RECONCILING TRUE AND INCURRED COSTS OF BLINDNESS IN NEW ZEALAND

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Abstract

In 2003 the Royal New Zealand Foundation of the Blind commissioned independent research to gain a greater understanding of the costs of blindness faced by its 11,300 blind, deaf-blind and vision-impaired members. The most common cost incurred by survey respondents was that of taxi use, which is used in this paper as an example of the difference between an incurred cost and a true cost of blindness. This difference is initially discussed in a qualitative framework, and then quantified. The survey data showed that many blind and vision-impaired individuals face restrictions on their use of such services as taxis due to their limited financial resources when mitigating the effects of their vision loss. This paper demonstrates why the constraints on expenditure need to be identified in order to provide better estimates of the true costs of blindness. These findings have relevance for the planning of any future investigations into the costs of disability or other similar social research.

INTRODUCTION

New Zealand is just one country where the costs of disability are partially funded through the provision of welfare support payments. The level of these payments must be set at a realistic amount to help meet the social policy objectives set by the Government for its community of disabled people. In turn, these policies need to be determined using accurate information about the actual cost of disability.

In 2003 the Royal New Zealand Foundation of the Blind (RNZFB) commissioned research into the costs of blindness in New Zealand. At that time the membership of the RNZFB included approximately 11,300 people who met the eligibility criterion that “In the opinion of a registered ophthalmologist or optometrist the person’s visual acuity does not exceed 6/24 in the better eye with corrective lenses, or there are serious limitations in the field of vision generally not greater than 20 degrees in the widest diameter.”[1] The membership of the RNZFB is growing, and stands at approximately 11,700.[2]

The vast majority of the RNZFB’s membership are 65 years of age or older, with approximately half its members over 80 years of age. While it may be interesting to investigate the quality of life for these older people and attempt to determine a financial cost for the reduction in the quality of life that results from vision loss, it is the working-age blind and vision impaired whose access to work and other aspects of social inclusion that have received the most scrutiny.

The increase in the development and implementation of “welfare to work" policies has, and will continue to have, an impact on the approximately 3,000 RNZFB members of working

1 www.rnzfb.org.nz.

2 www.rnzfb.org.nz, September 2008.

age. The merits of such policies are not considered in this paper, but this discussion may help inform the debate about how governments may wish to compensate for the costs of disability that arise as a direct consequence of an inaccessible society. The New Zealand Disability Strategy clearly recognises the social model of disability in preference to the medical model (Dalziel 2001), and it is in this vein that the current investigation was carried out.

The true cost of blindness could be defined as the total amount of extra time, money and other resources that a blind or vision-impaired person must expend or have expended on their behalf to attain the same quality of life as their sighted peers. The research commissioned by the RNZFB gave an analysis of the incurred costs for 200 respondents. However, the use of incurred costs has limitations when relating these costs to the definition of the true cost of blindness presented here. For example, no attempts were made to deal with reduced opportunities, whether through lost income, reduced avenues for recreational activity or the effects on interpersonal relationships.

The primary analysis was based on survey questions that were determined by the independent researchers using knowledge gained from the literature and from focus group sessions (Gravitas Research and Strategy Ltd and Market Economics Ltd 2006). The survey respondents were not a simple random sample of RNZFB members, with the working-age membership being over-sampled. Stratified random sampling was used, and this forced the primary analysis to incorporate the use of survey weightings when estimating average costs for all blind people. This paper does not address the quality of the data collected in the primary analysis. There are reasons why the data may be regarded as inferior, but the primary analysis is the best that has been conducted in New Zealand. Researchers wishing to undertake costs of disability research in the future should refer to that report and consider the decisions taken by those researchers separately from this supplementary analysis.

The quantitative data were collected during 2004 using a telephone-based survey questionnaire, chosen because of the inability of the target population to use other forms of data collection. It showed that a diverse range of costs were incurred, but, notably, the cost most frequently incurred by respondents was the use of taxis to undertake non-optional short-distance travel that was for purposes other than getting to work. This incurred cost should therefore take account of only those expenses that were borne by the survey respondent, but it is unclear whether the cost includes any subsidy through avenues such as the Total Mobility Scheme, which is not available to all blind people living in New Zealand due to geographic differences in the coverage of that scheme.

Anecdotal evidence suggests that taxi usage is the most-often questioned cost because taxis are often considered to be an expensive alternative to public transport such as buses and trains; there is also a view that the cost of taxi usage by blind and vision-impaired people should be compared to the cost of operating a motor vehicle by their sighted peers. Take, for example, the research produced by Ethical Strategies Ltd (2003), which did not consider the costs of transportation and did not state the reasons for not doing so. There are, however, factors supporting the use of taxis in preference to other forms of transport that can be directly linked to a person's vision loss.

An unfortunate consequence of using survey methodology to determine the true cost of blindness is that the financial resources of individual respondents may run out before all the effects of their vision loss have been mitigated. The principle reason for the additional research undertaken by the authors was to respond to the following comments made in the initial report:

> [E]xpenditure on taxis does not represent all travel undertaken or necessarily indicate total satisfaction of travel needs, i.e. the average spend on taxis by blind and vision impaired users may be low because users simply cannot afford to spend more than it. For twenty nine percent of the 18 to 65 year olds surveyed, cost is the main reason for not taking taxis or not taking taxis more regularly. This finding suggests cost as a constraint on the regularity or freedom with which travel is undertaken.

The survey data showed that an estimated 55% of RNZFB members used taxis for non-optional short-distance travel, while the authors, having reconsidered the raw survey data, estimate that 64% of RNZFB members use or would like to use taxi services. The increase in this estimate is based on the fact that some survey respondents indicated that they did not have the financial resources to pay for the taxis they would like to use. The issue of limited financial resources is not a new problem for researchers wishing to gauge the true cost of disability (see Baldwin 1985, for example), but this current investigation appears to be the first real attempt at estimating the true cost of disability in quantitative terms that allow for these constraints.

The next section discusses the reasons why it is appropriate to use the cost for taxi usage as a measure of the cost of blindness. A model for establishing the total cost of blindness is proposed in the third section, and subsequent sections investigate the issue of estimating the cost of taxis when the constraint of income is removed.

WHAT TAXIS MEAN TO BLIND TRAVELLERS

A primary concern in any social research is how the data collected relate to the information required to meet the goals of the research. Evaluation of the costs of blindness poses the extra difficulty that the way in which certain costs are perceived by different individuals (both blind and non-blind) may differ markedly. A case in point is the use of taxi services. The reasons a blind person chooses to use taxis are not identical to the reasons their non-blind peers would use them. There are the obvious reasons to do with the inability to drive a car, or ride a bicycle in safety, but the personal safety aspects for a blind person are different to those for a non-blind person.

Anecdotal evidence is easily obtained from blind people which suggests that taxi drivers are used as more than just people who can drive a motor vehicle. A taxi driver can help find a location that is not familiar to the blind passenger (Baker et al. 2000); they can provide additional information on alterations to the physical environment; and they can often help to obtain a working knowledge of a new city. Newbold (1987) reported that taxi drivers had even been used as impromptu guides while leaving the meter running. The cost of using a taxi must be weighed against using other forms of transport such as private motor vehicles. At times a blind person may choose to use a taxi instead of taking up offers from family or friends simply to avoid feelings of indebtedness (Winyard 2006), the convenience in terms of not having to plan around the time frames of others, and immediacy.

The New Zealand Disability Strategy identifies environmental barriers, both social and built, as the cause of disability and therefore follows the tenets of the social model of disability as opposed to the medical model (Dalziel 2001). Costs of disability relating to the medical model are easily identified (see Ethical Strategies Ltd 2003), but expenses incurred to mitigate the costs of disability relating to the social model are somewhat nebulous. The barriers to employment of blind and vision-impaired New Zealanders were investigated by LaGrow and Daye (2005) and show a wide range of barriers, both social and physical. Each individual who experiences barriers in life chooses the best way to circumvent them or incurs expenses to mitigate the effects of these barriers. Some of the expenses incurred are therefore not a direct expense of disability but do form a proxy for the financial value placed on disability. Whatever the particular reason individuals use taxis, the cost incurred was perceived by survey respondents to be a direct cost of blindness. This expenditure was incurred to mitigate the effects of blindness and can therefore be offset against the notion of the true cost of blindness.

A MODEL FOR THE TOTAL COST OF BLINDNESS

It is useful to put the costs of blindness into a framework or model so that we can identify what information we need to obtain to estimate the “total true cost of blindness". We need to recognise that not all blind and vision-impaired people incur exactly the same costs, and that when they do have the same expenditure items they may incur a different amount of expenditure.

Two values need to be identified for each demographic group of blind and vision-impaired New Zealanders if a model for the cost of blindness is to be formulated. Firstly, the proportion of individuals within each group that have a cost must be identified. We assume that not all blind people experience a given cost of blindness and that this may differ from group to group and from cost to cost. Secondly, for those people who do determine a particular expense as a cost of blindness, there will be an average cost those people expend, whether it be in dollars, hours or some other less quantifiable amount.

Given we can convert all costs into dollar terms, we use the model:

$$T_g = \sum_j p_{gj} c_{gj}$$

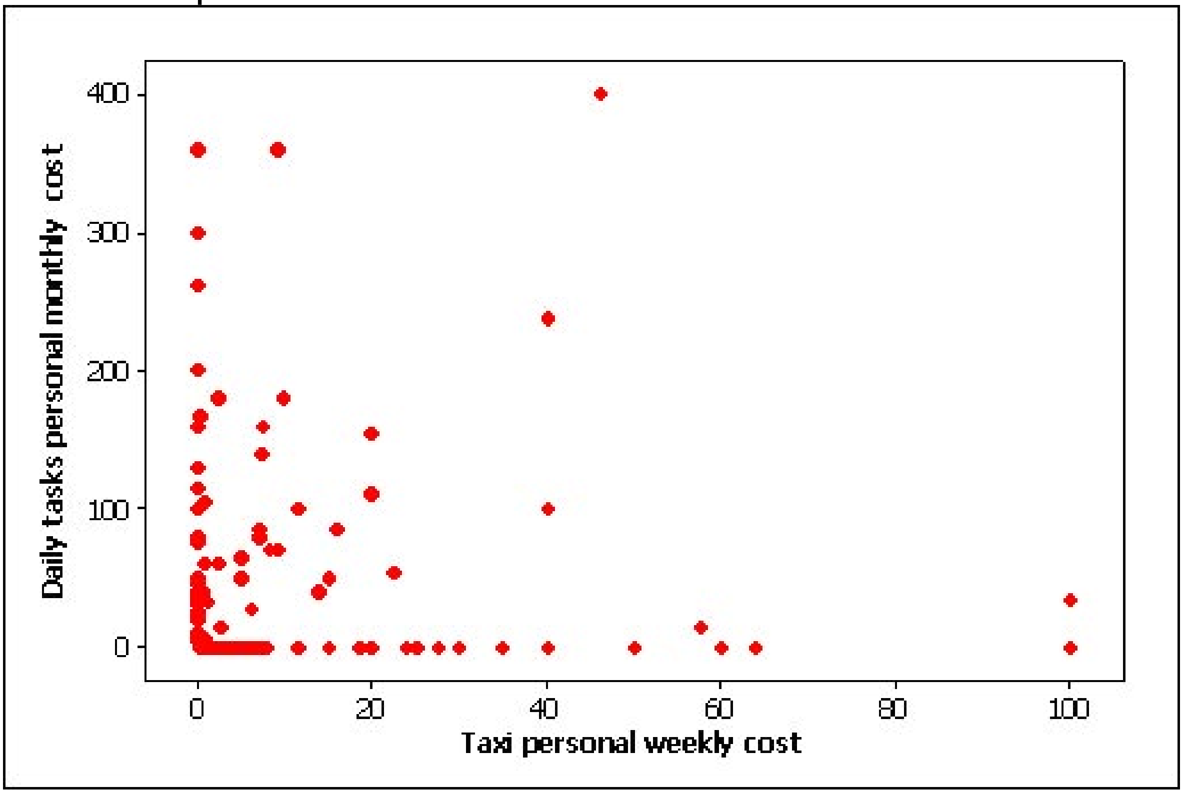
where the total cost T_g for a given demographic group g of people is the sum of the average cost C_{gj} of activity j for group g weighted by the propensity P_{gj} for members of group g to incur a cost. The model is then somewhat akin to an expected value formula. For example, if we know that there are only three broad cost categories faced by blind and vision-impaired people (travel, home help and equipment), and that these costs are incurred by only a portion of blind women of working age (say 2/3, 1/2 and 1/10), then we would need to combine the average costs for these activities as incurred by blind women of working age in the following way. If the costs incurred were on average \$30, \$20 and \$40 per week, we would multiply the fractions by the relevant costs and find that the average cost of blindness for blind women of working age was 2/3 × 30 + 1/2 × 20 + 1/10 × 40 = \$34 per week.

The problem we must deal with is how relevant the estimates we gain from survey data will be to the components of the model given here. It is fortunate that among the questions on taxi use in this research, respondents were asked why they did not use taxis at all or did not use taxis more than they currently do. Approximately a third of respondents stated that they did not need to use taxis more than they currently did, while another third said that taxis were “too expensive". The remaining third gave a range of reasons that were not as extreme as the first two categories and cannot be combined with either of them.

This leads to two sub-problems: the propensity to incur a cost for taxis is probably understated, and the average amount of incurred cost for those who did use a taxi is less than the total cost would be if the respondent were able to use taxis as much as they would like in order to mitigate the effects of their blindness.

Another source of restriction on funds is the fact that some blind and vision-impaired people may decide to spend their money on certain costs which they feel best mitigate the impact of their vision loss. This will have an impact on the average amount spent on certain activities, but in reality the true cost of blindness should not have any competition among the various costs. The model given here does not factor in any lack of independence in the incurred costs for this reason. The two most frequently incurred costs of blindness for all survey respondents that incurred either cost are plotted against one another in Figure 1.

Figure 1 Scatter Plot of the Two Costs of Blindness Most Frequently Incurred by Survey Respondents



In this figure the expenditure on taxis for non-optional short-distance travel is compared to the total of five expenditure items for general household upkeep, such as home help with cleaning or lawn mowing. It shows that many individuals who incurred one of these costs did not incur the other cost. The survey data did not enable the reasons for this behaviour to be determined. The interesting aspect of the numeric summaries that can be generated for this data arises as a consequence of the way any calculations treat the individuals who did not incur one of the costs. If the total group of individuals that incurred either cost is used, the Spearman's rank correlation coefficient for this data is −0.295 and might imply a trade-off, while this correlation is 0.198 if only the individuals incurring both costs are used for the calculation. This relationship was not given any deeper analysis due to the incomplete data on household income and the low number of respondents. As observed by one of this article's anonymous referees, any differences in expenditure for the two costs might be incurred by different subpopulations of the survey respondents. The referee's comments help justify the use of the model presented above whereby different subpopulations have a different chance of incurring a particular cost.

Another aspect of the model proposed is that it allows for differences in attitude among blind and vision-impaired people. Some people may describe a cost they incur as a direct consequence of their blindness, while others incurring the same cost may not describe it this way. The propensity to perceive a certain cost as a cost of blindness and an associated average cost for those perceiving the cost as such can be included in the model given here. For example, some people may associate the lack of a driver's licence with a cost of blindness, while others would not necessarily drive even if they could hold a licence. Valuing the cost of not having a driver's licence may prove rather difficult, but if it were measured in terms of lost income, reduced mobility, etc., this could be factored into the calculation of the total cost of blindness. It would certainly differ according to the demographic group whose cost of blindness is being determined.

A second example of a perceived cost of blindness is the difficulty of maintaining or establishing meaningful relationships. Anecdotal evidence suggests that acquired vision loss does have an impact on interpersonal relationships and, as reported on Radio New Zealand's Morning Report programme, can even contribute to the breakdown of a marriage (Radio New Zealand 2006). These examples may in fact be extremely difficult to evaluate accurately in financial terms, especially given the subjective nature of the values that would be placed on activities or events in a blind person's life, but nonetheless an attempt could be made if researchers were interested.

ADJUSTED AVERAGE COST GIVEN FINANCIAL CONSTRAINTS

In this section we show the impact on the total cost of blindness by allowing for the fact that some survey respondents clearly identified that financial constraints limited their use of taxis for non-optional short-distance travel. As noted previously, approximately one-third of the survey respondents stated that taxis were "too expensive" for them to use to any greater degree. For these people, the incurred cost given is assumed to be less than the amount they would have spent on taxis to mitigate the effects of blindness if their finances allowed. In statistics, this is known as "right-censored data" and is a phenomenon arising most frequently in survival analyses, whether these be on product evaluations or in medical research.

Survival analyses generally use time as the most common response variable, with explanatory variables and an indicator variable to state whether the event has or has not yet occurred. The technique is transferable to other data scenarios where right censoring exists, as long as model validity testing is undertaken and no model assumptions are violated.

It is important to note that the 200 survey respondents were not a simple random sample of the RNZFB membership, and that this means survey weightings must be used when analysing the data. Survey weightings determine how many members each survey respondent "represents" from the population, and failing to use them whenever there is any departure from a simple random sample biases analyses towards the over-sampled strata in the sample. The most obvious example of the impact of this use of survey weighting we can provide is the fact that the 100 respondents with an incurred cost for non-optional short-distance taxi use out of the 200 survey respondents actually represent approximately 55% of the 11,300 RNZFB members. We also know that some individuals who did not incur a cost could not do so because they said taxis were "too expensive". Including these additional individuals raises the estimated percentage of RNZFB members who want to use taxis to mitigate the effects of their blindness to approximately 64%. It is not the purpose of this paper to suggest improvements in policy that would improve the lot of these additional individuals, but the message that there are some people who do not currently meet their needs using taxis because they do not have enough money is clear. These findings support the views expressed as part of the Taken for a Ride campaign being run by the Royal National Institute of the Blind (RNIB) in the United Kingdom (Winyard 2006).

The authors used the statistical software package Minitab for this analysis, although similar analyses could have been performed using many other statistical software packages, including SPSS, SAS, and S-Plus. One note about the weightings must be made at this point. Because survival analyses are usually performed on a set of individuals, the weightings used needed to be integer-valued, and are therefore marginally different to the original survey weightings. Model assumptions were checked for this model and could not show that the use of the survival analysis technique was inappropriate.

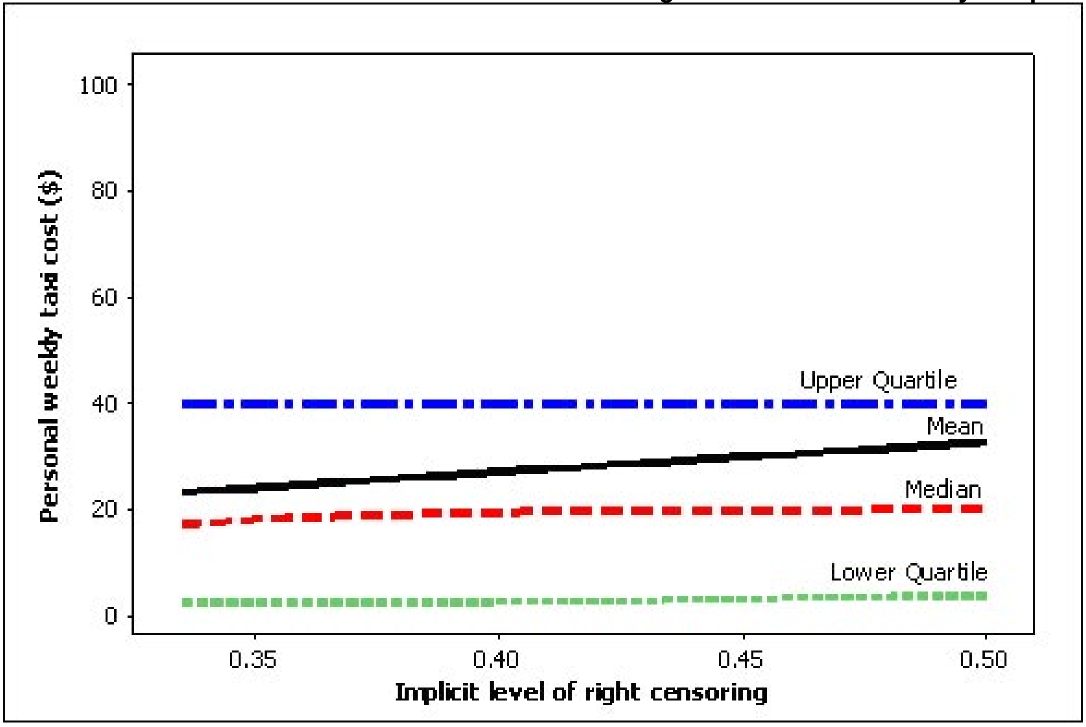
The estimated average cost of weekly taxi usage for non-optional short-distance travel was \$14.52 in the initial report. By allowing for the 34 survey respondents who would have spent more on this form of transport to mitigate their effects of blindness, the estimated average cost rises to \$23.43 per week. Given the low number of survey respondents with incurred taxi costs, no reliable subgrouping can be undertaken.

ADJUSTED AVERAGE COST GIVEN VARYING CAUSES FOR CONSTRAINED EXPENDITURE

This section deals with the problem that approximately one-third of the respondents gave alternative reasons for not spending more on taxis than were investigated in the previous section. Of the 100 survey respondents for which an incurred cost was available, 34 were determined to be right-censored, 33 to be uncensored, and the remaining 33 had an unknown censoring status. To show how these 33 individuals further affect the true cost of blindness met by taxi usage, their censoring status was randomly assigned in hundreds of simulation runs. It is felt that using random allocation of the censoring introduces no additional bias to the current investigation. Other (more subjective) allocations were considered, but each is arguable due to the assumptions made.

Results from the simulation runs leads to two items of information being generated. First, an estimate of the average cost of taxi usage was obtained, and second the implied level of censoring for the population was inferred. Recall that these values are a direct consequence of using a weighted analysis to link the sample weightings with the population weightings.

Figure 2 Estimates of the Mean, Median, Lower and Upper Quartiles of the Costs Determined via Simulation of the Unknown Censoring Status of Some Survey Respondents



Note: The lines have been generated using a lowess smoother.

Figure 2 shows the estimated mean, median, and lower and upper quartiles of the true cost of blindness met through weekly expenditure on non-optional short-distance taxi usage for differing levels of implied right censoring. Table 1 shows a selection of these results.

Table 1 Summary Statistics for Estimated Costs Compared with Different Levels of Censoring Obtained Through Simulation

Implicit level of censoring	Estimated summary measures			
	Mean	Median	Lower quartile	Upper quartile
33%	24.02	17.49	2.64	40.00
36%	25.30	18.45	2.69	40.00
39%	26.73	19.48	2.95	40.23
42%	27.61	19.85	3.29	40.98
45%	29.23	20.43	3.51	41.13
48%	30.56	20.69	3.83	49.46

Our results clearly show that the average cost of blindness as determined through the expenditure on short-distance non-optional taxi usage rises as the proportion of surveyed individuals who cannot afford the cost of taxis increases. This rise is caused by the distribution of costs spreading out, which is most easily seen by considering the inter-quartile range.

Without further investigations into the spending habits of survey respondents we cannot provide reliable estimates of the total cost of blindness, but we can see that the true cost of blindness is greater than the sum of incurred costs. We can only surmise that different costs will have different levels of censoring depending on the relative importance individuals place on different costs as mechanisms for mitigating their vision loss.

CONCLUSION

In this paper we have presented evidence of the impact financial constraints have on the true cost of blindness faced by New Zealand's blind and vision-impaired community. This impact has been demonstrated using short-distance non-optional taxi costs as an example; this was only possible due to the inclusion of a survey question on why taxis were not used more frequently by survey respondents. We found that the true cost of blindness was substantially underestimated if only the actual incurred costs were considered, and showed that this understatement is dependent on the level of censoring in the data.

Even if the value of the example is questioned due to any perceptions of poor data quality, the authors hope that more meaningful results will be obtained by including similar questions in social research surveys on expenditure. The addition of questions that uncover reasons behind any limited expenditure will lead to more informed policy decisions. Work remains to be done to determine how the issue of censored data could be incorporated into other data collection techniques.

We have shown that the additional sophistication of the statistical analysis is easily obtained by using the survival analysis routines available in the vast majority of specialised statistical software packages. These analyses can even be obtained when data are collected from a sample that is not a simple random sample from the population, meaning that survey weightings must be used.

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