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Submission No. 979
(Inq into better support for carers)

Inquiry into Better Support for Carers

Prepared for: House Standing Committee on Family, Community,
Housing & Youth

Prepared by: Fiona , mother of two children, one of
whom has a physical disability

Contents: Carer Inquiry FA 1 pdf
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4 July 2008

Contact details Fiona

SUMMARY OF THIS DOCUMENT:

Letter 1 The way it should be

Letter 2 The way Australian governments and agencies actually
treat the families of children with disabilities

Letter 1 The way it should be

Dear Ms Smith

On behalf of the nation, the Federal Government thanks you and your husband for the 2–6 daily hours of therapy you have supplied to your brain-injured son for the last 12 years, to ensure he is not a cost-burden on the nation's health or social systems.

We wish current medical science offered an explanation as to why a full-term baby from a healthy pregnancy could be born with severe brain damage, and acknowledge that lack of medical explanation does not imply lack of consequent care by the nation of the emotional, financial and physical impact of your's son's injury to your family.

The nation recognises that without your daily input of physical, occupational, cognitive and speech therapy for 2–6 hours per day, your son would not have developed the skills to enter full mainstream schooling.

Based on your son's full inclusion at school supported with appropriate learning technology and trained teachers, his participation in the regular curriculum and his regular school reports, we are pleased he shows every sign of capacity for tertiary training and becoming an employable, tax-paying citizen of Australia.

We are sorry that in your son's first 10 years it was necessary for you to give up your paid employment to invest this daily effort in your son, indeed the nation is in sore need of your skills, work experience and knowledge, including your tertiary qualifications of BA and M. Bus.

But of course as a wealthy first-world nation Australia wishes to support you and your family. Although we cannot restore your lost income of around \$900,000 over the last 10 years, we at least pay you a carer payment that matches unemployment benefits. We also pay your superannuation benefits so that eventually you and your husband may retire from your full-time caring role and enjoy the restful retirement you need, secure in the knowledge that your son will be able to choose the type of supported accommodation that suits his needs.

And as your annual tax returns demonstrate the clear financial loss of your foregone income and simultaneously your greatly increased health expenses, the nation is pleased to help in a small way by offering 100% tax deductibility on all the expenses you incur paying for therapy, services and equipment directly related to your son's disability.

We aim to assist you to keep paying an average \$35,000 per year in health/medical expenses from your teacher husband's net annual salary. We recognise that this ongoing financial commitment to pay for your son's therapy and equipment relieves the nation of a considerable financial burden. The nation thanks you for your determination to be responsible for meeting your son's equipment and therapy needs.

We acknowledge that your family has made a tremendous effort over the last 10 years to ensure your son has the same opportunities for education and social inclusion as every other child. You have undertaken the work that in other countries would have been performed or outsourced by government agencies, such as:

- Researching appropriate learning technology for use by your son (and children without disabilities) in school and
- Alternative therapies practised overseas with accumulated anecdotal evidence of sustained benefit to disabled children
- Developing draft plans to convert standard project home houses into universally accessible homes to meet the needs of homeowners of all ages and abilities

By the way, please thank your parents aged in their 70s for the years they spent lifting your son into their car when they collected him from school as there was no after school care for when your part-time employer refused to let you work school hours. We understand that have decided to discontinue this service now that your son weighs 44 kg.

As a nation we value your son as much as any other child. We try to demonstrate this by ensuring he can go everywhere, we have prioritised footpaths and made all public buildings accessible. We are also preparing for the future with legislation across all States and Territories to ensure all new residences are accessible and meet the needs of occupants regardless of age or ability.

We hope your son enjoys accessing all the regular social, community, and entertainment and sports facilities that a child his age would enjoy in the company of his family and friends and share your joy that he is considered to be just another kid in a diverse group of modern Australia.

Yours sincerely

The Australian Government

LETTER 2 HOW AUSTRALIAN GOVERNMENTS AND AGENCIES ACTUALLY TREAT
THE FAMILIES OF CHILDREN WITH DISABILITIES

Dear Ms Smith

We note you and your husband's tax returns for the last 10 years have demonstrated an average health-medical expenditure of around \$35,000 per year from your joint net salaries of up to \$105,000 per year, and that this expenditure was incurred providing therapies, equipment or services to improve the health and function of your son with severe physical disability.

However, although this expenditure is entirely related to your disabled son's health, therapy and equipment needs, we do not recognise any of this as essential and so you may not claim it as a 100% tax deduction. We regard your expenditure on your disabled son's needs as akin to any other tax payer who has spend more than \$1500 on for example, cosmetic dental surgery.

Further, although your son's level of physical disability requires 24/7 support, you are ineligible for the full carer payment of \$40 per week as you had the temerity to try to work part-time to pay for your son's equipment needs and so incurred a tax bill of \$2000 from your part-time income of around \$40,000 per annum.

When your tax bill is paid off in increments, you will be entitled to claim the generous carer payment of \$2540 per year, even though you may complain that is equivalent to about 8% of your actual disability-related financial expenditure. We don't acknowledge you are a mother". You are a carer, that's why we pay you so generously.

You should return to work full-time now your son is in high school. We do not choose to acknowledge that as he has a severe physical disability and cannot care for himself or walk or even open your front door, he therefore cannot look after himself after school. It is your job to try to find and pay for a service person to undertake your caring duties with your son after school until you come home from work.

The State and Federal governments see no reason to support your income generation and tax payments to the nation by supplying or subsidising such carer employees or allowing their payment by you to be a tax deduction from your gross income. You may claim your mobile phone as a work-related tax deduction; you may not claim in-home assistance to your disabled son to enable you to work as a work-related tax deduction.

We are not sure how your son will actually get home from school in his power wheelchair as you will be at work with your accessible van and so cannot pick him up from school. That is your problem. Unfortunately the local council and your state Roads and Traffic Authority have not seen fit to provide modern road crossings or a footpath, so possibly your son could travel less than 1 kilometre along the road in his wheelchair as he travels home from school.

And please don't whinge about the cost of buying a commercial van and converting it for wheelchair modification. Plenty of other people where you live spend \$85,000 on their luxury car, why can't you happily do so on a tradesman's van? If you were serious about working your husband would also buy an \$85,000 van and then you could share transportation of your son's 1 kilometre between home and school.

You need to understand that community expectation of "inclusion" refers to policies, not actual practices. Do not make the mistake of trying to get government authorities to actually do what they say they do. And don't refer to the United Nations Convention on the Rights of Persons with Disabilities. Fortunately Australia is merely a signatory to this Convention, we have not ratified it so we are not legally or morally bound by it.

You should be grateful your son is allowed to go to an ordinary school with normal children. However, it is too much to expect he should be able to access his community or participate in community club sports with his school peers. It is preferable that we keep "special" children like your son segregated with "special sports". Be grateful you can afford the fuel to drive him two hours per week to wheelchair sport. We are grateful we don't have to subsidise this sport in any way.

You should also be grateful your son is entitled to a free hip x-ray each year if you wish to spend a day waiting at your State children's hospital for this service. We think this is an important indicator of the nation's commitment to the health of children.

But we don't think the research you have done and money you have spent paying for medical services by practitioners who advocate intelligent use of nutritional supplements and foods, along with your daily commitment to provide intensive therapy which is not provided by the public system, are in any way responsible for your son never being admitted to hospital with illness and thus not costing the taxpayer any money.

And while we acknowledge that you have paid private health insurance and paid a gap for private surgery and medical services for your son's treatment in private hospitals, as you are not on a pension you are not a battler and so you should pay for everything.

If you have private health insurance and live in northern Sydney you must be rich, and can afford to pay all your son's disability-related expenses and eventually become self-funded superannuants. There may be some kind of supported accommodation for your son when you wish to retire, but it will be what the State decides is suitable, not what your son actually wants and needs.

Disabled people have some rights, but not the same rights and opportunities as the rest of the population. You need to accept that. Your extended stage of denial will not change the outcome. You may wish to consider consulting a professional to manage your attitude about this situation; merely living with the problems arising from an inaccessible, exclusive society does not make you an "expert". A medical degree and no relevant knowledge or experience does.

Yours sincerely

The Australian Government

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INVESTING IN OUR CHILDREN

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NOTE An edited version of this document was submitted in May 2008 to the Hon Bill Shorten, Parliamentary Secretary for Inclusion and Children’s Services

INVESTING IN OUR CHILDREN

"It is not our abilities, but our choices which determine who we are." Albus Dumbledore to Harry Potter

Enablement needs action

Australia is stuck in an **old-economy *disabling generic welfare/victim mentality*** towards people with disabilities and their families.

We don't need charity. We need to move to a modern, national, integrated, coordinated system which ***enables people to develop and achieve via a targeted support framework.***

We all know – don't we? - that people with disabilities are simply part of the diversity of humanity. Legally and ethically they have the same rights as any other Australian. Now we **MUST** move beyond platitudes and ensure that:

- Rights are practically supported by consistent policy application, irrespective of State
- Policy is not restricted by endless assessments and meeting administrative checklists
- Policy-based actions are flexible, innovative and respond to the needs of people with disabilities and their families, not the service providers

With a new Federal Cabinet portfolio including social inclusion, Labor governments throughout the nation, a review of the tax system, a(nother) inquiry into carers, the ratification of the UN Convention on the Rights of Disabled People, and increasing community expectation that governments show leadership and champion social inclusion, NOW is the time to ACT.

We call upon the Federal Government to listen and lead with progressive policies and practices which actively include all Australians in social and economic life

Enable the family to enable the child

As a mother of two children, one of whom has a brain injury and resulting physical disability, I have detailed some of my family's experiences which continue to **destroy the potential of many children and adults** with disabilities to be part of and contribute to our society.

PROBLEMS ...

THINK about the inter-connectedness of systems, or lack of them:

1. Negligible tax rebate for private expenditure on some, not all, disability equipment and services
2. Lack of relevant targeted allowances for disability equipment or services
3. High family income needed to buy equipment, therapy but both parents or single parent unable to work due to inadequate support to family and child with disability
4. Low levels of employment of "carers"
5. Low levels of employment of people with disabilities due to inaccessible transport, infrastructure, buildings, communities and facilities
6. Double the national divorce rate and higher risk of dysfunctional families

The result: Increasing, never-met demand for state-funded equipment, services and welfare

SOLUTIONS ...

It doesn't have to be so painfully dysfunctional. An intelligent, nationally coordinated system based on needs defined by families – not just departments, agencies or advocates – could overview and deliver at national, state and local level:

- **Choice in equipment and services via an effective tax system supplemented by state assistance**
- **Choice of therapies based on accumulated global evidence**
- **Choice of targeted support/respite where it will be most effective**
- **Choice of flexible, supported adult accommodation in the community**
- **Choice in education system and technology, capital or human support**
- **Choice in where to live, work, socialise because all transport, buildings, shops, community facilities, businesses and new homes are accessible to everyone**

Yes the key word is choice. We expect people with disabilities and their families will have the same rights to choice – and responsibilities – as the rest of the Australian population.

Yes this investment will cost money up front. Doesn't all business investment? But it has great potential to deliver a more economically sound, socially just and participative community. Which is what democracies need to survive and thrive. It's what Australia needs to throw off the shackles of 30 years of failure to recognise and support all our diverse population to contribute to our society,

PROBLEMS & SOLUTIONS – PARENT PROPOSALS

1 Disability equipment funding

There is always a waitlist where the child outgrows the equipment and develops muscle contractures while waiting. The equipment is rarely customised to meet individual need. There is usually a huge funding gap parents must fill on every single disability item they buy.

Private health insurance is useless – rebates \$2000 **once per lifetime** towards the cost of a wheelchair. A child who begins using a power wheelchair at age 4 will go through at least 4 powerchairs by age 25.

In NSW, there is a two-year wait for a wheelchair assessment and fitting through the Spastic Centre NSW, after which parents are told either to wait up to two more years for PADP funding, beg for help from charities or buy it themselves.

The year before a physically disabled child starts school is when families must partially or fully fund a **power wheelchair**, resulting in **house modifications** for the chair to move around in. They also need an **accessible van** so the child and powerchair can literally move away from the house. Anecdotally, the total cost of these 3 items is around \$300,000 - NOT tax deductible. Regardless of government rhetoric, it is families who bear the brunt of paying for wheelchairs, house and vehicle modifications.

A wheelchair-accessible vehicle – vital for anyone who needs a wheelchair to get anywhere – costs between \$50,000-\$85,000 to buy. Because of the high costs of new vehicles, reliable second-hand vehicles are almost impossible to locate. **Yet families do not receive one cent** in government financial assistance towards the costs of a wheelchair-accessible vehicle, regardless of what Kevin Rudd thinks is the case.

In some States, families pay nothing for tube-feeding supplies. In others, such as NSW, they have to find \$300 a month to pay for something that their child needs literally to stay alive.

Equipment and services bought for the child is an investment in the child's future health, independence and education, maximising the child's capacity to become a future tax payer instead of a welfare recipient

If Australian governments, Federal and State, say they will not fund equipment and service needs adequately and equitably, the only humane alternative is to financially enable more families to privately fund the equipment and services needs of their children with disabilities. This can be achieved by:

- Targeted transfer payments, such as occurs in the UK where families with children in wheelchairs get a generous weekly mobility allowance, which they can then choose to transfer to a wheelchair-adapted car leasing scheme known as **Motability**
- Reforms to the tax system to enable 100% tax deductibility of essential disability items

Option 1 – The NZ and British systems, where government funds ALL essential equipment and services. NZ and British families do not have to find the funds for anything classified as required for a disabled child's and/or their family's health and welfare.

In Australia, State governments fund a little – with wide variations from State to State, which is utterly iniquitous; families fund most and charities fill some of the gaps.

The NZ and British models free families to fund smaller items and additional therapy, while also guaranteeing humane and equitable access to equipment and services. It is morally reprehensible and may well be challengeable at law that in Australia, access to vital equipment and services so often depends on a family's ability to pay, and/or the State they happen to live in. Australia has ratified the United Nations Convention on the Rights of Persons with Disabilities.

Option 2 - A reformed Australian tax system that recognises the extra, essential costs of disability equipment and services could offer 100% tax deductibility for equipment/services privately purchased because a family member has a disability

Option 3 – Supplementary corporate funding of specific equipment – eg buy and modify a vehicle to transport child or adult who uses a wheelchair, needs specialised seating or security (NZ govt supplies/ UK govt partially funds, USA vehicle manufacturers subsidise)

2 Respite care and support – in-home and outside home

If were supplied, many parents would use “respite” support not to rest but to undertake paid work, use their skills and pay tax!

Provision of flexible funding **DIRECTLY** to families to access support where they decide they need it most – as happens in the UK - would help them manage family lives more smoothly and more akin to “regular” Australian families.

How is it possible for an 18 year-old Brisbane boy to be publicly educated to Year 12 and be dumped to spend all his post-school days and nights at home with his 61 year-old mother, because they have been told there is no funding for day programs, further study or employment? Why even bother educating him at school?

Examples of targeted support:

- Getting children ready for school in morning
- Help after school with homework, therapy, personal care
- Support on family holidays so parents don't exhaust themselves with physical care
- Support during family social activities/events to enable whole family inclusion
- Support for when a child stays with family or friends to enable extended social inclusion
- Vacation and after school care centre support
- Support when participating in mainstream social or sports activities, to demonstrate community inclusion

3 Parents and families recognised as “experts”

By the time a child with moderate to profound disabilities is school-age most families have tried many therapies. When orthodox therapies don't work they will look outside the square for those that do. Yet all Government funding continues to be directed only to orthodox therapies - which is great for orthodox therapists, but frustrating for those whom this funding is supposed to help.

Within certain limits, parents should have **complete choice and control** over how the public money provided to fund therapy services for their child is spent. This is a policy change which would both spur often complacent orthodox therapists to lift their game immediately, as well as permit innovative and often highly successful alternative approaches to demonstrate their worth. Consumers would be free to vote with their feet as to what approach worked and what did not.

Despite a dearth of research into the actual efficacy of orthodox therapy methods, therapists often argue against alternative approaches on the grounds there is no 'research' proving they work. To which the answer is:

1. Fund pilot centres providing alternative therapy approaches, and then set up research studies into their efficacy compared with orthodox therapy – as an NHMRC Expert Working Party recommended in relation to one alternative therapy approach, Conductive Education, in 1993
2. Acknowledge that parents are experts in research. Unlike professionals with vested career interests to protect, we live with the daily consequences of inadequate therapy or the incorrect or non-supply of equipment our child needs, just to get out of bed, go to the toilet, swallow food, get into the car/van, get to school.

Government health, community, education and inclusion bodies need to reflect in consultation processes, policy and action that parents – not advocates - are the experts.

When we say our child needs a new height-adjustable bed or new wheelchair as s/he has outgrown old one, we need it now and don't need to go on 9-month waitlist for an occupational therapist to write a three-line letter saying we need it.

People with intellectual disabilities need the protection of their family's knowledge and expertise even after they have reached chronological adult age.

**If you want to know how to do something better,
ask the people who are already doing it.**

4 Enabling family income generation and increasing tax revenue

This is so glaringly obvious it should not need to be spelt out. But as no policies recognise reduced family income in households which include a child with disability, we will define it:

The **opportunity cost** to individuals, families and the Australian economy of the inability family carers to participate in paid employment was estimated in 2005 by Access Economics at \$4.9 billion. The **replacement value method** estimates the value of this care at \$30.5 billion

Due to my inability to continue my work, our family has lost my income of around \$900,000 over the last 10 years, excluding superannuation contributions. Simultaneously our family has paid nearly \$400,000 for equipment, therapy and services for their child with physical disability.

Families with children who cannot physically or intellectually care for themselves must ALWAYS have a parent available when the child is at home or goes anywhere outside the supervision of school. The child does not have to be ill or even profoundly disabled. Just a mild physical or intellectual disability – enough to rob them of the capacity for self-care.

This means a parent or paid carer must be available for the child after school, during school holidays, weekends, when the child is sick, to attend medical, therapy and school appointments.

In the whole of Sydney there is only one vacation care centre for primary school age children with disabilities. There is zero regular after school or vacation care for high school students with disabilities.

So while the Budget papers "assume" a 12 year old child does not need after school care, there is no recognition of the reality of life with a child with a disability.

In the absence of State-provided support and without parent-determined, flexible, reliable, affordable or fully tax deductible support, there is no chance for both parents to work and increase family income, and no chance for a single parent to work also. Yet very few families are eligible for Carer Payment, based on current criteria.

- We can't work to boost our incomes
- We can't get Carer Payment which is still \$200 below average weekly income
- We don't get tax relief which recompenses us for the massive yearly expenditure we must make on disability equipment and services
- We must put up with poorly trained, inexperienced Centrelink or health department employees telling us we are trying to rot the system

5 Flexible supported accommodation

There is no question of returning to “institutional” living, which 6% of adults with disabilities lived in. But too many current supported accommodation models are bureaucratic, inflexible, unwelcoming, poorly managed and downright dangerous to the health of the residents. They do not meet the social inclusion needs of residents. They are just somewhere to sleep, and not always safely due to inadequate staffing.

To make supported accommodation functional, vacancy management must be returned to non-government organizations, which families are more likely to financially, and enable groups of families to define supported accommodation models which work for their children.

Often supported accommodation vacancies are filled by people who have come in contact with the criminal justice system and on the pretext of privacy, families and NGOs providing the services are not part of the compatibility-check. Would you allow someone you didn't know come and live with you? Particularly if your family member was intellectually disabled, non-verbal and highly vulnerable?

Choice and diversity should be the benchmark of support for carer families and people with disabilities. There should be no prescriptive accommodation for people with disabilities. Choice of accommodation models should reflect the choices of others in the community, underpinning Article 19 of the UN Convention of the Rights of People with Disability

UK pilot:

<http://www.communitycare.co.uk/Articles/2008/03/19/107655/individual-budgets-gathering-steam.html>

6 Single point of entry to services

To permanently eliminate the inconsistent funding and supply of services and supports to people with disabilities and their families which is conveniently attributed to the Federal-State “blame game”:

- The Federal Government must take responsibility for disability services and inclusion, which must be benchmarked against national population data
- States and localized services become the agents for delivery of targeted programs
- Overseen by the Commonwealth and answerable to the people of Australia through the Federal Parliament

People diagnosed with disabilities, regardless of cause or timing, and their families should receive support from a single Federal Government agency which brokers services from the public, private and not-for-profit sectors to meet the individual needs of the child/adult, with ongoing input from the family.

The formulation of such a “Life Plan” must be flexible to meet changing needs and circumstances, and focus on a whole-of-life approach from early childhood, school years, post-school and adult life. This process must focus on providing targeted supports to meet individual needs, not acting as an assessment provider.

7 Education – choice and support

Choice

Real choice of education system will only be guaranteed to families of children with disabilities by quarantining Commonwealth and State funding to go with the student, regardless of the system s/he is educated in.

A student does not lose his or her disability simply by moving from State to independent or faith-based education system. Yet this is the funding outcome. A student with disabilities receives from the Federal Government only 25% of the funding allocated to a student without disabilities. How is this in any way supportive of students with disabilities?

Where is parents' freedom to choose educational system? Why are students with disabilities discriminated against in this way? Where are the mandatory "strings" attached to Federal funding of non-government schools to force them to accept students with disabilities, along with their acceptance of Federal funding.

Support

For students with more than very mild disability, most families encounter at best lip service and more often indifference in their attempts to ensure their children are educated, as legally required.

Yet just like every other Australian child, **access to good quality education lies at the very heart of enabling children with disabilities** to become informed, productive, employable citizens.

Policies abound, but at school and regional level across Australia, the only children with disabilities who receive anything near the targeted supports they need are those of parents who find out and use every legal and political tool to demand real action, not slogans.

The education of students with disability **MUST** be practically inclusive by:

- Ensuring teachers are properly trained to use relevant tools, not just "chalk and talk"
- Learning technological supports are used in class work where required by students with disabilities to learn actively and engage in the curriculum – be it State or national
- Appropriate use of education and teachers' aides. Not all students need aides to help them learn. Aides, like wheelchair ramps, are merely one support which may be useful. Most schools expect aides to "teach" students with disabilities. This is the job of the trained teacher

The school setting must be appropriate to the needs of the student. There is validity in the notion of segregation only where the disability warrants such a school setting, and the best judges of this will be informed parents in partnership with education systems that want to actively support their children.

8 Carer family advocacy

Recurrent funding should be allocated for nationally consistent family carer advocacy services, to give family carers of people with disabilities a legitimate voice in policy and planning at the federal, state and regional level in all matters that affect them and those for whom they care.

The outpouring of problems – and solutions – on the wiki [WhatCarersNeed](#) is just one example of how family carers of children and adults with disabilities feel voiceless and disregarded, their unpaid job merely to do the often exhausting day-to-day work of lovingly caring for their family members.

Carer family advocacy should include representation by carer families on agencies responsible for financial supports to people with disabilities, such as management of Special Disability Trusts. For example, SDTs should be exempt from capital gains tax, should have more flexibility in application of funds and be subject to fairer tax rules. This would ensure greater relevance, accessibility and take-up.

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SUMMARY OF THIS DOCUMENT:

Comparison table, showing the expenditure costs on a child with a physical disability compared with the expenditure on his sibling, who does not have a disability.

All costs in this table were incurred by our family. We did not receive any government financial support.

DISABILITY- RELATED EXPENSES 1996 – 2008		
	Child 2 WITH disability	Child 1 without disability
1 powerwheelchair – age 5-10	\$18,000	Nil
1 manual chair – age 5-10	\$9,000	nil
Wheelchair repairs and maintenance	\$7,500	nil
Tradesman's van, modified for wheelchair accessibility	\$84,500	Sedan - \$17,500
Wheelchair locking system in van	\$6,000	nil
Seating for home, school, transport	\$21,000	Booster seat - \$300
Modified games and toys to stimulate physical and cognitive development age 1- 9	\$11,000	Regular toys age 1-9 - \$3500
Computer hardware and software modified for accessibility	\$9,000	Desktop computer - \$2500
House modifications	\$80,000	Nil
Private surgery in Melbourne (2.5 year wait list for public surgery in Sydney)	\$6,800	Nil - broken arm treated as public hospital outpatient
Orthopaedic shoes, orthotics	\$10,000	Regular shoes - \$3000
Private osteopathy, chiropractic, Hyperbarric Oxygen, medical GP, nutritional supplements, speech therapy, body splint, arm splint, occupational therapy, music therapy	\$55,000	\$2000
Swimming aids	\$1,000	\$45
Specialised bike	\$1,600	\$150
Therapy aids (therapy table, movement equipment)	\$8,500	nil
Physical therapy ongoing review and tuition, therapy clinic travel and accommodation	\$110,000	nil
TOTAL ESTIMATED COST	\$422,900	\$28,995