Costs of Disability

“Just in Case”

Six Case Studies

October 2005
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About the Ministerial Advisory Council on Disability

The Ministerial Advisory Council on Disability (Council) is an independent body established under the Disability Services Act of 1993 to provide advice to the State Minister for Disability Services on matters affecting people with disabilities, their families and carers. The Council also provides advice to the Australian Government Minister, responsible for disability services, through the National Disability Advisory Council as a State Disability Advisory Body under the Commonwealth State Territory Disability Agreement.

To facilitate balanced independent advice, Council’s membership reflects the spectrum of disability and includes people with disabilities, carers and service providers.

How the Council operates

To carry out its role, Council operates by way of an ‘issues model’ and operates on two levels commonly referred to as reactive and planned.

**Reactive issues** are issues that may arise at any time within the field or are raised by a council member.

**Planned issues** are identified annually by Council when priorities are set and action is determined to progress them further. A working group may be established to further identify and prioritise the specific issues and to recommend to full Council the outcomes and actions required.

Purpose of report

The purpose of this report is to obtain a snapshot of the additional costs of disability to people with disabilities, their families and carers.

There have been many studies undertaken on the costs of disability and the impact it has on people with disabilities, their families and carers. This report is not extensive but attempts to identify the costs of disability from a personal perspective.

Recommendations have not been provided, as the aim is to inform the Minister for Disability Services of the costs incurred by people with disabilities, their families and carers in addition to normal everyday living costs, through case studies of several Council members.
How the issue was identified

In February 2005, Council identified priorities to direct its work for the coming year. The priorities were grouped into three areas and Council working groups were established. One of which was the Assistance Working Group. This group identified several issues and classified the issues under two headings; Resources and Support and Financial Costs of Disability.

The area of financial costs of disability included unmet need, changed circumstances, Continence Aids and Assistance Scheme and the funding of aids and equipment. Stemming from the work on these issues and recent Welfare to Work changes, the personal costs of disability were identified.

How the information was gathered

Members were asked to document the costs of disability over a short period. This was to include not only the direct financial cost of disability but also the indirect cost, such as loss of time or opportunity, loss of income and additional effort and/or frustration. There was no formal method used, each member documented their costs in their own way.

Who was involved?

In total six Council members participated. It is also important to note that some specific disability groups were not included and the comments represent the membership of Council at the present time.

The case studies included the following perspectives:

- physical disability;
- sensory disability;
- intellectual disability; and
- family member / carer.
CASE STUDIES
Case Study 1

I am a 42 year old woman who has Athetosis Cerebral Palsy. I live independently in the community with the support of my family and of paid domestic carers. I cannot access public transport effectively, nor can I walk far. I drive and rely very heavily on my vehicle so it must be well maintained. I am an active member of my community and have a family of my own with three children, my husband and three step children. Our children range in age between 9 and 18 years.

1. Everyday Living
The major everyday extra costs I incur are the amount of unavoidable wastage.
1.1 A portion is wasted every time I open, pour or tip from milk to washing powder, shampoo to sugar.
1.2 A portion is wasted every time that I squeeze, from toothpaste to dishwashing liquid.
1.3 I use larger amounts of cling wrap, aluminium foil and other products for wrapping/covering, in order to grip the product and secure it effectively.
1.4 Household items like electric can openers and hairdryers burn out at a faster rate than for most consumers, due to heavy handed usage.

2. Shopping
2.1 I buy things that I can manage rather than what’s on special. For example, ring pull tins, sturdy stationary supplies, draw-string tea bags and grated cheese.
2.2 I buy large containers, rather than small which are much harder to handle.
2.3 I buy more of some items, more often than other people, especially personal items. For example, I drop and break make-up because it comes in small containers. I break hair spray nozzles by dropping the container, I use more tissues and cleanup items.

3. Clothing and shoes
3.1 Shoes are a big ongoing expense. I wear shoes out faster than the average person because I am heavy footed and do not walk evenly. I scuff and kick the toes of shoes.
   I can only wear flat, solid shoes that buckle or lace tightly to my feet.
   Mostly I need to purchase expensive shoes from stores like “The Athletes Foot”. I do not receive funding for specialised footwear.
3.2 I buy clothes that I can manage myself, not the clothes on sale. When I buy clothes, if they look complicated (buttons, ties etc) I reject the thought, even if I like the article.
4. **Time**

Everything I do, takes more time than it otherwise would. THE COST; some is obvious, time is money. The not so obvious cost is extreme frustration at knowing the task at hand is simple and yet almost impossible - “How can we expect a fast moving world to understand that”.

5. **Going without**

5.1 During this exercise of raising my level of consciousness regarding the cost of my disability, I was quite surprised at how much I go without, because it is easier. Example: If I’m having trouble getting something off a shelf in a shop, I leave it there. I never buy food or drink to eat spontaneously unless I am seated in a café or restaurant (Not even a chocolate bar). When my family buys an ice cream, I pretend I’m not hungry.

5.2 I don’t go into crowded shops.

6. **Keeping things in good working order**

I pay trades people to do what others might do easily, because I cannot afford to let maintenance go, whether it be my home, my car or my body.

7. **Transport**

7.1 My most practical and accessible mode of transport is my own motor vehicle - organised to exactly suit my needs. I must have a reliable well maintained vehicle at all times. I cannot manage as well in a small vehicle, so must always purchase a larger one for ease of getting in and out and manoeuvrability (I do not function in restricted spaces).

7.2 A larger vehicle is more costly to run and maintain than a smaller one.

7.3 I will not shop around for bargain fuel and risk not having personal customer service. (In direct respect to having a disability.)

7.4 Public transport is not an option; I cannot purchase tickets from ticket machines, I cannot stand for periods waiting for transport, it is difficult to maintain balance and stamina in crowds, I cannot get on or off a bus or train quickly (so it becomes a bit scary).

8. **Accommodation**

8.1 Even if I lived alone, I need a very spacious house in order to maximise function.

8.2 Security in the home and emergency safeguards are essential including monitored security and emergency alarm systems - these companies don’t give discounts to their best customers!

8.3 I cannot “make do” if a door is stiff or something is broken and I can’t fix things myself. Something as simple as a tap washer means I pay a plumber.
Case Study 2

I am a 46 year old woman with a medical degree from the University of WA. I lost my sight from complications due to Diabetes four and a half years ago. The very rapid deterioration of my sight left me totally blind and unable to work in my chosen profession. I live with my partner/carer, am involved in voluntary committee work and study part time Information Technology.

Fortnight Estimation: From 23 June 2005 to 6 July 2005

<table>
<thead>
<tr>
<th>Date</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>23 June 2005</td>
<td>Purchase Pakmate Notetaker with voice – approx $5000</td>
</tr>
<tr>
<td>23 June 2005</td>
<td>Taxi to and from West Perth - $20</td>
</tr>
<tr>
<td>24 June 2005</td>
<td>Professional hemming - $34</td>
</tr>
<tr>
<td>26 June 2005</td>
<td>Taxi to and from Victoria Park - $38</td>
</tr>
<tr>
<td>2 July 2005</td>
<td>Taxi to and from Victoria Park - $38</td>
</tr>
<tr>
<td></td>
<td>Independent living aid - $9</td>
</tr>
<tr>
<td></td>
<td>Membership - Association for the Blind WA - $11</td>
</tr>
<tr>
<td>4 July 2005</td>
<td>Taxi to and from Nedlands - $30</td>
</tr>
<tr>
<td></td>
<td>Dry-cleaning of pants [food spill] - $7.50</td>
</tr>
</tbody>
</table>

The following are costs that are difficult to quantify:

- Loss of income – approximately $3400 gross per fortnight.
- Maintenance costs of computer including updates of voice synthesizer software.
- Additional costs for Telstra 1300 calls for telephone banking - connection to operator at extra cost as the reference numbers are too long to be able to enter in the limited time of the voice menu.
- 1223 Calls to find numbers as I am unable to access phone book.
- Mobile phone calls to sort out problems with computer.
- Replacement of breakable items and damage to household furniture as a direct result of blindness.
- Necessity of being accompanied on any information seeking and shopping excursions.
- Costs of missing out on sale-type savings, as no access to information and unable to travel out of “known area”.
- Purchase of an expensive mobile phone for approximately $600, plus $200 for the software for audible conversion. This was the only type of phone that could accommodate the software - the phone is a security requirement.
- I require a microwave to cook with as my stove/oven is gas which is manually lit and therefore is not safe for me.
- I also need to have a companion, especially at night, as I experience very bad hypoglycaemic attacks from my Diabetes and can become disorientated, which when combined with blindness can be dangerous, therefore it would not be feasible for me to live alone. Luckily I have a partner but if not I would have to live with elderly parents.
Case Study 3

I am a 25 year old woman with a physical disability. I receive care from 4 different agencies, which enables me to live independently in the duplex I rent on my own. My additional costs relate to managing and paying for these services, for taxis I catch when public transport isn't an option and extra phone calls I make in regard to my disability. It also takes additional time for completing forms, attending doctor’s appointments and waiting for carers and taxis that are late. These waiting times and costs are more profound in people with disabilities.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Item</th>
<th>Cost</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monthly</td>
<td>Personal care from Perth Home Care Services</td>
<td>$3.00 per hour (max 80)</td>
<td>$80.00</td>
</tr>
<tr>
<td>Monthly</td>
<td>Personal care from Rocky Bay</td>
<td>$1.60 per hour</td>
<td>$19.20</td>
</tr>
<tr>
<td># Monthly</td>
<td>Telstra delayed hotline</td>
<td>$3.30</td>
<td>$3.30</td>
</tr>
<tr>
<td>* Monthly</td>
<td>Calls made to mobiles from 17/5/2005 – 16/6/2005</td>
<td>$1.49</td>
<td>$1.49</td>
</tr>
<tr>
<td>* Monthly</td>
<td>17 local calls made from home from 2/7/2005 – 29/7/2005</td>
<td>$0.175 each</td>
<td>$2.97</td>
</tr>
<tr>
<td>Monthly</td>
<td>5 Taxi trips made in July 2005</td>
<td>average $6.70 each</td>
<td>$33.50</td>
</tr>
<tr>
<td>Monthly</td>
<td>Electricity Account - disability related (charge hoist and wheelchair, keep air mattress on)</td>
<td>approx 50%</td>
<td>$30.00</td>
</tr>
<tr>
<td>Monthly</td>
<td>Prescription medicines</td>
<td>2 x $4.60</td>
<td>$9.20</td>
</tr>
<tr>
<td>Monthly</td>
<td>Herbal tablets (circulation)</td>
<td>$17.00</td>
<td>$17.00</td>
</tr>
<tr>
<td><strong>Monthly Total</strong></td>
<td></td>
<td><strong>$199.79</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Yearly Total</strong></td>
<td></td>
<td><strong>$2397.48</strong></td>
<td></td>
</tr>
</tbody>
</table>

The above care costs are paid in addition to funding received.

The above call costs are directly related to my disability.

# Telstra service that automatically dials a predetermined number if unable to dial (good for emergencies).

* Phone calls directly related to disability. For example booking a taxi or cancelling carer/nurse.

I attend physiotherapy once a week (for 1 hour and incur 1.5 hours in travel time). This would effectively equal lost earnings as I could work more hours if I didn’t require weekly physiotherapy.
I pay a higher premium for home contents insurance to include coverage for my wheelchair and other aids and equipment (extra $15,000 amount insured) and on my van for the hoist and restraints (extra $7,500 amount insured). The van is diesel so has a higher cost to run as well.

**Waiting times**

<table>
<thead>
<tr>
<th>Date</th>
<th>For</th>
<th>Length (hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>23 June 2005</td>
<td>Taxi</td>
<td>1.25</td>
</tr>
<tr>
<td>24 June 2005</td>
<td>Taxi</td>
<td>0.5</td>
</tr>
<tr>
<td>28 June 2005</td>
<td>Home helper (late)</td>
<td>1</td>
</tr>
<tr>
<td>4 July 2005</td>
<td>Accessible bus in rain</td>
<td>1</td>
</tr>
<tr>
<td>13 July 2005</td>
<td>Centrelink form</td>
<td>0.5</td>
</tr>
<tr>
<td>22 July 2005</td>
<td>Telstra form</td>
<td>0.75</td>
</tr>
<tr>
<td>27 July 2005</td>
<td>Urology appointment</td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Total time</strong></td>
<td></td>
<td><strong>6.5</strong></td>
</tr>
</tbody>
</table>
I am a 22 year old female with a high thigh amputation from the result of cancer when I was a teenager. The treatment for the cancer has left me with high fatigue levels. I do not use a prosthesis and use crutches as a means of mobility. Due to this I find it difficult to complete common tasks such as carrying things and therefore require low levels of support for various activities. I find it difficult to walk long distances and so rely on my car as the only means of transportation.

I am currently studying at university and do not have employment at this time, however I receive a Disability Support Pension, Mobility Allowance and the Pensioner Education Supplement which helps to cover the expenses I incur.

Disability Expenses 24 June 2005 to 5 August 2005 (7 weeks)

<table>
<thead>
<tr>
<th>Item</th>
<th>Cost</th>
<th>Time</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Petrol</td>
<td>$184.15</td>
<td></td>
<td>Unable to catch public transport due to disability</td>
</tr>
<tr>
<td>Parking close enough to facilities</td>
<td>$10.00</td>
<td></td>
<td>Free parking was too far away to walk to destination</td>
</tr>
<tr>
<td>People going shopping with me</td>
<td>N/A</td>
<td>11 hours</td>
<td>Family helps - can't carry heavy or too many things</td>
</tr>
<tr>
<td>Pain killers</td>
<td>$10.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>House cleaning</td>
<td>N/A</td>
<td>12 hours</td>
<td>Family helps - unable to complete some tasks and tire easily</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>$204.15</strong></td>
<td><strong>23 hours</strong></td>
<td></td>
</tr>
</tbody>
</table>
Case Study 5

The following details some of the costs incurred due to our son having a disability (Down syndrome). It should be noted that these are specific to our family situation. We are very fortunate that our son enjoys good health these days. Lots of people with Down syndrome have significant costs associated with medical care and medication. When he was younger, medical care as well as therapy costs were quite substantial.

While there are some obvious daily and weekly costs, we've also included things such as lost earnings in our estimate - hard to estimate but a significant factor. I began my own business working from home in preparation for our son leaving school as I need to be home with him or pick him up from work – not possible with other jobs. If the support worker calls in sick on a recreation day then one of us needs to be at home for him. If I have meetings or work scheduled then my husband will have to knock back jobs for that day. He has a graffiti removal business. Sometimes he can take our son, but often not. Declining a job can cost around $400. We both need the flexibility of not being in salaried full time jobs.

Basically what we've done is try to make a comparison between what would be the case if our son was a 21 year old without a disability, with our actual situation. For example – if we want to have a night away from home and the kids, we have to arrange and pay for a carer – whereas we wouldn't if our son didn't have a disability. I haven't included the costs for us having these breaks as we'd probably do this anyway. I have included my 2 weekends a year when I have a break with friends who are also Mums of kids with Down syndrome, as this really is a respite weekend for re-charging the batteries and talking with other people “in the same boat”.

Our son works 3 days a week for Good Samaritan Industries. He goes out 2 days a week with a personal support worker and another young man with Down syndrome. The shared support person cuts the costs a little bit. On weekends our son likes to watch DVDs or TV, listen to music, go shopping or take part in motorcycling events. He is a member of 2 off-road motorbike clubs. We have covered the cost of his motorbike and his other associated costs. We did try to get him a bank loan in his name for his motorbike so he could pay it off but the bank would not approve it – they weren't convinced he understood what was happening. He did but it's hard to demonstrate with very limited communication skills.

Our son earns $112 per fortnight and also receives a Disability Support Pension. He doesn't spend as much as he might if he didn't have a disability, partly because he can't travel independently. We drive him everywhere he needs to go. We do receive some Post School Options funding which helps cover the cost of the 2 days recreation per week.
**Weekly costs:**

Transport to and from work 3 days per week   $20
Wages for support worker 2 days per week   $275
Transport to motorcycle events – petrol   $20

**Sport costs:**

Purchase of current motorbike   $4800
Safety helmet, boots, clothing   $600
Annual license and club memberships   $350

**Lost earnings:**

Our son   unknown, but at least $300 per week
Husband   $400 per job – occasional cost
Myself   $30,000 per annum approximately

**Respite/ carer costs:**

Overnight   $100 (if we have our usual person.
If an agency it’s a lot more)
Respite weekends x 2   $500
Case Study 6

I am a 33 year old woman with a physical disability. I receive care from Harold Hawthorn Community Centre in the form of 2 hours domestic assistance weekly and 1 hour grocery shopping fortnightly. This care is subsidised, the cost to me is $6.50 per hour. I live with my husband and four year old daughter. My mother who lives next door assists me with the physical side of parenting. On days when it is raining my mother takes my daughter to school and collects her. I do not use taxis to assist me to collect my daughter as they are not reliable enough and I have been left waiting a considerable amount of time.

**Transport:** I have a modified van, which has substantially higher running/maintenance costs than the size of vehicle which I would have if I did not have a disability.

Paid for car hoist myself at $6,500.

**Household:** I have a cleaner for 2 hours a week. Although this is partially funded, I still pay $6.50 per hour.

**Grocery shopping:** Employ a person to shop for groceries at $6.50 per hour, 1 hour per week.

**Furniture:** Purchased 2 lift chairs at $1,300 each which is considerably more than I would have paid for normal armchairs.

**Housing modifications:** We are having a new bathroom built. It was not practical to modify the existing bathroom, as the space is too small. The total cost will be about $16,000, of which approximately $2,000 is subsidised.
Summary

The information in this report is based on a survey of six Council members and is not a randomly-conducted “opinion poll”. Most of the Council members who participated in the survey are employed; all have active lives and fully participate in community activities daily.

The following summarises the issues from the survey only and in no way reflects all costs of disability.

**Travel costs:**
- Increased cost for taxis.
- Inability to use public transport because of disability (excluding taxis).
- Use of car for short journeys – unable to walk long distances.
- Select service station where driveway service is provided rather than shop around for cheaper priced fuel.
- Increased use of paid parking because of too few “disabled parking” bays.
- Necessity of a larger vehicle for ease of access, however more costly to run and maintain.
- Additional use of car to take adult family members to work and recreation.
- Public transport too inaccessible/infrequent.
- Unable to drive or use regular vehicles, use “maxi taxis” for travel.
- Unable to do minor maintenance or cleaning of vehicle.

**Housing costs:**
- Home modifications.
- Requirement for larger houses for manoeuvrability and ease of access.
- Modified and additional fittings – such as handles, switches, knobs, taps.
- Replacement of equipment.
- Require durable furniture to withstand knocks.
- Security costs.
- Necessity to employ tradespeople and cleaners to carry out household maintenance and cleaning.

**Clothing and shoes:**
- Purchase clothing and footwear for suitability rather than cost or preference.
- Reliance on others to choose and buy clothes.
- Unable to access information on sales.
- Increased wear and tear on clothing and footwear.
- Additional dry cleaning costs.

**Care costs:**
- Personal, support, respite and overnight carers.
- Unpaid costs of companion for shopping, outings, exercise, housework, gardening and chauffeuring.
Aids and equipment:
- Costs for aids and equipment such as wheelchairs, hoists, modified vehicles and computer technology.
- Top up of funding – funding may only cover a proportion of actual cost.

Telephone / Communication
- Increased use of “Voice” mobile phone, as landline phone is too difficult.
- Use of 1300 numbers to access telephone banking.
- Require additional time for dialling.
- Require modified (expensive) software for computer.
- Require “voice” notepad.

Pharmaceuticals:
- Increased cost of general pharmaceuticals – both medical and general.

Consumables:
- Purchase of additional items due to breakage and spillage.
- Purchase of more expensive, easily manageable items regardless of price.

Doing without:
Respondents reported going without as many purchases and activities are too difficult to access or participate in. Spontaneous activities and purchases were also limited because of access difficulties and the need for prior planning.

Recreation
Additional costs for recreational activities borne by families because of limited income of adult sons and daughters.

Time:
Waiting times and additional time taken to carry out activities lead to immense frustration and represented lost time and therefore lost income.

Examples of wasted time in one typical fortnight:
- Taxis: 2 ½ hours.
- Accessible bus: (in rain): 1 hour.
- Home helper (late): 1 hour.
- Centrelink (to complete a form): ½ hour.
- Telstra (to complete a form): ¾ hour.
- Appointment: 1 ½ hours.

Lost Income:
Lost income was identified by all who were surveyed. Unable to work in their chosen or previous career because of their disability was stated throughout and in particular the aspect of having to choose casual, part time or flexible work.