PHYSICAL DISABIILTY COUNCIL OF AUSTRALIA

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TOWARDS A DISABILITY ALLOWANCE: OFFSETTING THE COSTS OF DISABILITY

- AN ANALYSIS -

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OFFSETTING THE ADDITIONAL COST OF LIVING AND PARTICIPATING DUE TO PHYSICAL DISABILTY: AN ANALYSIS

Dr. Jack Frisch
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EXECUTIVE SUMMARY

1. Methodological problems plague budget surveys that seek to measure a central-tendency dollar value of the additional unavoidable cost faced by a person with a disability. They are prone to significant under-reporting and over-reporting errors that do not necessarily cancel out; they are biased downwards to the extent that the incomes of people with disability are lower than they would otherwise be; and they do not account for individual financial and living circumstances, a community's social capital or local infrastructure, or individual taste factors. Most critically, they tell us less about the additional cost due to disability than they do about the budget constraint faced by the individual.

2. Expenditure surveys have only been useful in consistently showing that there is wide variation in expenditure across individuals, across impairments, and even across expenditure categories within an impairment grouping. These variations further undermine the usefulness of central-tendency estimates because their purpose is at least partly, if not most crucially, to review the position of individuals in greatest need – i.e. with highest additional costs.

3. The Australian Quadriplegic Association's (AQA) finding that additional expenditures are approximately 50% of incomes across income groups can be interpreted in one of two ways. One interpretation suggests that additional costs are discretionary and have no special status, since people consume them in the same way that they consume all normal goods, i.e. as income increases, expenditure on disability goods and services increases proportionally. An alternative interpretation suggests that people go without many goods and services because of disability-induced poverty, and that a 50% average propensity to consume suggests desperate need rather than discretionary choice.

4. Policy analysts fear that a generous offsetting of additional costs due to disability will lead to an unjustifiably large and uncontrollable increase in government expenditure. Such fears are ideologically based. To assert that there will be only minimal impact on expenditure is also ideological. The expected impact on government expenditure is an empirical issue, which depends on the details of any program, and the issue of whether the impact is justified or not depends on an empirical estimate of the benefits of such offsets.

   The impact will be less when:
   - assessment procedures and eligibility criteria are tight;
   - thresholds for income and assets tests low;
   - co-payment rates are high;
   - the range of goods and services defined as disability-related is narrow; and
   - penalties for fraudulent claims are severe.

5. For people with disabilities, The McClure Report was a missed opportunity. The brief was to examine the income support system with particular reference to creating more incentives for employment participation and to make the income support system more efficient. Because the Report failed to comprehensively study the total disability support picture and focused only on Commonwealth payments, it failed to recognise

the role of the States in discouraging employment participation and thereby failed to create a structure for rationalising the complementary relationship between Commonwealth and State supports; it failed to recognise that its final recommendations of a tripartite system of payments was not significantly different from the status quo; and it failed to spell out the participation disadvantage caused by an inaccessible social infrastructure and the consequent potential role of regulatory authorities in making the infrastructure more accessible.

6. An individualised disability allowance would enable people with disabilities to take greater control of their own lives instead of being dependent on service providers and assessors to determine the expenditures needed for greater independence. Such an allowance would arguably also lead to a more efficient system of disability goods and service provision, since it may encourage competition between providers and suppliers.

A complete shift to an individualised disability allowance from the current system of government-supported in-kind service provision is inappropriate, however, since an allowance system would disadvantage people with high support needs who currently receive an adequate quality of in-kind goods and service; it would disadvantage people who are less able due to their disability to manage cash; and it would be of little advantage to people in rural and remote areas, who would gain little from a more competitive service provision environment.

7. A workable system of offsets to the additional cost of living due to disability needs to be equitable, administratively simple and inexpensive to government, dignified to eligible claimants, transparent and accountable to taxpayers, and it would ideally encourage, and definitely not discourage, workforce participation.

Options for offsetting the additional costs due to disability include:

(i) maintaining the current system but increasing the funding to existing systems;

(ii)a replacing the Disability Support Pension (DSP) by:

- an *Income and Employment Participation Support Allowance (IEPSA)* that is granted to all long-term unemployed people with disability and without means; plus
- a *Disability Cost of Living Allowance (DCoLA)* that is granted without means tests to all people with disability who face additional costs of living (whether employed or unemployed), and only to those people with disability who face additional costs due to their disability; plus
- extension of tax concessions to self-funded retirees aged over 65 to self-funded unemployed people with disability;

(ii)b structuring the DCoLA of Option (ii)a in four tiers so that people with relatively low additional costs receive the allowance at the lowest tier, while those who face high additional financial cost receive the allowance at the highest tier;

(iii)a enhancing the system of category allowances, such as the Mobility and CAAS Allowances, to include an allowance for independent living, technical aids and appliances, personal care and home care, access to information and communication, extraordinary health care and therapy care, and housing.

(iii)b structure each category allowance of Option (iii)a with two tiers such that people facing low expenditure for the particular category receive a lower allowance than people with high costs for the particular category. Some individuals will be in a low tier for one or more categories and a high tier for others, or receive no allowance for the particular category.

(iv) grant offsets to individuals with disability on presentation of receipts and/or invoices for specified items – subject to co-payments and thresholds.

8. An analysis of criteria against the various options outlined above suggests that Option (ii)b would be the best way forward. Option (iv) is too complicated and too radical; Options (ii)a and (iii)a do not account for the high costs faced by the most disadvantaged people with greatest support needs; and Option (i) is inefficient and inequitable. Option (iii)b is not wholly unsatisfactory, but consultations in the disability sector revealed that many people felt that it would be overly intrusive as many recipients would be subjected to continual assessment for a range of expenditures.

   Option (ii)b is preferred to Option (iii)b also because it is felt to be more consistent with the government objective of simplicity, as outlined by the McClure Report, i.e.

   - to replace the current age-tied Disability Support Pension with Income and Employment Participation Support to unemployed people, ensuring that unemployed people with disability receive enhanced employment support to offset discrimination due to disability;
   - a tiered Disability Cost of Living Allowance where an assessment tool is used to ensure that people who have minimal additional costs due to disability receive the lowest allowance level, and where people with the high additional costs receive the highest allowance; complemented by
   - tax concession to self-funded people with disability who do not work as a result of disability – equivalent to the tax concessions provided to self-funded retirees over the age of 65.

1. INTRODUCTION

This report is the result of a project commissioned by the Physical Disability Council of Australia to report on a Needs Survey, which was completed in 1998 by 600 people with physical disabilities across Australia, with a brief to emphasise findings relating to the additional non-discretionary cost of living for people with disability.

The project has run parallel to the debate initiated in November 1999 by the Commonwealth Government when it set up the *Reference Group on Welfare Reform (2000)* (Reference Group), which reported its findings in August 2000, in a document that has become known as the McClure Report. It has been impossible – and it would have been wrong – to isolate the project from this debate, since the PDCA project was to a large extent initiated to inform precisely this type of debate. This paper, therefore, has a good deal to do with a challenge that was placed before the National Caucus of Disability Consumer Organisations by a member of the McClure Taskforce. The challenge was to outline a practical model to enable government to offset the non-discretionary additional cost of living for people with a disability.

The challenge has had a dynamic of its own, and what was originally a report became a consultation paper in which various options were presented and discussed with the disability sector for feedback. The current paper is the result of that feedback.

Before embarking on a discussion of models, there are a number of methodological issues, political issues, and some economic issues that must be raised. These issues are critical to an understanding of what is involved in a lobbying effort to offset the non-discretionary additional cost of living for people with a disability.

The Reference Group has made some of the work easier because a number of important points that people with disability have been making for several years have finally been acknowledged. In particular, the Report has acknowledged that:

- people with disability face a range of obstacles to employment, including infrastructure and equipment obstacles, and attitudinal barriers (p.26);
- there are additional costs of living for people with disability (p.23);
- there are additional costs of participating in the work force (p.29, p.38); and
- people with disability need to be seen as individuals with widely divergent (p.9).

Unfortunately, the Report did not go further than to acknowledge the obvious. It ignored the implications of infrastructure barriers; it remained vague on how to “individualise”; it went no further than call for more research on how to implement a tripartite income support system, with a base support level supplemented by a cost-of-living allowance and a cost-of-participation allowance.

Within the context of previous “cost of disability” studies, Part 1 of this paper outlines some of the policy issues that need to be addressed, including the context in which costs are measured, the biases of measurement, and the measurement process itself. Part 2 discusses some empirical findings. Together, these two parts argue that sample surveys are inevitably of extremely limited value for determining needs. Part 3 describes the policy background for discussing options, while Part 4 discusses the policy options against the previously developed policy background. Part 5 concludes that the preferred model is a targeted extension of the allowances that are already in place.

2. BRIEF REVIEW

There have been a number of “cost of disability” surveys[1] over the years. While they have used different sample groups and different methods, they have consistently concluded that:

- the majority of people with disabilities have few additional costs, while a minority have extremely high additional costs – resulting in the average additional cost across all individuals for particular items being significantly lower than the median expenditure across the few individuals with additional expenditure on particular items;
- there is a strong direct relationship between additional costs due to disability and disposable income;
- there is a weak relationship between additional costs and impairment; and
- the specific items that lead to additional costs vary with the type of functional disability.

The research has come up with little more than these unsurprising conclusions. Little has been contributed to understanding the relationship between additional costs and the social context of those costs, for reasons outlined below and in Frisch (2001, Volume 2).

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[1] Walsh and Chappell (1999), under the auspices of the Department of Family and Community Services (DFaCS), surveyed 1,000 Disability Support Pension recipients with a wide range of impairments. Hughes and Purdy (1999) surveyed 200 AQA members, most of whom had spinal cord injuries. Frisch (2001) analysed the additional costs due to disability, based on data from a survey of members of the Physical Disability Council of Australia.

a. *Interpreting Results – the Background Context*

The first point to make is that the policy interpretation of a disability expenditure survey is fraught with difficulties unless all the background context is made explicit and accounted for in the survey. What does it mean if the additional expenditure due to disability is low? Does it mean that there were few additional costs due to disability? Or does it mean that the respondent was poor? Or does it mean that the respondent's community is so inaccessible that the respondent can do nothing other than stay at home watching TV, incurring few additional costs? Or does it mean that additional costs were low because many products and services were made available at low cost – through charity, family or government services?

> Let us assume three wheelchair users with the same income and the same level of quadriplegia. *Angela* lives in a relatively accessible community and therefore gets out and about and plays boccia; *Brendan*, an ex-football star, lives in an inaccessible community and therefore stays at home most of the time because it is expensive to get out and about; and *Cheung* lives in a relatively accessible community, but stays at home most of the time because she feels insecure, and focuses on saving as much of her income as possible. *Angela* will spend more on taxis, wheelchairs and wheelchair maintenance than either *Brendan* or *Cheung*. Because of her frugal lifestyle, *Cheung* might even be able to save some of her income. Does this make *Angela,* with the highest non-discretionary costs and the most active lifestyle, worse off than Brendan, who has few additional costs because he stays at home most of the time?

Similarly, if average additional expenditure on transport is low, is this because a city has a relatively accessible public transport system, or is it because the city has such a poor public transport system that people with disability can't use it? If expenditure on adaptive technology is low, is this because it is freely available though one or another product or service provider such as PADP, or is it because the technology is so expensive that people cannot afford to buy it on their limited discretionary incomes?

Before the results of a disability expenditure survey can be interpreted, it is critical to understand:

- the nature of the social infrastructure – the building and transport access, the topography, and community acceptance;
- the individual's desire for social participation; and
- the extent and nature of supports available in the community.

In regular expenditure surveys of people without disability, these “background” factors can safely be ignored because they can be assumed to cancel out across individuals. But in the disability policy context, these “background” factors cannot be ignored because these other factors are integral to the additional cost due to disability.

Without accounting for “background”, we don’t know what results mean, and results are therefore without policy content. A comprehensive, robust and accurate survey that accounted for these factors would require a large sample size and a carefully crafted questionnaire. And even then, it would be fraught with the problems outlined below!

b. *Income-Constrained Expenditure versus Needs*

Expenditure surveys tell us little about needs, and mainly tell us that people spend money on things they **can afford**.

Let us compare *Martine* (who needs a $300 grab rail installed in the bathroom in the rented flat into which she has recently moved after being forced out of her previous flat) with *Norman* (who, in order to avoid getting wet when it rains, wants to install a $600 handrail beside the three steps down to the garage that he uses as a storage area). *Martine* cannot afford $300, particularly in view of the costs faced due to being forced to move, and she will have to wait six months before the local Home Modifications Scheme people come around to fixing the grab rail. Norman is relatively well off. Housing modification expenditure attributable to *Martine’s* disability will be zero, while modification expenditure attributable to *Norman’s* disability will be $600. Does this mean that *Martine* has fewer needs, or does it simply reflect the fact that she is poor?

There is a fundamental flaw in trying to assess needs using expenditure data because expenditure is mainly determined by income. It is not surprising that expenditure surveys generally find that the additional cost due to disability increases as income increases, i.e. as people can afford to buy the things they need.

When direct and indirect discrimination in the workplace and the community leads to lower income than would otherwise be the case, the use of expenditure data as an indicator of need adds insult to injury because those people with the greatest needs are also those facing the greatest discrimination, and therefore have the lowest incomes. An expenditure-based survey will show these people to have the lowest additional costs because of their poverty – not because of their needs.

The only type of expenditure survey that might give some information about need is one where the person with the disability feels unconstrained by a budget. This may be because of an adequate court-ordered compensation payment or because of sufficient acquired wealth. There are unlikely to be enough people with unlimited budgets and with a wide enough range of disabilities to make this type of expenditure survey feasible for informing policy, but an examination of court-determined estimates of costs may provide a more useful indication of the additional costs needed to accommodate disability than an income-constrained expenditure survey.

Saunders et. al (1998) provide another useful method for measuring need. Their “budget study” approach brought together a wide range of cost estimators and experts in diet, clothing, transport, housing, education, sociology, finance, costing etc., as well as consumer focus groups. The groups defined and estimated the budget needs associated with low, modest, and adequate standards of living for nine socio-demographic groups. The study planned a consumer focus group of people with disabilities, but the researchers abandoned the disability focus group because they were overwhelmed by the wide range of disability needs and the variation in those needs. They felt that any derived budget standard would not be robust enough to inform policy. The researchers sought, but did not receive, additional funding to develop disability-oriented budget standards.

This approach is made because:

- findings show need rather than biased income-constrained expenditure patterns;
- the over-reporting and under-reporting issues referred to below can be minimized;
- assumptions about need are explicit and therefore can be adjusted to individual situations;
- costs can be accurately assessed and validated; and
- results can inform the individualised tailoring of supports favored by the McClure Report.

It should be noted that Economics as a discipline is suspicious of this sort of study because the discipline does not have a methodology to distinguish “demand” from “need”, but this reflects the limitations of Economics methodology rather than the limitations of needs research.

b. Under-Reporting

One of the problems reported in Frisch (2001) is the extent to which expenditure attributable to disability is under-reported. Although there may have been technical reasons for under-reporting, some under-reporting was also attributed to:

- internalisation of the additional costs as part and parcel of daily living;
- ignoring small additional costs that are relatively insignificant, even though they may be significant in absolute terms;
- forgetting irregular small and large purchases, and underestimating large purchases made several years earlier;
- ignoring time costs and income loss costs, even though these are attributable to disability.

Thus, if a person thinks it is routine to pay a higher price for groceries at the local convenience store because s/he has less opportunity to get to the supermarket, then s/he will not attribute the higher price to her/his disability, even though studies show that the cost of shopping in local convenience stores is up to 30% higher than shopping in supermarkets. If a person thinks everyone makes phone calls to book taxis or to find out whether the place s/he is going to is accessible or not, or to find out why a taxi is 40 minutes late and whether it is on its way or not, then s/he will not attribute higher phone costs to her/her disability. If a person needs to have irregular modifications made to equipment or clothes, or to occasionally pay for home maintenance, then s/he is likely to ignore these small expenditures. If a person bought expensive capital items many years ago, s/he is unlikely to adjust the annual depreciation estimate for the higher current price unless there are clear instructions to do so.

Only a carefully constructed questionnaire with carefully explained cue cards and instructions can overcome these type of under-reporting errors. Although the PDCA Needs Project identified significant under-reporting of the costs of taxi transport, home modifications, personal care, telephones, and aids and equipment, the most significant under-reporting was evident in estimates of income loss and accommodation costs.

c. i *Income Loss*

People with disability and associates of people with disability generally have a lower income than they would otherwise have, but few people recognise the lower income as a "cost". It is not surprising that for the three respondents who reported income loss as an additional cost due to disability, the average loss was more significant than any other single category of cost, since income is the source of most expenditure and is therefore always greater than any single expenditure item.

It is also not surprising that only three people reported income loss as a cost, both because most "cost of disability" questionnaires focus on out-of-pocket expenditures and because recognition of income loss as a cost involves understanding the subtle and complex concept of "economic cost".[2] There are various sources of income loss (see Box below) including income loss due to discrimination, and income loss due to the lost time, where the lost time can furthermore be categorised as due to impairment or due to inadequate supports and infrastructure. In either of these cases, recognition of income loss as a "cost" also suggests that "cost of disability" studies should focus as much on the **time wasted** due to inadequate infrastructure and poor services as they do on out-of-pocket expenditure. To ignore time wasted due to inadequate services is to the detriment of people with disabilities as well as being offensive.[3]

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[2] While "economic cost" is a standard concept for economists, it is not one that is easily understood by people without economics training, and it is furthermore not a concept that is accurately measured. It compares wealth in one state with wealth in the next best alternative state. This is usually taken to be the price of a good (i.e. the difference between wealth if one buys an apple and wealth if one does not buy the apple), but in the present case, it can be taken to be the difference between wealth with a disability and wealth without a disability. Estimation of the loss is fraught with difficulties but the concept nevertheless stands.

- It is not difficult to estimate "what would have been" for a young person who has been fully employed with a reasonable income up to the point at which s/he acquired her/his disability and who subsequently becomes unemployed, but it is far more difficult to estimate "what would have been" if the young person is subsequently employed at a lower income, or if her/his income is much the same as before but promotion is thwarted. In the former case, there is total income loss, while in the latter the income loss is only partial.
- It is not too difficult to estimate the income loss of an unemployed or underemployed parent whose socioeconomic position suggests that s/he would have worked full time if her/his child did not have a disability, but it is much more difficult to estimate the income loss attributable to disability for a person born with a disability who misses out on a regular education and who subsequently has a lower lifetime employment income than s/he would have otherwise had.

[3] It is offensive because it implicitly values time at zero, and, given the economist's equation of price with value, in turn implies that people with disabilities are unemployable and without value.

SOURCES OF INCOME LOSS – A BRIEF DIVERSION

Because of the subtlety and complexity of the issues, it may be instructive to briefly describe some of the sources of income loss to a person with a disability and/or their family. Each of these sources of income loss has a different policy implication and a different measure of "economic cost".

Income loss may be due to discrimination; lost time because of inadequate support structures and infrastructure; lower productivity due to impairment; or to the lost time of associates because of inadequate support structures and infrastructure.

1. Discrimination:

Income loss may be due to labour market discrimination that results in unemployment or lower income than would be the case if there were no discrimination. This sort of income loss is a clear "social justice" issue because the discriminator or the person getting the job gains at the expense of the person with the disability. The "economic cost" is the potential wasted by not employing a person to the extent of their ability. This type of cost is best dealt with by anti-discrimination laws.

2. Inadequate Infrastructure

Income loss may also be due to the inadequacy of the transport and building infrastructure. It might mean getting to work late and developing a bad reputation because of unreliable taxis and inaccessible public transport; it means fewer seamless networking and communication opportunities with work colleagues and clients and a consequently lower likelihood of promotion because of inaccessible building design; it means wasting time negotiating and planning access, transport, and carers etc. The "economic cost" is the value of time wasted and the value of the goods and services not produced. This sort of loss is best dealt with by the promotion and adoption of universal design principles and anti-discrimination legislation.

3. Impairments

Income loss may also be due to lower productivity resulting from factors associated with a person's impairment. The lower productivity may be due to the impairment itself, or it may be due to the cost of aids and equipment and personal supports required to ensure the same level of production as other workers. This lower productivity will be passed on to the worker by one means or another – leading to lower income. The "economic cost" is the value of the product lost from lower productivity. The policy response to this sort of income loss involves prevention measures to reduce impairment, improved insurance arrangements to enable insurance against the financial losses due to disability, and subsidies to firms that invest to enable a person with disability to be as productive as other employees.

4. Associates On Call

Income loss may also be due to the inadequacy of home supports. This inadequacy may force family members to act as "carers" where they could otherwise be earning income in the labour market. This is particularly pertinent to parents of children with disabilities, spouses, and parents of adults with some disabilities. The "economic cost" is the product lost from unemployment or underemployment minus the value of goods and services involved in "caring". This sort of income loss is best dealt with by professionalisation of the "caring" industry, providing the financial means for employing professionals, and by reducing the demand for "caring" by the promotion and adoption of universal design principles that enhance independence.

c.ii *Accommodation*

Only four respondents to the PDCA Needs Project estimated accommodation costs as an additional cost attributable to disability. They estimated the additional costs to be between \$100 and \$400 per month, making average accommodation costs to those nominating such costs as the most significant out-of-pocket expenditure.[4]

A 10% premium is probably not unreasonable for an accessible home which is 15% larger than it would otherwise be and which has amenity value near accessible shops, and a 10% premium is consistent with the 10% premium paid for adaptable and accessible units in multi-unit apartment complexes. Assuming a weekly rent of \$300, a 10% premium would imply a monthly premium of \$130 attributable to a disability. While this is at the lower end of the four responses reported, it should be noted that with a higher rent and higher premium, the upper end would be reasonable for the wheelchair users and people with ambulant disabilities who are most likely to note this additional cost.

While it is important to note the size of the accommodation cost attributable to disability, it is as important to note the small number of survey respondents who attributed part of their accommodation costs to disability. It is important to note that at least 80 wheelchair users did not nominate accommodation costs as an additional cost due to disability even though they are more than likely to have incurred additional costs. This suggests the extent to which the additional cost due to disability is internalised by most people with disability, and therefore ignored in any self-reporting survey of out of pocket additional expenses.

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[4] This seemed extraordinarily high and warranted further investigation. Monthly visits to a specialist were ruled out as the cause of the high cost because the four all lived in a metropolitan area. Renovations and home modifications were also be ruled out because the responses were inconsistent with responses to the specific modifications questions in the survey.

Following an item in the Sunday papers about a wheelchair user's high bid for a detached dwelling, it became obvious that a wheelchair user needs more space for turning circles, pays a premium for the wheelchair-oriented amenity value of location, and would probably have to pay a premium for living in an adaptable or accessible unit. The wheelchair user paid over \$1 Million for a well-attended auction for an "almost"-accessible detached cottage on the lower North Shore of Sydney. The item noted that everyone at the auction was please at the result because the chap who bought it most "needed" it, whereas the other bidders only "wanted" it. It was not noted that the "winner" probably would not have paid the amount he did if he had more choice. One can only speculate as to whether the "winner" would have attributed any of the premium paid to his disability if he were responding to a "cost of disability" survey. (Cindy Martin, "Made to Measure", *Sun-Herald*, Sydney, 13 August 2000).

c. iii Other Under-Reporting Errors

People with disabilities face a higher cost of living not only because of expenditure on obvious goods and services, such as wheelchairs, personal care, home care, pharmaceuticals, etc. They also face less obvious higher costs, which are generally not reported because the costs are ignored, internalised, or forgotten. Nobody knows how much these unreported additional costs add to, but it would not be unreasonable to estimate them as being between 2% and 5% above the costs faced by people without disability. Some sources of costs that generally go unreported include:

- higher prices for similar goods because inaccessible buildings and shops and inaccessible transport mean there are fewer opportunities to shop for bargains and to take advantage of specials and sales, and a greater reliance on more expensive local convenience stores.

- higher prices for non-basic models instead of basic models because a person with limited mobility will need to buy more expensive ready-made completed furniture instead of less expensive DIY furniture; a person with limited hand or finger function may need a hands-free phone and microphone/earpiece instead of a basic handset; a person who cannot bend over may need a more expensive top-opening washing machine; a person with limited hand function may need to replace buttons with velcro; and a wheelchair user may need clothing altered to better accommodate their wheelchair.

- wasted purchases due to disappointed expectations. While undoubtedly all people occasionally buy goods which don’t live up to expectations and which they do not or cannot return, people with disabilities arguably experience disappointed expectations more than do people without disability. It is certainly the case for a person with a newly acquired disability, as well as for parents of children with disabilities, since these two groups lack experience and information about needs. Typically, such waste occurs when an item is purchased but can’t be used because of a small unanticipated design feature, and then it can’t be returned because it has been tampered with in attempts to accommodate the product to the individual’s disability. Even consumers who have done all the research and have an intuitive cynicism about products face such disappointed expectations!

- capital items, where respondents are likely to exclude or underestimate the current market depreciation value of capital items purchased many years previously unless directly instructed to do so and given guidance on how to estimate the depreciation value.

- the many small items that in themselves are not worth reporting, but can add to a significant amount, e.g. eating utensils, switches, phone calls, walking frames.

d. Over-Reporting

Expenditures surveys are also prone to over-reporting errors when products or services are not disability-specific, i.e. when they are essential for a person with a disability, but also widely in general use by people without disability, perhaps even as luxury items. Examples are mobile phones, gardening services, taxis, health insurance, cars, and automatic gears on a car. Over-reporting occurs when a survey respondent attributes the total cost of the good or service to their disability. A 100% attribution implicitly assumes that the respondent:

- gets no value from the product or service other than to accommodate their disability; and
- would not have bought the product or service if s/he did not have a disability.

The nature of the problem can be illustrated with a taxi example. As a result of inaccessible public transport and the nature of some impairments, some people can only use taxis for transport, and they are more than likely to attribute the total of their taxi fares to their disability.

This involves over-reporting because the additional cost attributable to disability should be the taxi fares less:

1. either (a) the cost of running and driving a car, or (b) the cost of public transport; and
2. the "service value" derived by use of the taxi.[5]

Thus, if taxi costs are $200 per month; public transport costs are $40 per month; the value of time saved, comfort etc. of private motor vehicle transport over public transport is $50 per month to the individual; and the cost of running and driving a car (including depreciation,

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[5] Taxis are a poor example of "service value" for people with disability, but if we assume for a moment that taxis were comfortable and never late or unreliable, and that drivers were all sensitive to the needs of people with disability and offered good service, then the amount a person would be willing to pay for a faster, safer, more comfortable trip than that offered by public transport should also be deducted from the figure arrived at for public transport users.

registration, parking etc) are $120 per month, then the added out-of-pocket expense attributable to disability would be:

- $110 per month ($200 – $40 – $50) where public transport is used; and
- $80 per month ($200 – $120) where a private vehicle is used,

instead of $200 per month, suggesting over-reporting of $90–$120 per month.

The cost of wheelchairs or some categories of personal care service may also involve over-reporting, even for products and services that appear to be clearly disability-specific. While there is no over-reporting involved in the cost of a regular day-to-day wheelchair, a sports wheelchair arguably involves over-reporting to the extent that the sporting wheelchair is a substitute for the expensive “sporting equipment” that would have been purchased if the respondents did not have a disability (e.g. fishing or scuba gear).

There may also be over-reporting if private health/hospital insurance is attributed to having a disability. It is possible that a person with a disability might not have purchased private health/hospital insurance if they did not have a disability, but it is hard to prove, given that a significant percentage of the population without disability also buys such insurance. Furthermore, even if one can be certain that the individual would not have purchased health/hospital insurance if they did not have a disability, it would involve over-estimation to attribute all the premium to having a disability because benefits need to be deducted to derive the net health insurance cost, together with the “service value” of the insurance cover.

Finally, there may be over-reporting where the buyer with the disability attributes lawn-mowing or home cleaning costs to their disability, even though s/he would have purchased lawn-mowing or home cleaning services even if s/he didn’t have a disability. On the other hand, it is undoubtedly the case that many people do mow their own lawns and clean their own homes, and it is therefore more than likely that for many people with disability, lawn-mowing services are an additional cost attributable to disability.

Finally, there is over-reporting where people attribute to a single year the total cost of an expensive item consumed over a number of years. Such items need to be depreciated at the replacement cost over the useful life of the equipment. While the accounting for this factor is manageable, it is too much to ask respondents to make the appropriate calculations on their own through a written survey.

e. *Conclusions re Surveys*

Section 2 has argued that:

1. interpreting the results of expenditure surveys is problematical unless one understands a lot more about the infrastructure, social security arrangements, financial supports, and preferences of survey respondents;

2. surveys tell nothing about needs, and by and large reflect little more than the incomes of respondents; and

3. expenditure surveys are necessarily subject to both under-reporting and over-reporting, and that there is no way of knowing the net effect of the biases.

Research needs to be conducted into modelling income loss, surveying needs rather than expenditures, and measuring the time costs due to disability. It is important to note that the resources required for quality research in these areas is beyond the capacity of consumer-based peak disability organisations, while the disability expertise required is beyond the capacity of organisations that are not intimately connected to people with disabilities.

3. EMPIRICAL FINDINGS

a. *Average Costs Ordering and Variations in Costs*

The ordering of expenditures from highest cost to lowest cost, for those nominating the cost as positive, as reported by the PDCA Needs Project, the Walsh/DFaCS survey, and the AQA survey, are shown in Table 1. Given the methodological problems outlined above and the different classifications used by the three surveys, it is sufficient to report that:

- personal care costs are at the high end of the expenditure ordering in each survey, except where HACC Home Care is separated from Personal Care in the AQA study, in which case Home Care costs are at the low end of the ordering;
- transport costs figure prominently at the high end of the ordering in each survey, with the PDCA study highlighting the particularly high expenditures on taxis;
- electric wheelchairs and scooters are at the high end of the expenditure ordering, even though other equipment costs are at the lower end after the high capital cost of the equipment is depreciated over the useful life of the equipment;
- medical practitioner costs, pharmaceutical costs and continence costs (each subsidised to some extent by government) are in the middle of the cost orderings, implying that the subsidies are not sufficient to eliminate costs, but sufficient to mitigate costs;
- paramedical and therapy costs, which are not subsidised, are towards the high end of the expenditure ordering; and
- home modifications and furniture are at the higher end of the expenditure ordering for the PDCA survey, but at the lower end for the AQA and Walsh/DFaCS surveys.

Walsh & Chappell (1999) found that the additional costs to the 409 DSP recipients with musculoskeletal impairments averaged only $936 per year, but noted that "*notwithstanding our specific efforts to address the issue of low-frequency high cost groups of people with a disability, we failed to cover these adequately in our population sample*" (p.10) and therefore referred readers to the Hughes & Purdy (1999) survey of AQA members. The latter survey found median annual costs varying from $5,054 for DSP recipients with incomes less than $10,000, to $18,225 for AQA members who had business interests, and $8,783 for wage earners.

Table 1

Unavoidable Expenditures Due to Disability[6]

PDCA Needs Survey	AQA Survey of 200 Members: median annual cost for people with non-zero costs for particular expenditure category	DFaCS Survey of Disability Support Pensioners: mean annualised cost for people with musculoskeletal impairments with non-zero costs for particular expenditure category
Loss of income Housing/Accommodation Personal/Home/Attendant Care/Assistance Home modifications and Furniture Taxis Wheelchairs, scooter Home maintenance, cleaning, garden Therapies and Exercise Transport excluding taxis Continence aids, and associated products Pharmaceuticals and health care products Respite Medical practitioners Food, Diet, Hygiene Wheelchair and Equipment maintenance Aids and Equipment Communications Clothing and footwear Power and Temperature Control	Personal Care ($2,860) Transport ($1,560) Medical and Therapy ($894) Other Medical and Pharmaceutical ($860) Housing Maintenance ($800) PADP, Community Nursing and Home Care ($264) Physical Aids ($225) Telephone ($204) *(Numbers in brackets show the median annual expenditure on the functional expenditure category for those respondents reporting non-zero costs)*	Care – incl. personal care, bathing, travel assistance ($943.80) Home tasks – incl. house cleaning, gardening, house maintenance ($743.60) Travel – incl. vehicle modifications, taxis, community transport, personal travel expenses ($660.40) Uncapped prescriptions ($267.80) Housing modifications – amortised ($265.20) Consumables – e.g. dressings, ointments, batteries, incontinence sheets, pads ($299) Health practitioners ($306.80) Aids and appliances incl. wheelchairs, special clothing, communication aids ($174.20) Furniture – amortised ($91) *(Numbers in brackets show the median annual expenditure on the functional expenditure category for those respondents reporting non-zero costs)*

Sources: PDCA Needs Project: Frisch (2001), Volume 2, Tables 2-3.
AQA Study: Hughes & Purdy (1999), Table 2, p.9.
DFaCS: Walsh & Chappell (1999), Tables 7.1, 7.4, 7.5, 7.6, 7.7, 7.9, 7.11, 7.12, 7.14 and 7.15.

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[6] The categories are shown descending order from expenditures categories with highest additional cost to the categories with lowest additional cost.

It is particularly important to note that for any cost category, a majority of respondents report zero costs, and that as a result, there is a wide variation even within impairment classes. This is confirmed by Hughes and Purdy (1999) where the vast majority of respondents had spinal cord injury, by the sub-sample of DSP recipients with musculoskeletal impairments in Walsh and Chappell (1999), and amongst the respondents who all self-reported as having physical disabilities in Frisch (2001).

This variation is illustrated in Table 2, which reports the mean, upper quartile and lower quartile estimates, and the number of respondents with musculoskeletal impairments who had non-zero costs for the expenditure categories shown. Thus, for example, 20 respondents had home task costs that were greater than $40.00 per fortnight; 20 respondents had home task costs that were less than $11.10 per fortnight; while average fortnightly cost for the 61 respondents with non-zero additional transport costs was $28.60 per fortnight, and 344 had zero additional home task costs.

Table 2

Central tendency estimates of fortnightly expenditures of respondents with musculoskeletal impairments and non-zero costs in the particular category shown

	Number of Respondents with Non-Zero Costs	Mean – $	Upper Quartile – $	Lower Quartile – $
Care Costs	4	36.30	41.30	14.40
Home Tasks	61	28.60	40.00	11.10
Travel	225	25.40	25.00	3.60
Health	90	11.80	8.10	2.00
Consumables	196	11.50	10.60	2.90
Uncapped Prescriptions	254	10.30	12.30	2.50
Housing Modifications	70	10.20	11.00	1.50
Aids and Appliances	180	6.70	4.80	.60
Furniture	147	3.50	3.80	1.70
Capped Prescriptions	254	2.40	3.70	1.00
AGGREGATE	369	36.40	38.90	6.90
Extra Costs	37	499.70	103.20	12.00

Note: 25% of respondents had costs higher than that shown by the upper quartile value and 25% had costs lower than that shown by the lower quartile value.

Source: Walsh & Chappell (1999), Tables 7.1, 7.4, 7.5, 7.6, 7.7, 7.9, 7.11, 7.12, 7.14 and 7.15.

It should be noted that the averages shown in Table 2 are substantially lower than a priori expectations based on consultations with activists with physical disabilities who live and work in the community. The low and biased averages are not surprising however both because expenditures are constrained by the $10,000 per annum DSP budgets of the recipients and because of the small number of low-incidence, high-cost respondents in the sample. A comparison of the AQA and DFaCS estimates in Table 1 shows that the validity of this "voice" is confirmed by the AQA Survey.

Table 2 highlights the inequity of maintaining parity between the Disability Support Pension and the Aged Pension. Only 35 DSP survey respondents with musculoskeletal disabilities had no additional costs due to their disability. By contrast, 92 had costs greater than $38.90 per fortnight, some of whom may have had additional costs as high as $150-$200 per fortnight[7]. Table 2 also highlights the wide variation that exists within expenditure categories even within a single impairment class, i.e. people with musculoskeletal impairments. Walsh and Chappell (1999) show how the variation is compounded across impairment classes.

b. Income and The Demand for Disability Products and Services

The second significant finding of the DFaCS and AQA studies relates to the close correlation between additional costs and income. The AQA survey had a wider variation in income than the DFaCS survey, which surveyed only low-income DSP recipients. The AQA survey found that the proportion of estimated income spent on disability products and services was more than 50% for all income classes, apart from the 41 wage earners for whom the percentage was 23%.

The finding is clear enough, but it can be interpreted in two ways. To some policy-makers, the positive correlation suggests that disability products and services are ordinary goods for which the demand increases as income increases. To most disability sector advocates, however, the positive correlation suggests that people are so desperate to buy products and services that will overcome the dependency created by the social

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[7] The additional costs of the highest-cost respondents is masked by the upper quartile estimate which ignores the high cost "outliers", but with the upper-quartile value ($38.90) so close to the mean ($36.40), the distribution implies some extremely high values at the upper end. It is important to note that in general it is acceptable for central tendency estimates to exclude "outliers", but such estimates are unacceptable where the primary object of interest involves the “outlier” estimates. It is important to note that from a Rawlsian social justice perspective, only the “outliers”, the people who are at greatest disadvantages, are of interest.

environment that they spend half of any increase in income on goods that they would not buy if they did not have a disability.

Policy analysts are concerned that the positive correlation suggests that it will either never be possible to fully offset the additional cost due to disability, or that to do so would be very expensive. This is because they believe that any offset to additional costs will lead to an increase in disposable income to the individual, and that this will lead to a further increase in expenditure on disability products and services, and a consequent further increase in the demand to offset the additional expenditure. They fear that this could lead to a spiral of limitless increasing demands to offset the additional costs due to disability products.

Some policy analysts would go further and cite the positive correlation as evidence that disability products are like other products and services and that expenditure on them is discretionary. Taking a wheelchair as the archetype disability product, they would argue that the positive correlation shows that as income increases, individuals seek improved design, greater function and greater speed etc., in much the same way that able-bodied individuals seek to have improved design, greater function and greater speed as their income increases. They would further argue that these additional features are avoidable and that government has no business subsidising the purchase of avoidable discretionary products and services.

The disability sector's response, focusing on the inaccessibility of the community’s infrastructure, would argue that the capacity of disability products and services to fundamentally increase an individual’s potential to independently participate in society makes such products quite distinct from ordinary products, which merely function to increase convenience at the margin. In particular, it makes such goods investments rather than consumption goods. In short, disability advocates deny that qualitative implications can be drawn from a statistical correlation between income and demand.

Disability advocates are also likely to argue that Governments are continually improving the transport, building and communications infrastructure to create improved design, greater function and greater speed to the able-bodied community, and that to deny people with disability the capacity to independently assess their own investment infrastructure needs because of a statistical relationship involves discriminatory hypocrisy.

4. POLICY BACKGROUND

a. The Current System

A brief general summary of the main benefits and concessions available for adults with disabilities aged between 15–65 is shown below,[8] followed by some observations:

Commonwealth Payments:

Disability Support Pension – financial to persons assessed as with disability; payment equal to the Aged Pension; subject to income and assets test;

Health Care Card – entitlement to Pharmaceutical Benefits Scheme concession and other discounts from various organisations;

Mobility Allowance – fixed annual allowance to persons over 16 who cannot use public transport and who work or undertake voluntary or employment-search activities;

Rent Assistance – rent assistance, subject to upper limit, to persons receiving Centrelink payments who rent premises on private market;

Continence Aids Assistance Scheme (CAAS) – fixed annual allowance to help cover costs for bowel and bladder care items;

Income Tax Rebate – income tax rebate of 20 cents in the $1 on all "medical expenses" over the net payment of $1,500, including wheelchairs, nursing support, personal care equipment and, in some circumstances, personal assistance services.

State Payments and Services (NSW):

Taxi Transport Subsidy Scheme (TTS) – half rate concessions on the prescribed taxi fare, subject to upper limit;

Program of Appliances for Disabled People (PADP) – direct provision of essential medical aids and equipment; subject to means test and assessment for need; organised at regional level through hospital system;

Home and Community Care (HACC) services – e.g. Home Care (including personal care); Home Modification and Maintenance Program; Respite Care; Transport Services; Food Services; Home Nursing; Community Options; Neighbourhood Aid; Dementia Support; Allied Health;

These services generally involve some user co-payment, subject to policy that no person is denied services if they cannot afford to pay;

Eligibility criteria vary across programs and across regions within programs; program structures and management styles vary;

The services are funded under Commonwealth State-Disability Agreement.

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[8] This information is derived from summaries provided by the Paraquad (NSW) information web site http://www.paraquad-nsw.asn.au/info1.html and the Ageing, Disability and Home Care Department (NSW) web site, http://www.add.nsw.gov.au/disability.htm as at March 12, 2001.

Isolated Patients' Travel and Accommodation Assistance Scheme (IPTAAS) – financial assistance towards travel and accommodation costs incurred by people who need to travel more than 200 kms to access specialist medical treatment; with $40 personal travel contribution and subject to maximum $30 per night towards commercial accommodation.

Electricity, Gas, Council Rates, Water and Sewerage, Bank fees – discounts and rebates to holders of Pension Card; generally at discretion of organisation.

Other programs funded under the CSDA program or from State government funds include:

- the **Attendant Care Program,** aimed at providing assistance to perform household management tasks; to persons who live in inappropriate and restrictive institutional environments or who are in danger of institutionalisation;
- Post School Options; Brain Injury Program; Supported Accommodation Initiative; Children's Services Program for Early Intervention; Outside School Hours Support; and
- Independent Living training, Advocacy services, and Information services.

This following observations are pertinent to the benefits and concessions outlined above:

- The Disability Support Pension is the same as the Aged Pension, even though people with disability generally have more non-discretionary expenditures than aged persons. **This parity effectively ignores the additional cost of living faced by people with disability**. Furthermore, the DSP provides the same level of basic income support to people with little non-discretionary additional support costs as it does to people with high non-discretionary additional support costs.
- **Asset tests and income tests for determining eligibility generally do not make any allowance for the additional cost of living due to disability**, except for a recent initiative whereby these extra costs have been recognised and accounted for in NSW's PADP eligibility criteria.
- The Commonwealth provides direct offsets to additional costs for eligible claimants (with employment or age tests) for only a small number of non-discretionary costs (transport and continence items) and expects the **States to manage other non-discretionary additional costs**. States provide some direct offsets to some of the additional costs of living (some equipment, some therapy, some transport, some personal care, some accommodation) to some people with significant additional costs due to disability. In general, there is assistance available to most expenditure areas, but because of inadequate funding, there needs to be rationing, and because there is little systemic management of

the totality of programs, people with little self-advocacy skills and without information about programs and services generally miss out on programs that they need.

- State and Local Governments supplement Commonwealth allowances with a host of schemes, programs and services which vary across States in their eligibility requirements, supports and services provided, and in the levels of funding and co-payment provision. Programs are developed in isolation from other programs or the objectives of other jurisdictions. **Employment participation is discouraged** because means tests are generally such that a person would become ineligible for programs if they earn income, and the income is unlikely to be sufficient to offset the loss of supports and services which results from earning income.

- The level of supports is such that many people **face substantial unavoidable costs on their own personal account despite the vast array of supports.** Co-payments are built into most supports, and although each single user-payment may not appear to be significant, for people with high support needs, the sum of the single payments can add up to a substantial proportion of disposable income. Thus, the CAAS and Mobility Allowances are capped such that most people need to make substantial supplements; the Taxi Transport Subsidy, the rental assistance entitlements, and IPTAAS are explicitly designed to require a significant co-payment; income tax rebates are kept at 20%, implying an 80% co-payment for allowable disability products and services; and HACC services require co-payment as a matter of policy.
- Relatively low consumer contributions are required for PADP, Home Modifications and Maintenance, and the variety of HACC, CSDA Programs and support services offered at the state level, but because the funding of these is grossly inadequate relative to demand, harsh eligibility rules and queuing mechanisms are used to ration the scarce resources. As a result, **most people cannot access these services and are therefore forced to buy the services in the open market using their own resources.**
- There is **limited recognition of the additional cost of workforce participation**. Most workplace equipment, personal care, and modification costs etc. are assumed to be financed by the employer or some outside agency (including limited Commonwealth assistance), though anecdotal evidence suggests than many of these costs are borne by the

person with the disability. The Mobility Allowance is unique in recognising the additional cost of workforce participation for people with mobility impairments.

- The Mobility Allowance is not related to the actual cost of transport to an individual, but is fixed. This means that some people who live close to their workplace and/or work part-time are likely to "profit" from the Mobility Allowance, while others who live a long distance and who work full-time are likely to be significantly out of pocket. Similarly, the CAAS Allowance, being fixed rather than based on need, is **sufficient for some people, but it is inadequate for others.**

Table 3 summarises the assistance and gaps in the provision of supports in terms of the expenditure orderings outlined in Table 1.

b. *The Commonwealth-State Division of Responsibilities*

Reference has been made above to the division of programs between the Commonwealth and the States. In general, in disability policy, the Commonwealth takes on the role of distributing money directly to individuals (DSP, Allowances) while the States arrange and finance the delivery of in-kind products and services (Home Care, taxi vouchers, accommodation, equipment etc.).

Calls for an individualised disability allowance can be seen as a call for a **shift in emphasis from in-kind supports to direct monetary allowances,** as well as a call for a more rational and equitable needs-based system of supports. An enhanced individualised disability allowance would enable people with disabilities to take greater control of their own lives instead of being dependent on service providers and assessors to determine what is needed for greater independence. Many people with disabilities see the emphasis on in-kind supports as characteristic of the charity framework that bedeviled disability in the past, and see a greater emphasis on direct monetary allowances as more consistent with a rights framework.

Table 3

Gaps in the Provision of Supports to Offset the Additional Cost of Living Due to Disability

Additional Cost	Form of Assistance	Gaps
Loss of income	Disability Support Pension (C'wealth)	No recognition of additional costs of disability relative to age; no recognition of variation in costs.
Housing/Accommodation	Rental assistance (C'wealth), Accommodation supports (State)	No recognition of higher cost of accessible homes.
Personal and Home Care	Attendant care (C'wealth), Home care (State)	Limited range of tasks funded; inadequate funding means many people without support.
Home and Furniture modifications	Technical Aid for Disabled (Non-government); Home Modifications and Maintenance (State)	Inadequate funding means many people without support.
Taxis	Capped 50% Taxi Transport Subsidy (State)	Cost still high relative to public transport cost.
Wheelchairs, scooter	PADP (State), 20% Income tax rebate (C'wealth)	Limited by PADP criteria and shortages; discourage workforce participation.
Home maintenance, cleaning, garden	HACC (State)	Limited range of tasks funded; funding inadequate.
Therapies and Exercise	Provided through services and schools (State)	Inadequate funding; mainly limited to children.
Transport excluding taxis	$1484.60 mobility allowance (C'wealth)	Mobility Allowance does not recognise wide variations in costs; Inadequate IPTAAS funding.
Continence aids, associated products	$450 limit (C'wealth)	CAAS does not recognise wide variation in costs.
Pharmaceuticals and health care	Pharmaceutical benefits scheme (C'wealth)	Satisfactory.
Respite	Respite and Recreation (State)	Inadequate funding.
Medical and hospital	Medicare system, private health insurance limited	Satisfactory; disadvantaged by "averaging" methods.
Food, Diet, Hygiene	Meals on Wheels (State)	No funding for special diets
Wheelchair/Equipment Maintenance	PADP (State), 20% Income tax rebate (C'wealth)	Limited by criteria and funding shortfalls; discourage workforce participation.
Aids and Equipment	PADP (State), 20% Income tax rebate (C'wealth)	
Communications	Telephone allowance (C'wealth); PADP (State)	
Clothing and footwear	No program	No funding
Power and Temperature Control	Discounts to Card holders (non-government)	Income earners with disabilities ineligible.

c. *The McClure Report*

The principal positive contributions of the McClure Report from a disability perspective are the recognition that people with disabilities have additional costs of living as a result of their disability, and the recognition that there are additional costs to participating in the workforce. A second positive contribution appears to be the focus on tailoring income support programs to individual needs instead of to broad categories.

The Report suggested a tripartite separation of support into three categories:

- income support aimed at general disadvantage;
- support to offset the additional cost of living resulting from disability (or other disadvantage); and
- employment participation support.

These contributions appear to be a small step forward, but they do little more than acknowledge what people with disability have been saying for a long time.

Overall, the McClure Report is a missed opportunity. McClure's brief was to examine the income support system, with particular reference to creating more incentives for employment participation, and to make the income support system more efficient.

Yet because the Report failed to comprehensively study the total disability support picture, it **failed to recognise the role of the States in discouraging employment participation, and it failed to create a structure for rationalising the complementary Commonwealth and State supports.** Although the Report alluded to the negative impact on workforce participation of high taper rates for income support arrangements, it focused only on high Commonwealth taper rates. It failed to recognise that 100% effective taper rates apply for those State programs where income thresholds are used as an eligibility criterion, and where earning above the threshold leads to withdrawal of support. It failed to recognise that taper rates are additive, so that a 100% taper rate for in-kind services on top of a 40% taper rate on the DSP is equivalent to a 140% marginal income tax rate.[9] Although the Report alluded to the difficulties of navigating the various programs and supports, it only focused on the

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[9] Frisch (1999b) calculated marginal tax rates to be as high as 148% at $25,000 incomes by accounting for Disability Support Pension taper rates, the loss of benefits from the state PADP program, and the additional cost transport to and from work.

Commonwealth programs, and failed to examine how in-kind services provided at the State level dovetailed with Commonwealth programs.

The McClure Report also failed to examine the environmental background behind the need for disability supports, and therefore failed to integrate the need for more comprehensive Disability Standards in Transport, Building, Education, Employment and Communication into either its employment participation vision, or into its income support vision. No improvement in employment participation by people with disabilities can be expected until **each of the basic building blocks** are in place, since each block is necessary and none by itself is sufficient. Thus, for example, there is little value to an accessible built environment unless the transport system is accessible, and there is little value to an accessible transport system unless the built environment is accessible, and there is little value to employment participation programs until both the transport system and buildings are accessible and affordable.

The McClure Report recommended a disability income support package made up of a base support, a cost of living supplement, and a further cost of workforce participation supplement. This seems to be a step forward, but the step involves nothing new in that the components are already in place. Thus:

(a) the DSP is equivalent to the base support;

(b) the Mobility and CAAS Allowances, the PBS and Rental Assistance Scheme, and funding of Attendant Care and CSDA programs can be viewed as cost-of-living supplements; and

(c) various employment services and one-off subsidies to employers can be seen as participation supplements – albeit aimed at the employer rather than the individual.

While it is unlikely that the existing system is the type of system that McClure had in mind, the lack of specificity evident in **the final Report means that the McClure recommendations are not inconsistent with the status quo.** To the extent, therefore, that the McClure recommendations are already in place, the McClure Report can be seen as a missed opportunity.

5. POLICY OPTIONS

Six options for offsetting the additional cost of living due to disability are discussed below. They are:

1. maintain the status quo at both Commonwealth and State levels, with some additional funding to enhance equity;

2a. increase the Disability Support Pension (DSP) relative to the Aged Pension;

2b. introduce DSP Tiers to account for extent of disability;

3a. increase and Extend Cost of Living Allowances;

3b. Tier Cost of Living Allowance Ranges to account for extent of disability;

3. Invoice/Receipts Based Subsidies for Verified Scheduled Products and Services.

The focus of attention is Commonwealth payments. These options are discussed in light of five standard and relatively well-defined criteria. No program can satisfy all criteria, partly because criteria can be inconsistent with one another. Ideally, programs should as much as possible be:

- **Equitable** in ensuring that people in similar positions are treated equally, and that relativities between people are in accord with social justice values.
- **Administratively simple and inexpensive** to implement – from the point of view of bureaucrats, assessors and government.
- **Dignified and simple** with respect to assessment procedures and tools – from the point of view of people with disability.
- **Transparent and accountable** – ensuring that entitlements and eligibility are unambiguous and verifiable in definition and understood through the community.
- **Economically efficient** in terms of encouraging workforce and social participation, and with minimal side-effects.

Option 1: Status Quo

Do nothing, i.e. maintain the current system of pegging the DSP to the Aged Pension, and maintain the current system of disability allowances and State supports.

Equity

Current arrangements at the Commonwealth level only recognise the extra costs associated with transport to work and incontinence, and ignores the other costs faced by people with disability. These additional costs are implicitly assumed to be dealt with by the States.

At the State level, however, the provision of in-kind product and service delivery is such that some people are over-serviced even as most people are under-serviced, with the result that most people with disability, including most people with severe and profound disability, finance most of the additional costs associated with disability from their own resources.

Administrative Simplicity and Expense

At the Commonwealth level, assessments are administratively simple. Once a person is deemed eligible for the DSP, arrangements for payment of pensions and allowances are made. Recipients are responsible for informing Centrelink of any change in circumstances. Annual reminders of this responsibility are sent to recipients. The Mobility and CAAS allowances are applied for, and simple assessment tools are used to determine eligibility for these.

By contrast, at the State level there is a thick layer of "gatekeepers" implementing complex and under-funded in-kind services, which stumble from crisis to crisis because of desperately inadequate funding. A thick overlay of middle managers is required for the continual reviews made necessary by this crisis management.

Dignity of Assessment

The assessment tools determining eligibility for DSP and the Mobility and CAAS allowance eligibility are not overly obtrusive, though forms are long and often need assistance.

By contrast, at the State level, the receipt of in-kind service usually involves substantial negotiation and personal interventions, which are demeaning and frustrating. Persistence, assertiveness, and diplomatic skills are too often needed if a person wants to receive a service. People with severe and profound activity restriction, and parents of children complain bitterly about Home Care, Taxis, PADP, and Therapy for Children, but the complaints are seldom formalised for fear of retribution from service providers.

Transparency and Accountability

At the Commonwealth level, eligibility criteria for the DSP and allowances, and the review and complaint-handling procedures are relatively clear; and entitlements are fairly well promoted and understood, though people with “complex” impairments and people with “invisible” disabilities often fall between programs. Fraud is verifiable and prosecuted. Eligibility and means tests, and the low level of the DSP ensure that there is little advantage to being a DSP recipient.

By contrast, at the State level, eligibility criteria, and review and complaint procedures are generally unclear, and there is a high degree of negotiation and skill needed to find out about services and clarify entitlements.

Employment Effect

The effective marginal “tax” rate (or taper rate) for a couple on the DSP is 20%, while for a single person it is 40%. These rates do little to encourage employment participation, and for a single person are significantly higher than the marginal tax rate deemed necessary to encourage other low-income workers to participate in the workforce. The lack of a means test on Commonwealth allowances is the only redeeming feature of the current arrangements, since it makes the employment-discouragement less than it would be if allowances were means-tested.

By contrast, the means tests for provision of State services means that people lose services if their means are known or believed to have increased their income or assets to a level above the eligibility threshold. This discourages both workforce participation and saving. The lack of a taper rate means that the effective marginal “tax” rate on income earned near income thresholds can be greater 100%.

> *Conclusion 1: The current system is inequitable and inefficient. Its only advantage is its simplicity at the Commonwealth level, but even this advantage is offset by the complexity, expense and inefficiency of the State system of supports.*

Option 2a: Disability Cost of Living Allowance separated from Income and Employment Participation Support Allowance

a) ***Grant an "Income and Employment Participation Support Allowance" (IEPSA) to persons with disabilities who do not have significant additional costs of living due to disability but are disadvantaged in employment opportunities. The IEPSA would be a blend of the support and income tax advantages offered to long-term Unemployed Persons and Aged Persons.***

b) ***Introduce a separate Disability Cost of Living Allowance (DCoLA) to people with disability who have significant additional costs of living due to disability. The Allowance could be pegged at 60% of average wage instead of the current 25%.***

Persons with impairment and **without** significant additional costs have greater employment participation needs than long-term unemployed persons without an impairment, but income supports needs might not be significantly different. These additional non-income needs include increased consideration of the need for flexibility in employment times, employer supports at the workplace, and training and employment placement issues. But if there are not significant additional due to an impairment, there seems little basis to offering a DCoLA to a person with impairment simply because they have an impairment.

There are, however, good grounds for applying the same income tax concessions to all unemployed self-funded people with disability as that offered to all self-funded Aged Persons over the age of 65.[10] The same income tax rates ought to apply whether or not the person has additional costs of living due to disability, and independent of the ownership of assets and/or ability to earn income occasionally for short periods. Because people with disability are likely to face greater difficulties in employment than long-term unemployed persons without disability, people with disability are more likely to face permanent unemployment. If they have accumulated wealth during their working years and can no longer find employment, or if they have inherited assets that make them ineligible for the means-tested IEPSA, there is no rational justification for taxing them differently from the way self-funded permanently retired

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[10] Following the Commonwealth's 2001 Budget, significant tax advantages will be available to self-funded Aged Persons over the age of 65 and not necessarily with disability (including those too wealthy to be receiving an Aged Persons Pension). These income tax advantages have not been extended to self-funded people with

persons (i.e. over the age of 65) are taxed. The justification for taxing people with disabilities at the same rate as self-funded retirees over the age of 65 is strengthened to the extent that younger persons with disability have a shorter life expectancy than people of the same age cohort without disability.

The DCoLA would be pegged at a higher rate than the current Aged Pension/DSP because people with disability face higher non-discretionary costs than do aged persons without disability. Whether the average additional cost of non-discretionary goods and services is 45% of average wage or 75% of average wage is an empirical issue.

In order to avoid discouraging employment participation and saving by people with disability, the DCLA should not be means-tested.

Table 4 below summarises the initiatives outlined above in terms of whether or not a person is unemployed, has additional costs due to disability, or has means.

Table 4

Equity Initiatives for People with Disabilities

With additional costs	*Employed*	*With means*	*DCoLA*	*New*
		Without means	*DCoLA*	*New*
	Unemployed	*With means*	*DCoLA, Tax concessions*	*New*
		Without means	*DCoLA, IEPSA*	*Replace DSP*
Without Additional costs	*Employed*	*With means*	*Nothing*	
		Without means	*Nothing*	
	Unemployed	*With means*	*Tax concessions*	*New*
		Without means	*IEPSA*	*Replace DSP*

Equity

Abandoning the DSP, introduction of the IEPSA and DCoLA, and offering self-funded unemployed people with disabilities the same tax concessions as those offered to self-funded retirees aged over 65 would be a marginal recognition of both the additional cost of living due to disability and the permanency of their unemployment prospects. A flat rate (or single-tier)

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disability under the age of 65, despite the permanency of their unemployment prospects, and despite the higher cost of living faced by many people with disabilities.

DCoLA would continue to ignore the wide variation in unavoidable costs across individuals, so people with high support costs would continue to finance most of the additional costs due to disability from their own resources.

Administrative Simplicity and Expense

Administration of an IEPSA and DCoLA, and granting of income tax concessions to self-funded long-term unemployed people with disability would be marginally more complex than the current system because it would be necessary to have separate assessments to determine:

i. whether or not a person has a disability;
ii. whether or not a person's lack of employment participation is permanent or temporary;
iii. whether or not they have assets or income;
iv. if with a disability, whether or not there are significant additional costs due to the disability.

It should be noted that the first two assessment tools would not be significantly different from those already in place for the DSP and employment placement services, and the third is already implicitly in place by means of tax returns.

The additional expenditure impact of Option 2a is an empirical question. The additional budget impact would depend on:

- the size of the DCoLA and the IESPA;
- the number of self-funded unemployed people with disability to whom the tax concessions are granted;
- the thresholds at which eligibility for DCLA and IESPA are set; and
- the revenue effect of increased employment participation.

Dignity of Assessment

There is no reason to expect that the assessments for IESPA and employment status would be significantly different from the assessments that unemployed people with disability face currently. The additional cost assessment would be new, but the assessment need not be objectionably intrusive, and it is unlikely that there would be substantial objection if it led to significant assistance towards offsetting the additional cost of living due to disability.

Transparency and Accountability

Separating the disability, the cost of living, and the employment participation issues would enable significantly improved targeting of needs, and therefore a greater sense of accountability and transparency. The accountability and transparency would also depend on the robustness and accuracy of assessment tools used, but since many of the assessment tools are already in use and tested, there is no reason to expect any deterioration from this source.

Employment Effect

Improved targeting of payments to needs, and greater offsets to the additional costs due to disability would encourage greater employment participation, to the extent that the offsets would be used to purchase goods and services that would be used for increased participation opportunities. The size of this effect is an empirical question, but it is an effect that cannot be ignored.

> *Conclusion 2a:There would be an improvement in equity and employment participation if the current Disability Support Pension was replaced by an*
>
> - *Income and Employment Participation Support Allowance;*
> - *a single-tier Disability Cost of Living Allowance; and*
> - *Income Tax concessions to self-funded unemployed long-term unemployed people with disability.*
>
> *People with high support costs would not be significantly better off.*

Option 2b: Tiered Disability Cost of Living Allowance

Introduce tiered DCoLA rates instead of the single DCoLA rate of Option 2a. The rates would be determined by a "score" measuring the unavoidable additional cost of living due to disability.

Individuals with the lowest scores would be granted a low allowance level, while individuals with the highest scores would receive the highest levels.

The assessment tool that determined the "score" would ideally be focused on the additional cost of living due to disability rather than on impairment, because empirical evidence has shown the relationship between impairment and additional cost to be weak.

Toto create equity, a greater number of tiers would be more equitable than a small number because it would enable a better targeting of payments to need. A greater number of tiers would also be more costly to administer and more intrusive because the assessment tool would need to be more complex. Four or five tiers would probably strike the right balance between equity and cost.

Equity

A tiered structure of DCoLA rates, based on additional costs due to disability, would be more equitable than the current payment or a single-tier DCoLA structure. Equity would be seriously compromised if there were less than four tiers, or if "impairment" were extensively used as an indicator of "additional cost".

"Documented expenditures" as evidence of additional cost would also compromise equity for two reasons. Firstly, documented expenditure would disadvantage people whose disability-induced poverty makes it impossible to buy needed goods and services. Secondly, actual expenditures congeal preference factors as opposed to uniquely need factors, and this would mean that a person with expensive tastes would document higher expenditure simply because of their taste rather than their need.

Administrative Simplicity and Expense

A robust, equitable, dignified and accurate assessment tool to measure the unavoidable additional cost of living due to disability would be expensive to design, test and maintain. The issues noted in Section 2 would be as relevant for an assessment tool as for an expenditure survey, i.e. environmental factors, subjective factors and ambiguities need to be accounted for, and need must be distinguished from ability to pay.

The cost of designing, testing and maintaining an assessment tool will vary with the number of tiers. Thus, a two-tier structure would not need the assessment tool to be as finely tuned in its ability to discriminate between tiers as would a five-tier structure, and it would not therefore be as expensive.

A poorly designed assessment tool might be less expensive than a high-quality assessment tool, but this would be a false economy since it would lead to costly administrative appeals as people appeal the tier to which the tool assigns them.

Dignity of Assessment

A more complex assessment tool would be more obtrusive and more complicated than the assessment tool currently used. Assessment is invariably always unwelcome, but most people with high additional costs due to their disability would not feel overly burdened by a more complex assessment tool, provided that the increased payments more than outweighed the greater inconvenience and obtrusion. It would be important to ensure that support and advocacy be offered through the assessment process.

Transparency and Accountability

The transparency and accountability of a tiered structure depends on the quality of the assessment tool. A poor assessment tool creates uncertainty and greater use of personal discretion by assessors and bureaucrats. Such personal discretion diminishes accountability and transparency.

Employment Effects

A more finely targeted DCoLA would allow people to buy more disability goods and services that increased participation opportunities.

Conclusion 2b:A tiered Disability Cost of Living Allowance would involve a significant and substantial improvement in the standard of living of people with high additional non-discretionary costs due to disability.

Fewer than four tiers would compromise equity significantly, while more than six tiers would involve too much complexity, and would therefore compromise both efficiency and acceptability.

Option 3a: Extend Range of Functions for which an Allowance is Provided

Extend the range of disability allowances for specific purposes beyond the existing CAAS and Mobility Allowances to also include allowances that support independent living and personal care, and provide for technical aids and appliances, access to information and communication, extraordinary health care and therapy care, and accommodation (Cooper, 1993).

The Mobility Allowance provides $ 1,510 per year (without a means test) to people with disabilities who are in paid employment, voluntary work, vocational training, or a combination of paid work and training, and who are unable to use public transport without substantial assistance, while the CAAS Allowance provides a voucher to the value of $450 per year to people with a permanent disability-related continence condition, who are of working age and in receipt of specific income-support payments. These are adequate for many people, but inadequate for many others, and exclusively focused on employment participation, thereby excluding people out of the workforce, aged persons, and students in non-vocational courses). Despite the limitations, these Allowances serve as a relatively inexpensive and unobtrusive model for the provision of Allowances for other needs.

The benefits of an extended range of allowances over the current system of in-kind provision of goods and services are:

- it establishes allowances as a matter of individual entitlement instead of service-provider offering – thereby giving individuals greater security and making them less dependent on service-provider budget allocation processes and the non-transparent rationing devices;

- it enables people to make their own purchase choices instead of being dependent on assessors – thereby encouraging more efficient buying decisions in a what would become a more competitive market in the supply of disability goods and services; and
- it gives individuals greater control of their purchases and therefore of their lives.

The disadvantages of an extended range of allowances are that:

- some people are less able (as a result of their impairment) to make self-interested purchasing decisions, do not have access to an advocate, have inadequate personal access to information, and/or do not have geographical access to a sufficiently wide choice of products with which to make informed choices.

Equity

A single-tier system of functional allowances would be more equitable than the current system for people with needs who are currently unable to access in-kind services. But to the extent that the allowances substituted for in-kind services, it would disadvantage people with high support needs who receive the appropriate quantity and quality of in-kind services, and it would also disadvantage people who would not be able to take advantage of the greater purchasing power offered by make functional allowances.

Administrative Simplicity and Expense

The administration of a system of allowances would be more expensive than the cost under current arrangements simply because of the wider range of functions that would need to be assessed. The assessment tools would not need to be overly complex since the tools would be quite specifically targeted to the verifiable functional disability or to the additional costs pertaining to specific functional disabilities.

Dignity of Assessment

There are few complaints from recipients about the assessment process involved with the Mobility Allowance and CAAS Allowance, both because the assessment tools are simple and because there are only two assessments.

A wider range of assessments could, however, become overly obtrusive, particularly if the assessments are undertaken at different points of time by different "gatekeepers".

Transparency and Accountability

In general, there is greater accountability with a voucher system, where vouchers can only be used as means of payment with registered product and service providers. There is less accountability where cash payments are made, because the cash can be used for purposes different to that intended. Thus, there is less accountability in how the Mobility Allowance is used by recipients than there is for the more voucher-oriented CAAS Allowance.

The appropriateness of a cash or voucher system depends on the nature and industry structure of the product or service for which the allowance is intended. Because there are relatively few suppliers of incontinence products, the administration of a voucher system for CAAS is not prohibitively expensive. But because there are thousands of mobility service providers, a voucher system applied to the Mobility Allowance would be prohibitively expensive since thousands of distribution outlets would each presumably only have a small number of vouchers.

It is impossible, therefore, to determine the transparency and accountability characteristics independently of the program characteristics and administration.

Employment Effects

The Mobility and CAAS allowances do not discourage employment participation, both because the allowances are not means-tested and because workforce participation is a condition for receipt of the allowance. This contrasts sharply with the existing PADP system, for example, where means tests directly discourage employment participation.

Workforce participation could be further encouraged if cash allowances and/or vouchers were offered for services and products supplied at the workplace or in education/training, or, if employment participation allowances were part of a revamped allowance package.

> *Conclusion 3a:Extension of the range of functional disability allowances to account for the additional costs of independent living and personal care, technical aids and appliances, access to information and communication, extraordinary health care and therapy care, and accommodation would enhance the equity of the current system. It would however disadvantage people with high support needs, and it would not advantage of people who prefer in-kind services to cash.*

Option 3b: Tiered Extended Disability Allowances

Vary the rates at which the Mobility and CAAS Allowances and the extended range of Allowances referred to in Option 3a are applied. People with greater additional costs due to disability receive more than do those with fewer additional costs.

Option 3b is an extension of Option 3a, in much the same way that Option 2b is an extension of Option 2a. There would be a broadening of the range of products and services whose costs are offset, but instead of having a single-tier allowance, there would be a number of tiers. Whether an individual would be in the high or the low tier would depend on assessment. There is no reason to expect that an individual would be in the same tier for different allowances, and there is no reason to expect that an individual will receive each functional allowance, though undoubtedly there would be a few people with multiple impairments who would receive each allowance.

A two-tier structure for each allowance would more than likely be equivalent to the four-tier structure of Option 2b because a person with high additional costs in more than one or two functional areas would probably be at the fourth tier of Option 2b, while a person with high additional costs in one functional area and low additional costs in another would probably be in the third tier in terms of Option 2b, while a person with low additional costs in only one functional area would be in the lowest tier in terms of Option 2b.

Equity

A tiered range of allowances recognises that there are variations across individuals and impairment groups in the additional cost of equipment, therapy, personal care, communications etc., and it would therefore be more equitable than any flat allowance structure. A tiered range of allowances could target the additional costs due to disability more closely than the other options considered above.

But people with high support needs who currently receive the appropriate quantity and quality of in-kind services would be disadvantaged by a two-tier structure of extended allowances if the allowances did not fully cover the cost of needed goods and services that are currently available through in-kind services. Substitution of an extended range of tiered allowances for cash would also disadvantage people who would not, for the reasons outlined in the discussion of Option 3a, be able to take advantage of the greater purchasing power offered by functional allowances.

Thus, although there are improvements in equity with an extended range of two-tiered allowances, these improvements are conditional on a strong advocacy support base, and guarantees that a substitution of cash for in-kind services would not disadvantage people who currently receive a high degree of quality in-kind support from service providers.

Administrative Simplicity and Expense

While a two-tier assessment tool would be more expensive and more complex than a single-tier tool, it is unlikely to be prohibitive, and it may arguably be less expensive and less complex than the assessment tool for Option 2b. Whether Option 3b would be more or less expensive and complex than Option 3a is an empirical issue that would depend on the design of assessment tools.

The assessment for Option 3b might be less expensive and less complex because the assessment tool for a multi-tiered DCoLA (Option 2b) would need to assess the full range of functions, and it would need to assign finely tuned scores, while the assessment tool for an extended range of two-tiered functional allowances (Option 3b) could more easily avoid allowances that are irrelevant, and the scoring/assignment task would not need to be as finely tuned. This advantage of Option 3b over Option 2b would be lost as the number of tiers for the functional allowances increased.

Dignity of Assessment

The assessment tool for an extended range of two-tiered functional allowances would not be significantly more complex or intrusive than single-tiered allowances, but, as outlined above, assessment of a wide range of assessments could become overly complex if the assessments are undertaken at different points of time by different “gatekeepers”.

Transparency and Accountability

Tiered allowances would involve marginally less accountability than with a single allowance because of the inevitable ambiguities involved in measuring “degree of severity” or “additional unavoidable”. Ambiguities necessarily lead to increased discretion on the part of gatekeepers, and a consequent diminution of accountability and transparency.

Employment Effects

As for Option 3a, workforce participation would be encouraged if cash allowances and/or vouchers were offered for services and products supplied at the workplace or in education/training, or more specifically, if a specific employment participation allowance were part of a revamped allowance package.

Ensuring that allowances are not subject to means tests would also ensure that employment participation and savings are not discouraged.

> *Conclusion 3b:Subjecting an extended range of functional disability allowances to a two-tier structure, where people with high additional costs for the function receive a higher allowance than those with lower additional costs, would enhance equity by comparison with a single-tier allowance.*
>
> *Substitution of several two-tier allowances for the current regime of in-kind goods and services provision would be to the advantage of many people with high additional costs, though it could disadvantage the small number of people who currently receive an adequate quantity and quality of in-kind goods and services. Substitution of cash for in-kind services would also not be to the advantage of people who have difficulty managing money independently. Offsetting these two problems could be expensive.*

Option 4: Reimburse Self-Assessed Additional Costs

In an ideal world, the community would accept the legitimacy of offsetting the additional unavoidable costs due to a person's disability. In an ideal world, people with disabilities would be able to distinguish the avoidable costs due to disability from the unavoidable costs. In an ideal world, neither people with disabilities nor people without disabilities seek to take advantage of programs that sought to offset the additional unavoidable costs due to disability. In an ideal world, people with disabilities would be easily identifiable, and there would be no prejudice or discrimination based on such identification.

In such an ideal world, it would be possible for the people with disabilities to present invoices from a product or service provider to a Centrelink or Medicare office, and the office would fully meet the cost of the product or service. The invoice/receipt would show the additional unavoidable costs due to disability, and the individual would bear none of the additional unavoidable cost due to disability.

Unfortunately, we do not live in an ideal world. Unavoidable additional costs are not easily distinguishable from avoidable costs. People are sufficiently selfish to make it reasonable to expect that both people with disabilities and people without disabilities would seek to take advantage of a system where payments were made on the basis of self-assessment. Community values are not in accord with the proposition that society ought to fully underwrite a reasonable standard of living for people disadvantaged by a past event.

As a result, an unconstrained self-assessment procedure would not be politically acceptable to the community unless constraints and rules were placed on self-assessment-type programs. These would include:

- limiting the schedule of products and services that could be presented;
- audits and penalties to minimise fraud;
- caps and floors on payments to limit community expenditures;
- co-payments to control total expenditures, and to encourage economy and discourage inefficiency and "waste"; and
- assessment tools to distinguish legitimate claimants from illegitimate claimants.

The able-bodied community's acceptance of a self-assessment process would depend very much on the details of the rules and constraints governing the process. Because a self-assessment process would be a radical departure from current practice, it is reasonable to expect that the community consultation, community education, and research. required to develop the details of a self-assessment-type program would take a long time to develop. The details would not only need to balance the interests of the able-bodied community and the disability community, but also the interests of the various sections of the disability community. Development of the details of this type of system would delay implementation of a more equitable allowance system for years.

The disability community's acceptance of a self-assessment process would also depend very much on the details of the rules and constraints. In this regard, it should be noted that the interests of people with high additional costs is likely to be inconsistent with the interests of people with low additional costs; the interests of people with disability who are in employment are likely to be different to the interests of people who are unemployed; and the interests of people with disabilities who are satisfied with status quo provision of in-kind services would be inconsistent with the interests of people with disabilities who want more control over their expenditures and who therefore prefer cash to in-kind provision of services.

Although a self-assessment system is ideal on paper, it would be administratively expensive, complex and intrusive in practice.

> *Conclusion 4: While reimbursement of self-assessed additional costs would be the ideal means of offsetting the expensive additional costs due to disability, the implementation of such a system would be overly complex.*

6. RECOMMENDATIONS

1. In view of the methodological problems that plague expenditure surveys seeking to measure the additional cost of living due to disability, alternative methods need to be used. Options include desk-based "budget needs" estimates, along the lines conducted by Saunders et al. (1998) and experience-based measures based on pilot programs testing the impact of alternative budget constraints. The small sample size of people within any particular cluster will always inhibit sampling techniques.

2. To account for the additional costs of living due to disability, the Disability Support Pension needs to be replaced by an *Income and Employment Participation Support Allowance (IEPSA)* and a *Disability Cost of Living Allowance (DCoLA).*

The IEPSA should be granted to all long-term unemployed people with disability and without means, irrespective of whether or not they face additional costs due to disability. Because the needs of long-term unemployed people with disability are often different from the needs of long-term unemployed people without disability, the income and employment participation support arrangement should also be different. People with disability need greater flexibility in working hours, as well as workplace equipment and architectural layout modifications.

The DCoLA should be granted without means tests to all people with disability who face additional costs of living (whether employed or unemployed). Only people with disability who face additional costs due to their disability should receive DCoLA.

The DCoLA should be structured with four tiers. People applying for DCoLA should be assessed for the additional cost they face as a result of their disability. Those people who face a low additional cost would be granted the lowest allowance rate, while those facing very high additional costs would be granted the highest allowance rate.

3. As a matter of equity and to take into account the additional costs of disability faced by employed people with disability, the tax concessions made available to self-funded retirees aged over 65 should be extended to self-funded unemployed people with disability. People with disability who have accumulated capital before acquiring a disability, or received a compensation payment, or been given a bequest from a relative, and who choose to stay out of

the workforce (due to their disability), and who receive no other assistance from government, should, as a matter of equity, be given the same tax concession as aged persons who have accumulated capital, choose to stay out of the workforce because of age, and who receive no other direct government assistance.

4. For equity and to avoid discouraging workforce participation and savings, asset and income tests for allowances, pensions and the provision of in-kind services at both the Commonwealth and State levels should account for the additional costs of living due to disability as well as the additional cost of participating in the workforce.

5. To improve accountability, transparency and to encourage efficiency in the broad sense of encouraging workforce participation, the next Commonwealth-State Disability Agreement should seek to integrate Commonwealth and State systems to ensure that there are no unintended effects that discourage workforce participation. This includes integration of income and asset tests between Commonwealth and State jurisdictions, and accounting for the additional costs of living (including co-payments for services) due to disability.

6. Government authorities need to put more effort into ensuring that the community infrastructure does not discriminate (overtly or covertly, directly or indirectly) against people with disabilities. Such discrimination increases the cost of living and induces poverty by decreasing employment opportunities and increasing the cost of goods and services. Critical infrastructure, which is currently lagging seriously in terms of access, includes buildings, transport, communication and financial services.

7. Increased research is needed to find the most equitable and efficient means of encouraging employers to provide more stable and long-term career opportunities to people with disabilities. Best-practice methods from the US and Europe need to be fully explored. Increased research is also needed on measuring the additional needs of people with disability, as well as the opportunity costs. Income-constrained expenditure surveys should be discontinued.

BIBLIOGRAPHY

Anderson, P., & Wisener, K., 1997, *Open employment services for people with disabilities 1995,* Australian Institute of Health and Welfare, AGPS, Canberra, ACT.

Andrews, R.J., 1993, *Additional costs of education and training for people with disabilities*, Department of Employment, Education and Training. AGPS, Canberra, ACT.

Australian Council of Social Service, 1998, *Income support for people with disabilities: Response to Social Security Review Issues Paper No. 5*, Surry Hills, N.S.W.

Cass, B, Gibson F., & Tito, F., 1998, 'Towards Enabling Policies: Income Support for People with Disabilities', *Social Security Review*, Issues Paper No. 5, Dept of Social Security, Woden, ACT.

Cooper, M. 1993, 'Targeting a Disability Allowance', *Australian Disability Review: Journal of the Disability Advisory Council of Australia*, No 2, 1993, pp.73 +

Dickson, H.G., & Webster, I.W., 1992, The Disability Support Pension and the "new math", *The Medical Journal of Australia*, Vol 156, May 18, 1992, pp. 676–677.

Doenau, S., 1983, *Breaking the barriers, USA: Towards a New Deal for People with Disabilities,* Galleon Publications, Pennant Hills, N.S.W.

Egan, S., 1997, *Cost of Disability: Submission to Department of Social Security Study,* Physical Disability Council of Australia, Brisbane, [Online: http://www.ozemail.com.au/~pdca]

Frisch, J., 1999a, *The Benefits of Accessible Buildings and Transport*, Physical Disability Council of NSW, Sydney, NSW, [Online: http://www.pdcnsw.org.au/Access.pdf] and http://www.members.optushome.com.au/jackfrisch]

Frisch, J., 1999b, *Discussion Paper on Welfare Reform*, Physical Disability Council of NSW, Sydney, N.S.W., [Online: http://www.pdcnsw.org.au/WelfareReform.pdf and http://www.members.optushome.com.au/jackfrisch]

Frisch, J., 2000a, *The Economics of Disability, Measuring Benefits and Measuring Adverse Effects*, Working Paper delivered for Disability and Law Conference, Canberra, ACT, [Online: http://www.members.optushome.com.au/jackfrisch]

Frisch, J., 2000b, *Response to Interim Report of Reference Group on Welfare Reform*, Physical Disability Council of NSW, Sydney, NSW [Online: http://www.pdcnsw.org.au/WelfareResponse.pdf] and http://www.members.optushome.com.au/jackfrisch]

Frisch, J., 2001, *The Voice of People with Physical Disability,* Volumes 1 and 2, Physical Disability Council of Australia, Brisbane, [Online: http://www.ozemail.com.au/~pdca and http://www.members.optushome.com.au/jackfrisch]

Graham, S. & Stapleton, C. 1990, *The extra costs of participation in work, education or training for people with disabilities: an exploratory study*, Kensington, N.S.W., Social Policy Research Centre, University of New South Wales.

Hughes, D. & Purdy, F., 1999, A *Survey of the Unavoidable Cost of Disability Among 200 People with Quadriplegia,* The Australian Quadriplegic Association, Sydney.

Parsons, I., 1994, *Oliver Twist Has Asked For More: The Politics and Practice of Getting Justice for People with Disabilities,* Villamanta Publishing Service, Geelong, Vic.

Purdon, S., & Noble, J., 2000, *Opening the door to employment for people with disabilities: a skill development program for employment professionals,* Diversity@work, Melbourne, Vic.

Rawls, J., 1971, *A Theory of Justice*, Oxford University Press, Oxford.

Reference Group on Welfare Reform, 2000, *Participation Support for a More Equitable Society, Final Report*, Canberra, ACT.

Ronalds, C. 1991, *National employment initiatives for people with Disabilities: Report of the National Consultations with People with a Disability*, Australian Govt. Pub. Service, Canberra, ACT.

Saunders, P., Chalmers, J., McHugh, M., Murray C., Bittman M., & Bradbury, B., 1998, *Development of Indicative Budget Standards for Australia*, Policy Research Paper Number 74 – Social Policy Research Centre (UNSW), Department of Social Security, AGPS, Canberra ACT.

Shapiro, J. P, 1994, *No pity: people with disabilities forging a new civil rights movement,* New York Times Books, New York.

Walsh, J. & Chappell, P.,1999, *Cost of Disability Survey Stages 2 and 3 – Demonstration of Relationship: Severity of Disability v Cost,* Department of Family and Community Services, AGPS, Canberra, ACT.