Counting the Costs of Blindness:
Lessons for a Cost of Disability Allowance

- by Maryanne Diamond, Executive Officer, Blind Citizens Australia, for the Australian Social Policy Conference, 10th July 2003, Council Chambers, Kensington Campus, University of New South Wales.

Introduction

Blind Citizens Australia is the peak body for people who are blind or vision impaired. We are the only national blindness organisation that is controlled by people who are blind.

The need for a cost of disability allowance is a key issue for us. The Government’s recent consultation paper on the income support system, Building a simpler system to help jobless families and individuals, proposed that a cost of disability allowance be introduced but offered little detail about how it might work.\(^1\)

People who are blind have received a non means tested pension since 1954. This has effectively meant that blind people who work have received a cost of disability allowance. This provides us with a unique opportunity to explore the impact of a cost of disability allowance on the social inclusion of people who are blind.

This presentation will look at this issue and will explore conceptual issues related to a cost of disability allowance including the purpose of such a payment and the effect of participation on disability-related costs. Utilising research by Blind Citizens Australia and others, the effectiveness and equity of various models for a cost of disability allowance will be explored, including a capped allowance and a tiered allowance system.

To begin, I’ll outline the current situation for people who are blind in terms of income support. The DSP (Blind) is not means tested, which means that people who are blind keep their pension if they earn income from another source. This means that people who are blind who work can use the pension to offset the non-optional costs of their disability.

What impact has this had on the social exclusion of people who are blind? I’ll look at employment first. In terms of job seeking, the available data isn’t good, but what we have suggests that people who are blind are more likely to be looking for work than people with other disabilities, but are no more likely to find it.\(^2\) It is arguable that this higher labour force participation rate reflects in part the fact that the pension isn’t means tested and therefore people don’t have to worry about effective marginal tax rates or taper rates. People who
are blind are also not subject to capacity tests and this would also have a strong impact on participation rates.

There is no doubt that the means test free pension helps people who are blind to stay in employment. In recent years Blind Citizens Australia has conducted research into the non-optional costs of blindness. Blind people who were employed who took part reported many costs that were specific to work, including taxi travel, the purchase and repair of adaptive hardware and software, and greater wear and tear on clothes. They reported spending large amounts each year on items like the purchase and servicing of a Perkins braille writer – like a typewriter, only braille – and paying for professional assistance to complete work tasks.

Receiving the pension as a cost of disability allowance was vital to most people we spoke to. People who are blind who are fortunate enough to work tend to be employed in low paying occupations such as factory work, telemarketing or switchboard work. Many work part time. Members have told us that if they didn’t have the pension, they couldn’t stay in the workforce because the additional costs of working when you are blind are so great that without an allowance, it would not be financially worthwhile.

Even with the pension as a cost of disability allowance the costs of blindness can be so great that work is not financially viable. The direct, indirect and opportunity costs of blindness can have a compounding impact, as the experience of one of our member’s demonstrates. Frank was in his early 40s when he lost his job after losing his sight. He told us:

“After I was made redundant I could no longer afford to meet the mortgage repayments on my house so I moved out of town... Now I can’t afford to work because there is no public transport and the cost of a taxi to the city is $50 each way. I can’t find a job that pays enough to make this worthwhile.”

Of course, there are other measures of social inclusion that are as important as employment. Our research included people who were not employed but had income from other sources which would reduce their pension if it were means tested – that is, they were in effect receiving a cost of disability allowance. They reported being more active in their communities, undertook more voluntary work and had richer social lives than people who relied solely on the pension.

They could do this because they could afford the equipment and accommodations they needed – a computer, scanner, closed circuit television, speech and screen magnification software, or the range of home modifications that a person who is blind needs. They could afford to take taxis when public transport was unsafe or unusable.
Clearly, receiving the pension as a cost of disability allowance assists people who work or who have another source of income, but the majority of people who are blind rely solely on the pension.

Our research showed that people in this group had only low levels of direct blindness related expenditure which is not surprising. The report of the 1988 Social Security Review acknowledged that putting a dollar amount on the cost of disabilities is difficult because of the un-met demand of people on low incomes. If you ask people who rely on the pension how much extra they spend each week because of their disability, the answer will be not much. How can a person who barely gets enough to live on each week have significant additional costs?

More revealing is the proportion of income that is being spent on blindness. For example, one participant in our research spent more than $2,000 annually on non-optional costs of blindness, which was equivalent to 26% of his annual income and 13% of his household’s - a substantial proportion for someone with almost no discretionary income.

The link between a lack of financial assistance to meet disability related expenses and social exclusion are evident for this group, who tend to have only basic unmet needs – filling a prescription means you can’t afford to go out, visits to friends and family are rationed because the cab fare is $5.

People with only the pension are struggling. We need a cost of disability allowance model that can assist those who work, parents, retirees and the unemployed.

Competing models for such an allowance system have been suggested. The Physical Disability Council of Australia has proposed tiering payments based on the severity of a person’s disability and providing payments on a reimbursement basis. The Federal Government has considered an in-kind system, where people get expanded access to services such as the Health Care Card, in lieu of a cash payment. ACOSS has suggested that a capped allowance be considered.

I will consider each of these suggestions.

I have already demonstrated that a reimbursement model is not just or equitable because of the link between income and participation. We must encourage participation, not reward it. Another problem with reimbursement models is they are difficult to negotiate, particularly if you are blind. We need an allowance model that is simple to apply for and receive. This excludes any system requiring detailed record keeping.
The proposal that the allowance level be linked to the severity of disability cannot be supported by research. Research in this area has found that the most significant costs of disability arise from systemic discrimination and so tend to be common across disability types, irrespective of the severity of the disability. For example, the cost of living close to public transport and amenities, the cost of lost income through exclusion from the workforce and the cost of alternative forms of transport because public transport is inaccessible.

This reinforces what people with disabilities have long argued: that disability is a social problem, not a medical one. In terms of capacity to participate in society, actual medical impairment will rarely be important. What is important is the extent to which social infrastructure and community attitudes accommodate the impairment. For example, the cost of transport for someone who is blind would be greatly reduced if public transport was safer to use, if reasonable services were provided on weekends and at night, and if technology was introduced to make it more accessible, like a system that tells a person who is blind or vision impaired when a bus is arriving and which bus it is.

Taking a social approach to a disability allowance would mean rejecting tiering based on the medical severity of a disability, in favour of tiering that reflects the level of assistance a person needs to overcome systemic barriers.

The major problem with an in-kind cost of disability allowance is its lack of flexibility. Our research identified that the non-optional costs of blindness are highly personal. Although everyone had some costs in common, the sheer range of met and unmet need which people identified was astonishing – from a computer, scanner and talking software so that a person could assist their children with their homework, to the installation of sky lights and additional lighting in the family home, to paying some one to accompany you on a social outing. Our research also found that gender and cultural norms and geography all impacted on the cost priorities reported by people.

It is important to note that few of the direct costs of blindness identified in our research were for things that could be provided by Government. The notable exception to this was the need for cleaning and home maintenance which could be provided through an expanded Home and Community Care program. Similarly, with the exception of information in alternative formats and a reading service, participants did not identify unmet need for items or services currently being provided by blindness agencies.

It is vital that any allowance supplements other support which is currently provided to people who are blind, including the Health Care Card and allowances such as Mobility Allowance. It is essential that the introduction of
an allowance does not lead to charities or service agencies introducing access fees or user pays charges.

Finally, it has been suggested that a capped cost of disability allowance be introduced – that is, if a person earns more than a certain amount, for example, $60,000, they are not eligible for the payment.

This proposal confuses an allowance with income. A cost of disability allowance is just that – an allowance. It is not income support. It is assistance to meet the additional costs of having a disability that the general population do not have. The cost of disability allowance should form part of the social wage, like Medicare, and should be provided to all eligible recipients, irrespective of their incomes. For this same reason, the allowance should not be taxed.

Blind Citizens Australia’s preferred model for a cost of disability allowance is for eligibility for income support payments and a cost of disability allowance to be separated.

The allowance should be tiered to reflect the relative cost of overcoming the structural barriers to participation and for people who are blind should be set at the current level of the Disability Support Pension. It should be universally paid at the same rate to all people who are blind and aged over 16, irrespective of their relationship status.

The allowance should not be means tested or taxed. It should be a cash payment, which supplements, not replaces, existing forms of assistance and additional support for high cost items of technology and for housing should be provided.

However, even if such a system was developed, as a society we would still need to determine what to do about arguably the biggest cost of disability: lost income.\textsuperscript{iix}

Most of the population relies on income from employment to accumulate wealth. It follows that ongoing exclusion from the labour market and from opportunities for career advancement will considerably increase a person’s chances of living in poverty.

Australia has chosen to pursue universal income support instead of social insurance, meaning that people with a disability are not compensated for lost income. This means that the base level of income support for people with disabilities must be high enough to keep those who are dependent on it for a long period out of poverty.

Thank you.
References

i Commonwealth of Australia (2002), Building a simpler system to help jobless families and individuals, p. 15.


iii Blind Citizens Australia (2002), The Non-Optional Costs of Blindness: Can we count the costs?, unpublished paper.


v Physical Disability Council of Australia (2001), Towards a Disability Allowance: Offsetting the Costs of Disability, PDCA.

vi Commonwealth of Australia, op. cit., p. 15.

vii Andrew McCallum, President, Australian Council of Social Service, 13 May 2002, in discussion with Blind Citizens Australia President, Robert Altamore.

viii Physical Disability Council of Australia, op. cit., p. 6.

ix Physical Disability Council of Australia, op. cit. pp. 11-12.