if you consider the costs of hospital beds by the Carer performing the duties of nurses and hospital staff.

THE CARER ROLE:

- parent
- nurse
- orderly
- medical manager & PA – organise appts, medicines etc
- therapist – OT, PT, Speech
- child care worker
- teacher
- taxi driver
- enable child a life of access and inclusion
- raise child to be valuable contribution to society as adult

AN INSIGHT INTO MY CARER ROLE:

Firstly, I am a parent, I chose this.

My beautiful daughter, Asialee, had a seizure several hours after birth… I didn't choose this. Asialee suffered significant brain damage, resulting in CP. Asialee is 3 and is unable to sit, stand, crawl, move, walk, talk, and eat/drink without aid.

Three years ago I became nurse (feeding her by eyedropper, then haberman teat, then naso-gastric tube feeds & now orally with much difficulty), orderly (sterilising n-g tubes, giving daily enemas, changing nappies), OT (devising play activities to develop muscle control & ability to perform self care tasks), Physio (performing stretches and seeking equipment to enable a life of access & inclusion), Speech Pathologist (performing stretches to encourage drinking & eating, learning to use assistive learning devices – books & computers to give my daughter a voice & give her the foundation of communication to have an education), Teacher (teaching communication, concepts, movement), Medical Manager & PA where some weeks we have scheduled appointments with 10 different medical departments (Paediatrics, Neurology, Gastro-enterology, Orthopaedics, Ophthalmology, Muscle Rehab, Dental, Speech Pathology, OT, Physio..) as well as allied health (Naturopathy, Chiropractic, Acupuncture) and Conductive Education Classes, needless to say these weeks I am also a taxi driver.

THE CARER ROLE IN SOCIETY:

I have 5 Degrees, have been a tax-payer for the past 16 years and have worked as a health professional for 7 years, and been the Director of a health clinic for 7 years and the CEO of a charity for the past year.

My role as a carer is by far the most physically, intellectually and emotionally demanding of any of these vocations. The job description is unpredictable, the hours endless and the pay... minimal. The recognition and respect for the role of "carers" in society seems insignificant.

Never in all my employment history have I experienced a job where the pay was determined by how much my partner earned ("means test"). As I carer I work 24 hours a day, seven days a week, yet as my partner earns more than 50K per annum, I do not qualify for the carer wage (Carer Payment). I am remunerated $50.30 per week and am not eligible for superannuation. This speaks volumes for the value society places upon the "Carer" role.

- Government payments for carers include the Carer Allowance ($100.60 per fortnight) and the Means Tested Carer Payment ($546.80 per fortnight). For a single carer receiving both payments this works out to $323.70 per week, which is nearly $200 less than the weekly minimum wage of $522.12.[6] Those receiving the Carer Allowance Only (like myself) receive around $470 per week less than the minimum wage.

CARER CONTRIBUTION TO SOCIETY:

- Carers save taxpayers an estimated $30.5 billion annually (the cost of replacing carers providing informal care with paid care-workers).[3]
- Many carers enable children with special needs (and disabled adults) to have a life of access & inclusion, and raise future tax payers (rather than tax liabilities)
- Carers Provide Hospital Beds to those in need (each night carers care for complex needs kids, this saves Medicare around $1000 per hospital bed and frees this bed to another child in the community)
- Carers assist people to remain living in the community for longer. They also make substantial savings on premature admission to costly residential care or supported accommodation options.
- Myself and many carers I know, spend vast amounts of money on Allied Health Services, Pharmaceuticals, Dietary Supplements, Equipment, Personal Hygiene (nappies), Laundry, Travel (petrol) expenses for those that they care for.... Much of this going into the GST & fuel excise kitty and much of this supporting Australian Businesses.
- Carers are a demonstration of selflessness, generosity, of sharing, of inspiring and empowering those who they care for to live a life they love, of access and inclusion. This is a gift to the future generations and a contribution to society today.

MY CONTRIBUTION TO SOCIETY:

Several hours after birth, my daughter had a seizure, leaving her brain damaged and unable to move any of her limbs, sit, roll, verbalise, drink. Doctors expected she wouldn't survive more than 3 hours. 3 years later, with me playing the role of carer (nurse, OT, physio, speech pathologist, teacher etc) Asialee is non-verbal but able to communicate, she can move all her limbs, reach & grasp objects, use a head operated switch to access computerised books, play independently with switch operated toys and knows a life of access, inclusion and a world of possibility. I am raising a future tax-payer (rather than another tax liability).

My daughter's brain damage lead to significant reflux last year, she was vomiting up to 8 times a day/night. I could have put her in hospital care, but chose to care for her in the comfort of our family home (whilst also caring for my husband who was recovering from intensive chemotherapy for cancer, and our newborn son). By caring for Asialee at home (for the 90 days she could have been hospitalised), I saved the government around $1000 per night ($90, 000) and made a bed available to 90 children in need.

My Remuneration: $50.30 per week and a $600 one time Carer bonus.

<u>When I first found out my daughter has special needs I had so many questions, like:</u>
What services and supports are available? Where do I find information on her condition? What are her therapy options? What are her equipment options? What are our childcare & respite options? What are her education options? What are my career options? ...
It took a long time to find the answers to these questions... I co-founded and self-funded Special Kidz Special Needz (a charitable organization) that answers these questions on a website so no other carers have to waste precious time looking for answers. This website provides answers for carers of children and could be linked to Disability First Stop (a very basic website, that doesn't answer all of these questions).

HOW THE ROLE & CONTRIBUTION OF CARERS CAN BE RECOGNISED:

- Public Media Campaign to acknowledge the skills and tenacity of the "Carer" role, and to recognise the SIGNIFICANT contribution carers make to society. Perhaps if the public understood I made it possible for 90 children to access hospital beds and saved taxpayers $90, 000 in 3 months they would see the valuable contributions we carers make daily and support an increase in carer funding.

- Recognise the met and unmet needs of carers by formerly registering carers to a National Carer Database and mailing an annual survey to discover met and unmet needs, and create practical measures to best support carers. This database can also be accessed for future carer inquiries, so that all carers are given the opportunity to present a submission.

- Abolish means testing and give all Carers the right to be paid as Carers.

Whilst this may appear to cost the taxpayer, when you examine the cost to society and the economic impact of not paying Carers, it will create more government wealth to pay all carers.

For example many carers I know, have come from high demand professions like teachers, police officers, nurses, Allied health. Being paid only $50.30 per week limits the carer ability to return to workforce in any capacity. Having <u>no</u> access to child care facilities suitable for complex needs children and not qualifying for child-care rebate further limits employment options.

Giving all carers payment for their "caring" role, will enable carers to return to the workforce (thus to pay income tax, and provide services that are in high demand – ie. Nursing). This can only see an increase in health and education service provision and access, positively impacting the health and wellness of society.

2) Barriers to social and economic participation for carers; with a particular focus on helping carers to find and/or retain employment; (Pages 5-11)

BARRIERS TO SOCIAL PARTICIPATION:

Equipment & Its Relevance to Social Participation for Carers

3,958,300 people have a disability – 20% of the population[4]

Lack of access to Equipment (no store or showroom) where carers can view & try what equipment is available for their children with disabilities IE. Chairs that can enable a child to sit, Standers that can enable a child to stand, Walkers, Potties (enabling children with high needs to toilet), Car Seats enabling safe car travel... the list goes on.

> *"When I want to buy a pram or a high chair for my able bodied son, I can go to any store, try which one best meets his needs and buy it then and there. When I want to buy a chair so that my daughter can sit independently, there is no store, no option, no opportunity."*

This denies children and carers their basic right to access and inclusion.
Without this equipment I would have to carry my 3-year-old child everywhere (she cannot even lay down safely). This is a huge barrier to my and her social participation and for 1½ years I did carry her everywhere, perhaps the reader can imagine the barriers to social participation.

For an investment of $250K per state/territory (a total of $2 million), the Australian government could offer these children and their carer's access to this equipment and access to social inclusion. (That's $532 million less than the government has already spent on the cervical cancer vaccine).

It may seem like a lot to invest, but particularly in the early intervention years, access to equipment that can enable postural support, airway protection not to mention independence & inclusion, will lead to better short term health (less risk of aspiration pneumonia, spinal deformity) and better long term health (spinal deformity, muscle movement, communication) outcomes so will be less of a burden to taxpayers pockets, by way of saving hospitalisation costs, medical visits. This equipment can also enable communication and accessibility to education aids, so can enable the development of future taxpayers rather than tax liabilities.

So you may wonder, how do these children and carers ever get to see the equipment that could so significantly impact their future?
This is reliant on the child's therapist knowing about the existence of such equipment, then successfully contacting a supplier and requesting a viewing. When parents initiate this process it can take up to 6 months (as often the equipment is flown in from interstate or overseas), and longer if the parent has to wait for the therapist to initiate.

CURRENTLY there is an average 12 MONTHS WAIT for CAEP Funded Equipment, once the application has been made.

This urgently needs to be addressed. No child (or adult) should have to wait for basic and essential equipment that gives them access to sit, move, toilet independently or travel safely.

CAEP Guidelines for Basic & Essential Equipment are very limited and URGENTLY NEED REVIEW. They do not enable child or carer to participate fully in society.

Car seats are essential for inclusion in the community and are currently not CAEP Funded. Many computer programs, switch devices & communication aids are not CAEP Funded and are vital to a child's access, independence, development of communication and concepts and for the opportunity of inclusion and education.

- Equipment is necessary to enable participation in play groups, social groups.
  Asialee requires a postural seat with high support to be able to sit. Aside from this she needs a mobile base that can be raised and lowered to varied heights to participate in playgroup activities with able bodied kids (to sit at the same table as the others).

- For me to walk to the shops, do grocery shopping or even exercise- I need equipment (a specialised chair for Asialee). Currently there is a 12mth wait for CAEP funded equipment.
  Even with the chair, grocery shopping is a challenge- there is only1 checkout Asialee's chair fits through. I cannot push her chair and a trolley so it involves sometimes 3 trips to the car and back or I will do several small shops per week (in my already time challenged week).

- As Asialee silently aspirates (can regurgitate food and choke on this), she requires a specialised car seat to more safely travel. This is not funded by CAEP. It costs $150 for regular child seat and around $3000 plus for special needs seat.

- The size of some equipment (wheelchairs, specialised prams) can prohibit access to some public/private toilets, cafes, venues

- Playgrounds often don't cater for special needs kids. It would be great to see at least one swing offering postural and head support at all new playgrounds.

- Communication – lack of access to communication aids and devices limits child participation in playgroups and is a barrier for carer to enjoy social playgroups

LIFESTYLE

Outgoing lifestyle - bike riding, hiking, camping involves more planning, EQUIPMENT and some places/activities are inaccessible as carers.

HEALTH

When I'm not taking Asialee to her medical appointments, I'm often taking her to my own Chiropractic or Naturopathy visits. Firstly I can't allow myself to be ill, a "Carer" is the one job you cannot call in sick, and secondly the "Carer" role places such a high physical, intellectual and emotional demand on my body, I require the health care.

A national survey of carers' health and wellbeing (2007)[8] revealed:

- Carers have the lowest levels of wellbeing of any Australian group
- Over half reported some level of depression, with one third found to be severely or extremely depressed
- More than one third of carers are experiencing severe or extreme stress
- Caring does not get easier with time
- Caring compounds the effect of any other factor that leads to reduced wellbeing
- Any level of consistent, daily, immediate caring responsibility is sufficient to severely damage wellbeing
- Wellbeing decreases as the number of hours spent caring increases
- The presence of a person in the household who requires care severely compromises the wellbeing of other family members, whether they have primary carer responsibility or not.

TIME

With all the extra time spent feeding, toileting, doing physio/OT at home and then all the medical appointments, this limits my availability to have a social life. If there were a spare moment of time (and both kids were sleeping at the same time) I would opt for sleep over social catch up most days. Sleep deprivation is another of the job demands on many carers.

CAREER

The carer role is full-time and often results in loss of career and the social interaction and fulfilment this brings.
(The lack of child-care and respite options for complex needs kids, prohibits even part-time career options).

Economic barriers to participation for carers

- High equipment costs ($10, 000 for a chair, $3000 for a car seat) can become a barrier to purchasing equipment needed to enable social participation.
- Total expenses associated with being a carer can impact the monies available to afford and enjoy social activities, holidays etc (View my carer related expenses table for an insight into expenses associated with being a carer)
- Income reduced from double to single as carer no longer employed (50K loss for us, larger loss for other couples) – big impact to our social activities and lifestyle, loan affordability (we re-mortgaged several properties) yet our expenses have increased with huge equipment costs (20Kplus per yr), therapy costs etc
- Car size has to increase to accommodate equipment needs
- Travel – car seat expense
- Travel – overseas (child 0-2 generally travel free if child has postural support needs have to pay for a chair $1500 to Canada to visit relatives)
- Travel – overseas (time as you have send equipment for inspection prior to flying)
- FUTURE PLANNING – forfeiture of employment to become full-time carer ends regular income and superannuation savings for Carer retirement. This also impacts funds available to child with special needs, after parents pass.
  Perhaps the government can consider a Carer Superannuation Scheme. Some ideas are paying 10% of Carer Payment into a Super Fund; the government matching $1 for $1 on every $1 carer invests into Super Fund (not means tested).
- Disability Trusts – exorbitant administration costs and reporting see these being very under-utilised by carers.
  Purchase of property for those being cared for (under Disability Trust) attracts capital gains if the person with a disability needs to sell and purchase a more appropriate dwelling (even if this is their primary residence). It is inequitable. Disability Trusts could be a fantastic way of future planning for children with disabilities and their carers, however this system needs revision.
  It seems that these trusts have been set up with the intention of assisting future planning for the disabled, however somewhere along the way there was such a fear that these trusts would be exploited that they were created with so much reporting, and the addition of capital gains on property that they are under-utilised and have not achieved what they set out to. These trusts should enable carers to purchase cars, housing, equipment for the disabled people they care for without any attraction of capital gains and with minimal reporting (carer time is already limited). These items are for personal use and necessity.

My Carer Related Expenses on a $50.30 per week income:

CARER EXPENSE	COST FOR CHILD WITH SPECIAL NEEDS	COST FOR CHILD WHO IS ABLE BODIED
EQUIPMENT		
Car Seat	3000	150
Cot/Specialised Sleep System	3000	200
High Chair/Up-Down Mobility Base	500	35
Pram/Specialised Chair on Pram Base	10000	400
Stander	2000	0
Shower Chair & Specialised Potty	1000	30
Bike Carrier (With Modifications)	1400	400
Communication Aid Book	200	0
Super Talker (Electronic Talking Device)	500	0
Step by Step (Electronic Talking Device)	200	0
Jelly Bean Switch (Toy access)	100	0
Head Switch (Computer access) vs mouse	2000	10
Computer	1500	0
Computer Books, Communication & education programs vs baby books	1000	100
Environment Control Unit (access radio, tv, lights)	1000	0
Double Stroller (Modifications vs cost)	1000	200
Little Room vs Play Centre	750	100
Feeding Cups	40	5
TOTAL	$27790	$1230
THERAPIES/MEDICINES	**$ PER ANNUM**	**$ PER ANNUM**
Chiropractor	2340	90
Naturopath & Nutritional Supplements	1200	100
Acupuncture	2000	0
Conductive Education	200	0
G-Therapy	6000	0
Dental	100	5
TOTAL	$11840	$195
TRAVEL/PETROL		
Plane Seat to Canada (0-2 age)	1500	0
Petrol to Therapy, Medical Appts	2600	50
Car (upsize to fit equipment)	24000	0
TOTAL	$28100	$50
HOUSEHOLD		
Extra Laundry (2 loads/day)	260	0
Extra Water (clean vomit, excrement)	200	0
Extra Water (longer shower)	100	0
Electricity/Gas for safe body temp	360	0
Home Modifications	2000	
TOTAL	$2920	$0
GRAND TOTAL	$71650	$1875

FOCUS ON CARER ABILITY TO FIND/RETAIN EMPLOYMENT

474, 600 Australians Are Primary Carers[5].

Many of these are skilled in high demand vocations like teaching, nursing, allied health, mining & industry... they are potential tax earners and assets to the health, wellness, education and economy of our country's future.
Finding a solution to enable carers to continue their carer role, whilst participating in part-time employment can only benefit the carer, the person cared for and the wider community.

- Review CAEP (Community Aids and Equipment Program) Basic and Essential Guidelines) This will enable the people cared for greater opportunity to have their equipment needs met, thus allowing carers the possibility of child care in the community, or in-home child care for the more complex needs child, and in-home care for the complex need adult.
- Review CAEP Funding (Currently there is a 12 month wait for basic & essential equipment). Without adequate equipment it is difficult to find care-workers that can care for children/adults with high needs, prohibiting "carers" from returning to the workforce.
  "There is a need for all carers to be consulted on met and unmet equipment needs on an annual basis. This will enable the government to more accurately assess funds needed, and to provide the opportunity of access and inclusion for all."
- 474,600 Australians are primary carers.[5] Only116,614[7] (25%) receive the Carer Payment, making care-workers impossible to afford and return to the work force in a part-time capacity inconceivable. By abolishing means testing for Carer Payment, carers could use this money to pay for a care-worker to enable part-time employment.
- Another solution- remove means testing on child care rebate for Carers OR offer a special Child Care/Respite rebate that considers the costs of hiring a RN to care for child/adult (a rebate that is not means tested).
- The ratio of respite workers to disabled people is disproportionate. Perhaps introducing an industry minimum wage and standards would increase the number of available workers. Perhaps the implementation of better equipment provision will also see a rise in respite worker numbers. More respite workers, will increase carer opportunity to return to the workforce.
- Reviewing the operations and management of government funded respite programs, with a focus on staff retention and understanding: what attracts people to a respite career?, what creates job satisfaction (pay, acknowledgement, achieving goals, being treated well, career path)?, working with carers and families to ensure care-worker has clear job description and is acknowledged for their contribution. I think that taking this approach will lead to an understanding of the issues and acting upon these to create operations and management that nurtures the respite worker, will increase the numbers and retention of respite workers. This may be pivotal in enabling carers to return to the workforce.
- For carers that are no longer in a full-time caring role and wanting to make a transition back into the workforce this can be daunting. If a public media campaign emphasising the physical, intellectual and emotional demands of the carer role was launched, Carers may become sought after employees rather than being viewed as people who are unskilled and out of touch. Perhaps the government could also offer a rebate to potential employers for any courses undertaken to upskill the carer and allow re-entry to the workforce.

- Perhaps the government could offer an annual Carer Skills rebate, for full-time carers who want to maintain their industry specific skills, so when they are able to return to the workforce they can easily make the transition.

- Carers are often caring for people whose health is volatile and unpredictable, requiring unforeseen medical appointments and hospital stays. This makes it difficult for carers to have a routine or predict hours of availability to contemplate a return to the workforce and employers often cannot offer the flexibility they desire. Perhaps the government could appoint Careers Counsellors for carers. These counsellors could look at the carer's skills and work history, their carer role and look at viable options for integrating the 2 roles and act as mediators for negotiating work place arrangements.

Whilst the solutions I have forwarded will no doubt come at a cost to the government, the impact is that it will create more tax payers and see a return of high demand professionals such as teachers, nurses, doctors, engineers, health, mining & industry workers to the workforce. This will increase the health, and wellbeing of our communities and economy and pave the way for future generations.

References:

1. 2.6million Carers in Australia – 13% of Population (ABS 2004, 2003 Survey of Disability, Ageing and Carers: Summary of Findings)
2. 7500 WA Children Unable to Perform Vital Aspect of Self Care (ABS 2006, Census of Population and Housing)
3. Carers save Australian taxpayers an estimated $30.5 billion per year (Access Economics 2005, The Economic Value of Informal Care)
4. 3,958,300 people have a disability – 20% of the Australian population (ABS 2004)
5. 474, 600 Primary Carers in Australia (ABS 2004, 2003 Survey of Disability, Ageing and Carers: Summary of Findings)
6. Carer Payment $100.60 and Carer Allowance $546.80 fortnight, together are $200 less than minimum wage (Australian Fair Pay Commission 2007, Federal Minimum Wage. Accessible at: http://www.fairpay.gov.au/fairpay/MinWageDecisionJul2007/MinimumwagedecisionsJuly2007.htm
7. 25% Carers receive Carer Payment (Australian Government Department of Families, Community Services and Indigenous Affairs 2007, FaCSIA Annual Report 2006-07. Accessible at http://www.fahcsia.gov.au/annualreport/2007/2_2_3.htm#link2)
8. Carers Health Statistics (Carers Australia, Australian Unity, and Deakin University 2007, Australian Unity Wellbeing Index Survey 17.1 The Wellbeing of Australians: Carer Health and Wellbeing)

3) The practical measures required to better support carers, including key priorities for action and 4) Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices in their caring roles, transition into and out of caring, and effectively plan for the future. (Pages 11-18)

Key Priorities

1. Determine Carer Needs: There are 2.6 million Australian Carers of People with Disabilities.[1]

Create a National Carer Database, which registers all carers. All carers can receive an annual survey questioning their carer-related expenses, equipment needs, equipment access, respite needs, respite access, child-care needs, child-care access, carer health needs, carer health access, to determine the met and unmet needs of carers. When these factors are known, then there is a clear path to finding practical measures to better support carers.

2. Inform Carers of their support options

- Create National Carer Database (with names, addresses and email addresses)
- Create a website (and booklet) informing all carers of: (Perhaps One Booklet for Carers of children, one for carers of the aged

"When I first found out my daughter has special needs I had so many questions, like:
What services and supports are available? Where do I find information on her condition? What are her therapy options? What are her equipment options? What are our childcare & respite options? What are her education options? What are my career options? ...
It took a long time to find the answers to these questions...time that is precious to carers like me. Time that could be saved by one resource- a website."

Proposed Information to include on website:
A-Z Directory of Services & Support Agencies
Links to information on the condition of the person cared for (if a diagnosis has been made)
What Next? An action plan for all carers
Therapy Options
Equipment Options
Toy Options
Childcare Options
Respite Options
Education Options
Funding & Financial Assistance
Leisure & Play Ideas – includes communication building ideas
Self Care Tips – includes feeding, bathing, toileting, dressing
Family Time – explores relationship building, self nurture, career options
Travel With Ease – includes car, taxi, bus, train, plane tips
Advocacy
Events Calendar
Chat Forum for Carers – Carers can offer peer support to each other and exchange useful info
Chat Forum for Kids with Special Needs- peer support & info exchange worldwide
Chat Forum for Siblings of Kids With Special Needs – peer support & info exchange

Special Kidz Special Needz has already created this website, which would be easy and cost effective to reproduce as a booklet for carers with no/limited access to the Internet.

- Distribute booklet and website address DIRECTLY (via mail and email) to all new carers, all hospitals, support agencies (like DSC, Centrelink and associations for people with disabilities like TCCP)
- Media Campaign to all hospitals, therapy service providers to ensure booklet is distributed to all new carers.

3. <u>Address Lack of Access to Equipment</u> (for people cared for), which increases the demands on the Carer (physically, emotionally and financially).

For example my daughter cannot sit without head, thoracic, hip & pelvic support (a specialised chair), and if I lay her on the ground she could aspirate and potentially die. Without this chair (the first 1½ years of her life) I had to carry her everywhere, so you can imagine how my Carer job description and demands increased and how this impacted my back and health.
3,958,300 people have a disability – 20% of the population[4]

- Fund a Showroom In Each State/Territory Showcasing Equipment for Children and Adults with disabilities.

Independent Living Centres have been established for this purpose, however they have been reliant on suppliers providing the equipment. (Currently there are 3 paediatric items in the WA showroom).

There is a lack of access to Equipment (no store or showroom) where carers can view & try what equipment is available for their children with disabilities IE. Chairs that can enable a child to sit, Standers that can enable a child to stand, Walkers, Potties (enabling children with high needs to toilet), Car Seats enabling safe car travel... the list goes on.

> *"When I want to buy a pram or a high chair for my able bodied son, I can go to any store, try which one best meets his needs and buy it then and there. When I want to buy a chair so that my daughter can sit independently, there is no store, no option, no opportunity."*

This denies children and carers their basic right to access and inclusion.
Without this equipment I would have to carry my 3-year-old child everywhere (she cannot even lay down safely). This is a huge barrier to my and her social participation, growth and development and for 1½ years I did carry her everywhere, perhaps the reader can imagine the extra demands on myself and the 474, 600 other primary carers in a similar position.

For an investment of $250K per state/territory (a total of $2 million), the Australian government could offer these children and their carer's access to this equipment and access to social inclusion. (That's $532 million less than the government has already spent on the cervical cancer vaccine).

It may seem like a lot to invest, but particularly in the early intervention years, access to equipment that can enable postural support, airway protection not to mention independence & inclusion, will lead to better short term health (less risk of aspiration pneumonia, spinal deformity) and better long term health (spinal deformity, muscle movement, communication) outcomes so will be less of a burden to taxpayers pockets, by way of saving hospitalisation costs, medical visits. This equipment can also enable communication and accessibility to education aids, so can enable the development of future taxpayers rather than tax liabilities.

Special Kidz Special Needz has a comprehensive business plan and strategy for implementing an Equipment Showroom in the ILC of WA, and would encourage the government to consult with our board of directors with the view to providing similar showrooms in each Australian State or Territitory.

- Currently there is an average 12 Month Wait for CAEP Funding, Once Equipment is Applied for. No child or adult should have to wait for a basic & essential piece of equipment that enables them to sit, stand, move, walk, bathe, toilet or communicate.

Increase funding to address this unmet need.

Assess unmet need by conducting a nationwide survey of ALL carers. As a carer I have been told there are some items (like a potty, leg othoses, communication device) I needn't bother to apply for as there is such a huge waiting list already and I am concerned that this unmet need is not heard or understood by the government.

- Review CAEP Guidelines for Basic & Essential Equipment and Extend these to include specialised Car Seats, Environmental Control Units, Communication Devices, Switches (to enable toy access).

Essential items such as specialised car seats have not qualified as basic and essential. A regular car seat costs around $150, a special needs seat $3000. My daughter requires a specialised seat to protect her airways (from aspiration of food & vomit) during travel. Given her condition it is essential she travels to medical appointments, aside from the necessity of travel to one's basic right to access and inclusion in the community. Other items like communication aids and devices, switches enabling toy access and environmental control units (enabling access to lights, tv, radio) may also be considered essential to basic access and inclusion rights. Having these items available will decrease the demands on the carer and give more independence to those cared for.

- Review CAEP Guidelines for Equipment Provision.

Much of the PAEDIATRIC equipment (in the way of postural seating) is custom made, with minimal allowance for growth, and not much consideration for the child's changing postural needs. This limits the lifespan of the equipment and its potential to be re-used by another child when its first user is finished with it. These funds and equipment are not renewable, and the user re-enters the funding request pool rapidly. I propose CAEP funding ONLY growth and postural adjustable equipment. I can provide a long list of postural seats, mobility bases, prams, wheelchairs, standers, walkers, car seats, shower, bath and toileting equipment that are growth and needs adaptable and therefore can be recycled. By only funding recyclable equipment within 1-5 years (depending on equipment type), there will be a pool of equipment (valued up to $15,000 an item) able to be used by another without dipping into the CAEP annual budget.

- Review CAEP Guidelines for Equipment Tracking and Recycling

$ million is allocated to the CAEP annually. Where is this expensive equipment and how can we recycle it? Then perhaps the funds available will enable people with disabilities access to all their equipment needs with minimal wait period.

There is a huge amount of money invested by the Government into the CAEP Equipment, yet a lack of infrastructure to track which equipment is recyclable, where the equipment is housed, when the user is likely to be finished using the equipment, what is the predicted lifespan of the equipment. I propose the government develops a national database, capable of auto-generating follow up reminders to check equipment status. Thus when users are finished this equipment can be re-used for others. This database could be accessed by major service providers (DSC, Cerebral Palsy etc) to view what equipment is available online (at the click of a mouse).

4. Address Carer Remuneration: There are 474,600[5] Australian primary carers 116, 614[7] of them pass the means test and are eligible for the Carer Payment.

  - Abolish means testing the Carer Payment.
  - Increase Carer Payment to meet that of minimum wage at the very least.

Government payments for carers include the Carer Allowance ($100.60 per fortnight) and the Means Tested Carer Payment ($546.80 per fortnight). For a single carer receiving both payments this works out to $323.70 per week, which is nearly $200 less than the weekly minimum wage of $522.12.[6] Those receiving the Carer Allowance Only (like myself) receive around $470 per week less than the minimum wage.

Never in all my employment history have I experienced a job where the pay was determined by how much my partner earned ("means test"). As I carer I work 24 hours a day, seven days a week, yet as my partner earns more than 50K per annum, I do not qualify for the carer wage (Carer Payment). I am remunerated $50.30 per week and am not eligible for superannuation. This speaks volumes for the value society places upon the "Carer" role.

- Allow carers to subtract carer related expenses from annual tax return for Carer or working partner (reducing their taxable income). Items such as equipment, therapy, supplements, child care, respite could be considered Carer related expenses.

5. Address Lack of Access to Respite

- Introduce Industry Minimum Wage & Standards for Respite Workers

There is a nationwide shortage of respite workers. The number of respite workers is disproportionate to the number of disabled and aged people being cared for.
Perhaps introducing an industry minimum wage and standards would increase the number of available workers. Perhaps the implementation of better equipment provision will also see a rise in respite worker numbers. More respite workers, will increase carer opportunity to return to the workforce.

- Reviewing the operations and management of government funded respite programs, with the intention of attracting NEW respite workers and retaining existing workers.

Review the operations and management of respite programs with a focus on staff retention and understanding: what attracts people to a respite career?, what creates job satisfaction (pay, acknowledgement, achieving goals, being treated well, career path)?, working with carers and families to ensure care-worker has clear job description and is acknowledged for their contribution. I think that taking this approach will lead to an understanding of the issues and acting upon these to create operations and management that nurtures the respite worker, will increase the numbers and retention of respite workers. This may be pivotal in enabling carers to return to the workforce.

"In 2006 my husband was diagnosed with cancer (the same day as we found out we were pregnant with our now nearly 2 year old son), and I became his carer whilst he underwent a gruelling chemotherapy treatment schedule as well as carer to our now 3 year old daughter who cannot sit, stand, walk, talk, move, toilet, feed without assistance. At this time I was heavily pregnant. I was turned away from seven respite agencies, not because they didn't want to help, but because they didn't have workers. Mid-way through his chemo our son was born, and still many agencies could offer no respite."

6. <u>Review Carer Access to Child Care</u> (for Complex Needs Children)

- Remove means testing on child care rebate for Carers
- Offer a special Child Care/Respite rebate that considers the costs of hiring a RN to care for child/adult (a rebate that is not means tested). I propose a rebate that enables 2 days per week child-care (as this will enable Carers the opportunity to return to the workforce and the opportunity to participate in social activities).

7. <u>Address Carer Career Options</u>

474, 600 Australians are primary carers and 2.6 million Australians are carers of people with disabilities.[1] Many of these carers are highly skilled and from professions that are in high demand such as teachers, nurses, doctors, allied health, engineers, mining and industry. It would be an asset for Australia to have these carers return to the workforce in any capacity.

- Attend to point 2 (carer information booklet) point 3 (addressing access to equipment), point 4 (addressing Carer remuneration), point 5 (addressing access to respite), point 6 (addressing Carer access to childcare). Addressing all these essential issues, will enable carers the CHOICE to return to the workforce and plan a career.
- Public Media Campaign

For carers that are no longer in a full-time caring role and wanting to make a transition back into the workforce this can be daunting. If a public media campaign emphasising the physical, intellectual and emotional demands of the carer role was launched, Carers may become sought after employees rather than being viewed as people who are unskilled and out of touch. Perhaps the government could also offer a rebate to potential employers for any courses undertaken to up-skill the carer and allow re-entry to the workforce.

- Annual Government Funded Carer Skills rebate

For full-time carers who want to maintain their industry specific skills, so when they are able to return to the workforce they can easily make the transition.

- Government Funded Careers Counsellors

Carers are often caring for people whose health is volatile and unpredictable, requiring unforeseen medical appointments and hospital stays. This makes it difficult for carers to have a routine or predict hours of availability to contemplate a return to the workforce and employers often cannot offer the flexibility they desire. Perhaps the government could appoint Careers Counsellors for carers. These counsellors could look at the carer's skills and work history, their carer role and look at viable options for integrating caring and a chosen career, and act as mediators for negotiating work place arrangements with potential employers.

8. <u>Address Carer Future Planning Options</u>

Forfeiture of employment to become full-time carer ends regular income and superannuation savings for Carer retirement. This also impacts funds available to child with special needs, after parents pass.

Attend to point 4 (addressing Carer remuneration). Paying Carers for the job they do, will enable them to have some funds to put towards future planning. (Often there is no retirement for carers of children with complex needs who often out live their parent carers).

- Government Funded Carer Superannuation Scheme

Like other professions, carers should receive access to compulsory employer superannuation contributions. As the government is the "employer" or wage payer the government could pay 10% of wage superannuation in addition to Carer Payment and Allowance.

- Carer Superannuation Fund

Carers should be entitled to a Superannuation Fund, where their working partners can contribute pre-tax funds.
The government matching $1 for $1 on every $1 carer invests into Super Fund (not means tested). This will effectively plan for carer future.

9. <u>Review Guidelines and Reporting of Disability Trusts</u>

Disability Trusts should exist to enable Carers and their working partners to distribute funds (before tax). Carers should be entitled to use Trust fund money for any equipment, housing, therapy, medicines, personal hygiene products, vehicles, home modifications, required to enable the person with a disability access, inclusion and to improve their quality of life.

If trusts were utilised this way, perhaps there would be less burden on the CAEP funds.

- Minimise Reporting Obligations of Disability Trusts

Perhaps request carers keep receipts and records of proof of funds use, and practice audits on individuals if fraudulent activity is suspected, but minimise reporting obligations otherwise.

- Abolish Capital Gains Taxing

Remove any capital gains taxes on any property, equipment or other asset that has been used for the personal benefit of the person with a disability. Ie. If a house or car has been purchased by a Disability Trust, for private use by the person with a disability and that person (for whatever reason) wishes to sell said property, do not charge capital gains tax.
Ie. If I bought my able bodied son a house and he lived in it, sold it and moved house, he would pay no capital gains tax as this was his primary residence. However, if I bought my daughter a house (with funds from a Disability Trust I established), and she sold it and moved house, she would have to pay Capital Gains Tax. This is inequitable and denies the right to equal opportunity.

- Abolish ceiling limits on equipment costs, housing costs etc. This limits the choices and lifestyle of a person with a disability.

Currently the ceiling limit on housing purchased by Disability Trust funding is $500, 000. For families able to obtain sponsorship or funds above this level they may wish to purchase housing above this price. My vision for my (now 3 yo) daughter is for her to live in her own house as an independent adult, with RN carers and access to all the equipment that best meets her therapy and day to day needs. This will require LED lighting and sensor controlled doors, appliances and many modifications to the average building plan, closer to the $1 million price-tag so we would love to begin fund-raising now in a trust that can be interest bearing.

- Allow Disability Trust to buy and sell assets, invest funds and accrue interest with NO TAXES or tax penalties.
- *Give Disability Trusts DGR and TCC status (in a similar vein as charities). Allow any* carer of person with profound disability (as per criteria of Carer Allowance) ability to establish a disability trust.
- Allow Disability Trusts to be set up for children from birth. (Not 16) View my expenses associated with caring for my child with special needs ($71, 650) in 2 years.

10. Address Future Planning for Carers caring for children with profound disabilities

Attends to issues raise in point 9 (review guidelines and reporting obligations of disability trusts)

- Government to train financial planners/accountants in all aspects of Disability Trusts
- Government to keep a register of accredited financial planners/accountants versed in all aspects of Disability Trusts.
- Give new carers government-funded financial planning sessions to effectively plan for their children's future. I propose 2 funded sessions per annum.

This will enable Carers to have an informed choice and a say in the future of those they care for, and enable Carers to effectively plan for "retirement" from their caring role or transition into part-time caring.

Allowing Carers to fund raise and future plan utilising Disability Trusts will reduce the burden on government funds of community housing, CAEP, respite in the long term.

11. Address Impact of Caring Role on Carer Health

Carers have the lowest level of wellbeing of any Australian group. [8]

- Provide 12 government funded allied health sessions per annum. Modalities may include chiropractic, osteopathy, naturopathy, psychology or remedial massage.

Carers are often faced with lifting, twisting, and physical demands of enabling those they care for to sit, walk, bathe, toilet etc This often leads to back pain and in the long term spinal subluxations (deformation) and arthritis. This can put a burden on aged care, if the carer becomes incapacitated and reverses roles and needs to be cared for.

Regular chiropractic or osteopathic visits to prevent spinal damage, will not only alleviate back ache and maintain spinal health, but will also ensure optimal immune health, which is vital for carers who cannot afford to be ill. Remedial massage will also be beneficial to preventing muscle injury and ensuring muscle recovery from demands of caring duties.

Carers are often overworked, under-rested, sleep-compromised and thus have lowered immunity and are very susceptible to viral and bacterial infections. This impacts their ability to provide care and burdens government funded crisis-care respite programs. Giving carers access to regular naturopathic visits, will enable optimal health.

- Provide tax rebate for additional therapy and nutritional supplementation for all Carers eligible for the Carer Allowance.

Allow carers to subtract carer related HEALTH expenses from annual tax return.

SUMMARY

It is essential to determine carer needs in the development of practical measures and strategies to better support carers.

Some key strategies and priorities identified in this submission to best support carers include:

1. Determine Carer Needs
2. Inform Carers of Their Support Options
3. Address Lack of Access to Equipment
4. Address Carer Remuneration
5. Address Lack of Access to Respite
6. Review Carer Access to Childcare
7. Address Carer Career Options
8. Address Carer Future Planning Options
9. Review Guidelines & Reporting of Disability Trusts
10. Address Future Planning for Carers of Children with Profound Disabilities
11. Address Impact of Carer Role on Carer Health

If all of these key priorities are addressed, and suggested strategies explored and adopted Carers would be better supported.

The strategies suggested in this submission would also greatly benefit the economy of Australia in the short, medium and long term.

Carers with high demand skills and professional experience such as teachers, nurses, doctors, allied health and engineers who (through the adoption of the strategies suggested), will be enabled the CHOICE to return to the workforce. Having these professionals return to the workforce will increase the social and economic future of our communities.

REFERENCES

References:

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9. 7500 WA Children Unable to Perform Vital Aspect of Self Care (ABS 2006, Census of Population and Housing)
10. Carers save Australian taxpayers an estimated $30.5 billion per year (Access Economics 2005, The Economic Value of Informal Care)
11. 3,958,300 people have a disability – 20% of the Australian population (ABS 2004)
12. 474, 600 Primary Carers in Australia (ABS 2004, 2003 Survey of Disability, Ageing and Carers: Summary of Findings)
13. Carer Payment $100.60 and Carer Allowance $546.80 fortnight, together are $200 less than minimum wage (Australian Fair Pay Commission 2007, Federal Minimum Wage. Accessible at: http://www.fairpay.gov.au/fairpay/MinWageDecisionJul2007/MinimumwagedecisionsJuly2007.htm
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