

Appendix 4: Geographic classifications: RRMA, ARIA and ASGC Remoteness

Until recently, rurality had been described almost exclusively by the seven-level Rural, Remote and Metropolitan Areas (RRMA) classification. This classification is based on the size of the local population centre as well as a measure of remoteness (DPIE & DSHS 1994).

Work by the National Key Centre for the Social Applications of Geographical Information Systems (GISCA) from 1996, saw the development of improved measures of remoteness: the Accessibility/Remoteness Index of Australia (ARIA), a continuous variable with a remoteness score of 0-12; and its successor, ARIA+ (with a remoteness score of 0-15).

From ARIA, the Department of Health and Ageing developed its five-level classification (also called ARIA), and from ARIA+, ABS developed its six-level classification, the Australian Standard Geographic Classification (ASGC) Remoteness structure (DHAC & GISCA 1999, ABS 2001b).

Note: taken from AIHW 2002b:216.

Map of Australia by ASGC regions

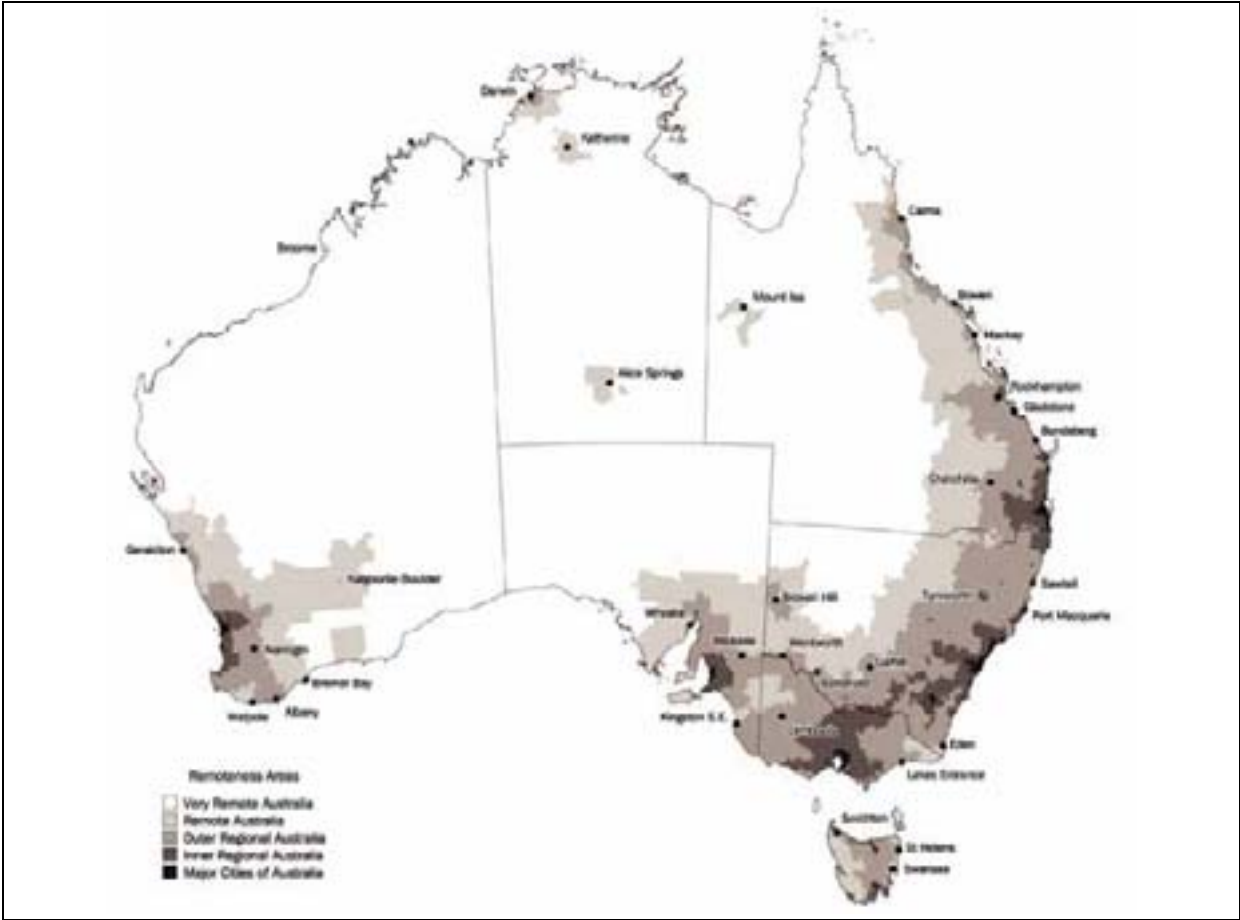


Table A4.1: Remoteness classifications

Broad category	RRMA			DHAC ARIA			ASGC Remoteness		
	Fine Category	Population ('000,000)	%	Category	Population ('000,000)	%	Category	Population ('000,000)	%
Metropolitan	Capital Cities	11.6	64	Highly Accessible	14.9	81	Major Cities*	12.1	66
	Other Metropolitan centres	1.4	8						
Rural	Large Rural centres	1.1	6	Accessible	2.2	12	Inner Regional*	3.8	21
	Small Rural centres	1.2	7				Outer Regional*	2.0	11
	Other Rural areas	2.4	13	Moderately Accessible	0.8	4			
Remote	Remote centres	0.2	1	Remote	0.2	1	Remote*	0.3	0.3
	Other Remote areas	0.3	2	Very Remote	0.2	1	Very Remote**	0.2	0.2
							Migratory*	<0.1	

Notes

1. This table is a rough guide only, the various classes in each classification are not equivalent.

2. This table is taken from AIHW 2002b :216.

Source: AIHW Population Estimates.

Appendix 5: Disability Adjusted Life Expectancy and Disability Adjusted Life Years as performance measures for health status and outcomes

Background and purpose

In February 2000 the National Health Performance Committee (NHPC) embarked on the development of a new Australian health performance framework. It took as a starting point a framework developed by the Canadian Institute of Health Information as part of the Canadian Roadmap Initiative that was established in 1999. The Canadian framework was incorporated in an NHPC Discussion Paper which was disseminated widely for comment to jurisdictions, government and non-government providers, and consumers in the health system (NHPC 2000). An NHPC workshop to refine and improve the proposed framework was held in July 2000 and a revised version of the framework has now been published in the NHPC's *National Health Performance Framework Report* (NHPC 2001).

The framework consists of three tiers:

1. Health Status and Outcomes,
2. Determinants of Health, and
3. Health System Performance.

These tiers do not represent a hierarchy but reflect the fact that health status and outcomes are influenced by health determinants and health system performance.

Each tier in turn comprises a number of dimensions and the intention is that performance indicators will be developed for each dimension. In particular, Tier One (Health Status and Outcomes) has four dimensions:

Health conditions: Prevalence of disease, disorder, injury or trauma or other health-related states.

Human function: Alterations to body, structure or function (impairment), activities (activity limitation), and participation (restrictions in participation).

Life expectancy and wellbeing: Broad measures of physical, mental and social wellbeing of individuals and other derived indicators such as Disability Adjusted Life Expectancy (DALE).

Deaths: Age and/or condition specific mortality rates.

The *life expectancy and wellbeing* dimension includes broad measures of physical, mental and social wellbeing of individuals and other derived indicators. It is one of the goals of the health system to assist people to live a potentially achievable life span with minimal

disability or disease. The NHPC has identified disability adjusted life expectancy (DALE) and disability adjusted life years (DALY) as indicators that (together with self-assessed health) may give an impression of the performance of the health system in achieving these goals (NHPC 2001:10).

The DALE and DALY measures were originally developed as tools to measure and compare the overall burden of disease in different communities and nations. The value pointed to by the proponents of this type of measure is that it combines the impact of a wide range of disease and disability into a single measure of 'health' status which combines the total mortality and morbidity experience of each community.

However, the use of these concepts as performance indicators by the NHPC raises the possibility that they may be used to assess the performance of health service delivery systems and to quantify funding needs as well as to describe the burden of disease which each system is called upon to address. It is therefore important that the values and assumptions underlying this methodology be understood and discussed by both the immediate organisational clients of the NHPC and by a wide spectrum of the general community.

This paper represents an attempt to explain and comment critically on these values and assumptions and to identify issues that need to be addressed when using the DALE and DALY measures in Australian health service planning. It was prepared for the NHPC by officers of the Victorian Department of Human Services and incorporates comments contributed by other officers of that Department and of the South Australian Department of Human Services and the Australian Institute of Health and Welfare. However, differences of opinion remain as to the relative importance of these issues.

The meaning and derivation of DALE and DALY

Both Disability Adjusted Life Expectancy (DALE) and Disability Adjusted Life Years (DALY) are summary measures of population health.

Disability Adjusted Life Expectancy (DALE) is defined as life expectancy adjusted for the average time spent in states of less than full health weighted for severity. This measure estimates the number of years that a person could expect to live in a defined state of 'health' and is therefore a health expectancy measure. It is a measure of years lived in full health combined with years lived in states of less than full health weighted for severity of disability.

Disability Adjusted Life Years (DALY) is defined by the formula

$$\text{DALY} = \text{YLL} + \text{YLD}, \text{ where}$$

YLL = Years of life lost due to premature mortality, and

YLD = Years of life lost due to disability.

In other words, this measure is the number of years lost due to premature mortality (relative to a standard life expectancy) combined with the number of 'healthy' years lost due to disability and is known as a health gap measure. At the population health level, it can be interpreted as the gap between current health status and an ideal in which everyone lives into old age free of disease or disability.

Both of these concepts incorporate a number of social values. For example, the use of a 'standard life expectancy' in calculating the DALY measure means that years of life lost (YLL) are not calculated against an arbitrary norm, say 75 years. Instead, YLL are calculated against a standard life table and hence a death at any age (even at age 100 years) accrues

YLL; in fact, the Australian studies use the cohort life expectancy—that is, the life expectancy for the current period adjusted upwards to include a projected further decline in mortality in future years.

An ‘economic discounting’ issue also arises as to the value assigned to an additional period of life experienced in the future as against the same period experienced now.

Social values also impinge on the definition of disability and the weights assigned to each disability. In both the DALE and DALY measures ‘disability’ is defined as any departure from full health, and can include a short-term disability from a common cold through to a long-term disability such as quadriplegia. This is a broader definition of disability than that often used in common language. Each type and level of disability is assigned a weight reflecting social value choices based on social research in a range of countries at various stages of economic development.

The ‘Person Trade-Off’ methodology underlying these measures, and the associated social issues, are discussed more fully in the Australian Burden of Disease and Injury Study published in 1999 by the Australian Institute of Health and Welfare (Mathers et al. 1999) and in the Victorian Burden of Disease Study published in the same year by the Victorian Department of Human Services (Public Health Division 1999).

The purpose of this paper is to comment on the social values and issues raised by the use of disability weights, including the underlying ‘Person Trade-Off’ methodology and the need for Australian disability weights, and their implications for performance reporting. The issues raised by age weighting and economic discounting are also important but are not discussed in this paper.

Limitations on the use of DALE and DALY as health outcome measures

By including ‘Life expectancy and wellbeing’ as a dimension of the Health Status and Outcomes Tier of its framework, the NHPC has raised the possibility that the DALE and DALY measures could be used, not just as descriptors of the health status of the community, but as health outcome measures for health service performance.

In its 2000 discussion paper, the NHPC defined *health outcome indicators* in the following way:

‘A health outcome indicator is a statistic or other unit of information which reflects, directly or indirectly, the effect of an intervention, facility, service or system on the health of its target population, or the health of an individual.’ (NHPC 2000:10)

The implication here is that two different health interventions or services which lead to an equal increase in a health outcome indicator are of equal value, at least as measured by that indicator. There may of course be other indicators against which the interventions or services may yield different values but as far as this indicator is concerned they are of equal value.

However, this ‘equal value’ criterion is disavowed by the authors of the Australian Burden of Disease and Injury Study in their explanation of the interpretation of disability weights. They explain:

‘All other things being equal, society would prefer to prevent or cure a case of paraplegia (weight 0.57) rather than a case of low back pain (weight 0.06), if each case could be restored to full function for the same cost and there were insufficient resources to do both. However, the use of health state preferences and DALY or

QALY measures to quantify loss of health or health gain carries no implication that society will necessarily choose the maximisation of health gain as the main or only goal for the health system. Additionally, the disability weights should not be further interpreted as giving a value to the maximum benefit obtained by saving the life of a person with that health problem, but leaving them in the health state. We should not interpret a weight of 0.5 for paraplegia as saying that saving the life of a paraplegic person (but not changing their disability status) is given only half the value of saving the life of a person in good health'. (AIHW: Mathers et al. 1999:12)

The implication of this important qualification is that the DALE and DALY measures may have value as a broad measure of the burden of disease, and in particular the impact of non-fatal disease, but serious issues about the value of human life may arise if they are used to assign a value to different health outcomes either for individual clients or at the aggregate level for different population groups or communities. Some of these issues are identified and discussed in this section. The NHPC does not claim to be able to resolve these issues but considers it important that they be exposed for public discussion.

Should changes in mortality and morbidity be combined in a single measure?

DALYs can be used in cost-effectiveness analysis to measure the difference in outcomes between an intervention and a comparator (for example, current treatment practice). To cite an Australian example, this has been done in the ACE-Heart Disease and ACE-Mental Health studies where the research design has required benefits from changes in mortality to be combined with benefits from changes in health related quality of life. The use of DALYs and similar measures such as quality adjusted life years (QALYs) for this purpose is common practice in economic analyses as well as their use as broad measures of burden of disease.

However, there is an alternative view that any attempt to combine changes in mortality with changes in morbidity or quality of life must inevitably be an attempt to combine 'apples and oranges' by counting the years of life of a disabled person as some fraction of the years of life of a 'healthy' person. Acceptance of this alternative view would require economic analysts to quantify mortality and quality of life benefits separately without making any judgement on how the two compare. This would be left to the users of the research, some of whom might find it difficult to make a decision for or against an intervention with a small risk of death but an improvement in quality of life.

There is a range of views as to the desirability of this. Some researchers believe that measures such as DALYs or QALYs are the only way to make this type of distinction explicit. Others would claim that it confounds and masks the trade-off being made in these decisions, by artificially equating two very different performance factors. Still other groups in the community might argue for other ways of making this type of choice, such as giving an absolute priority to reduction in mortality or maximising the ability of the individual health service consumer to make an informed choice.

Should the DALY and DALE measures be used to guide resource allocation decisions?

It is becoming increasingly recognised that health service resources are finite and that choices must inevitably be made in their allocation—and in fact are being made although the basis of choice is not always explicit. Burden of disease and cost-effectiveness analyses can

be used to help policy makers to base decisions in this area more on a composite aggregation of available evidence that involves a careful weighing of 'clinical' need and the costs of an intervention. This recognises that if the cost per aggregate unit of benefit is very large then the community may forego opportunities to spend the same resources on more cost-effective interventions. The proponents of such analysis argue that DALY and DALE measures provide a single aggregate output unit that can be used for this purpose.

However, this approach to policy making can only occur in the context of the general policy constraints imposed on the delivery of Australian health services. In some clinical situations it may be necessary to ask individual clients to 'gamble' by deciding whether or not to accept treatment which might either improve their health or result in death. There may also be situations where there is less uncertainty but a clear understanding that a given treatment will provide a shorter but healthier life. At present, however, any systematic attempt by Australian public hospitals or health authorities to remove these choices from the individual client and their clinician and base them on planning, funding or performance measurement criteria is likely to be inconsistent with the Australian Health Care Agreement principle (enacted by all state and territory governments as a condition of Australian government funding) that 'access to public hospital services by public hospital patients is to be on the basis of clinical need and within a clinically appropriate period'.

Moreover, any attempt by an individual health service provider to deny health services to people on the grounds of disability would expose those responsible to prosecution under anti-discrimination legislation and probably to other legal and professional sanctions. One purpose of these sanctions is to limit the ability of health service providers and planners to make choices which may divert resources away from interventions which extend the lives of disabled people. In the current composite measure combining mortality and morbidity, interventions that extend the lives of disabled people while leaving them in the same disabled state 'would deliver less DALYs' than interventions that extend the lives of healthy people while leaving them in the same healthy state.

An issue of this nature arose in the US State of Oregon in the well known 'Oregon experiment'. In the early 1990s a list of about 700 pairs of conditions and treatments to be given priority for funding under the Medicaid scheme was drawn up and submitted by the Oregon legislature to the US Federal Government for approval. The first list was rejected on the grounds (which some commentators believe questionable) that it was inconsistent with the Americans with Disabilities Act 1990 because the ranking of condition-treatment pairs was based in part on an assessment of the potential for restoring a full quality of life, an outcome not possible for people with disabilities. Extensive revision to avoid this type of discrimination was required before agreement was given for the list to become operational in February 1994 (Bodenheimer 1997 Ham 1998).

In practice, therefore, any attempt to use DALYs or DALE to 'ration health services' must be constrained by other policy considerations. While this constraint will obviously occur in the post-research decision-making process, it may also impact on research design. For example, if policy constraints will prevent discrimination in providing treatment for one condition (such as heart disease) to people with or without a long term disability (such as deafness), this may limit the extent to which comorbidity or the combined effect of these conditions may be factored into the research design or the economic analysis.

The NHPC acknowledges these issues and notes that it has explicitly included equity considerations in its performance measurement framework—for example, in the 'Accessible' dimension of Tier Three and more generally in the overarching question 'Is it the same for everyone?' (NHPC 2001:8).

Issues raised by the use of DALE and DALY as health status measures

Notwithstanding this limitation, burden of disease measures such as DALE and DALY are considered by many health service researchers to have value as a measure of health status. This is acknowledged by the Director of the Australian Institute of Health and Welfare in his Foreword to the Australian Burden of Disease and Injury Study:

‘Burden of disease analysis provides a unique perspective on health—one that integrates fatal and non-fatal outcomes, yet allows the two classes of outcomes to be examined separately as well.’ (AIHW: Mathers et al. 1999:v.)

For example, the Study shows that mental disorders are the leading cause of non-fatal disease burden in Australia, accounting for 27.2% of the years of life lived with a disability in 1998, in dramatic contrast to their contribution of only 0.8% of deaths and 1.4% of years of life lost (AIHW: Mathers et al. 1999:88). It is arguable that the message which these figures send to those responsible for determining health service priorities is not really strengthened, and may even be somewhat diluted, by combining the figures to show that mental illness is the third highest contributor (13.3%) to the total DALY measure.

However, the validity of findings such as these rests not only on the accuracy of the epidemiological data on mortality and illness used in the measures but on the validity of the weights assigned to various disabilities (in this case non-fatal mental illness). These weights are based on overseas research, for example in the United States and the Netherlands, and on the judgements of valuation panels with male/female experts from a range of countries at various stages of economic development. There may be an issue around whether the weights determined in this way actually reflect, or even should reflect, the values held in the Australian community.

One aspect of this issue which may need to be highlighted in community discussion is the fact that, in this context, disability is given a particularly broad definition which includes any departure from full ‘health’, and can include a short-term disability from a common cold, through to a long-term disability such as quadriplegia.

Many disabled people believe that disability does not necessarily equate to poor health. In the early stages of an acquired disability such as paraplegia or quadriplegia this may be the case and individuals may have a greater dependence on health services but once stable, can lead a normal healthy lifestyle. Moreover, people with congenital disabilities such as cerebral palsy or intellectual disability may have no greater dependence on health services than a person without a disability.

If a person with a severe disability (i.e. paraplegia or quadriplegia) has an active and participatory lifestyle with appropriate equipment and ‘maintenance medication’ they more often than not have full health. There is considerable research here and overseas that indicates people with a disability when actively engaged in employment, tend to have less sick time and hours away from work than people without a disability.

How does this ‘burden of disease’ term relate to the World Health Organization’s definition of disability under the new International Classification of Functioning, Disability and Health (ICF)? In the ICF, disability is an umbrella term for impairment, activity limitation or participation restrictions. ICF lists environmental factors that interact with these constructs.

People with disability have been striving for years to portray disability as something separate from poor health and illness. In doing so there has also been a consistent effort to see disability and difference as something that can be adjusted to and that it was not

necessarily negative. There have been real efforts to distance disability from being a burden and show that people do not 'suffer' simply because they have a disability.

An alternative view reflecting these perceptions is that 'burden of disease' research should try to measure the level of dependence on the health system and/or community, rather than the willingness of people to trade off years of life in various states of disability. This would require (for example) research into this dependence by people with musculo-skeletal type conditions in comparison to paraplegia and/or quadriplegia. It is not clear whether decisions made under the Person Trade-Off methodology are based on levels of dependence ascertained by specific research or assumptions made on the 'severity' of each disability. It would also be interesting to know whether any 'weighting' is given to length of time with disability to take into consideration the 'stabilisation' effect (which may include a period of personal adjustment but also experimentation with aids, appliances and medications in order to achieve stability) or the availability of maintenance resources.

Specific issues will arise in relation to every type of disability and to some extent the issues will be specific to each disability. For example, the burden of severe deafness on each person will depend on a number of factors including:

- the extent to which each person has been able to acquire language skills, which will depend on the age of and rapidity of onset of deafness—to some extent this is taken into account by assigning different weights for deafness arising in young children but this may not adequately discriminate between different levels of language skills;
- although the weights discriminate between treated and untreated conditions, they may not adequately take account of differences in the ability of the individuals to access modern technology—for example, the burden may be less if the individual is able to spend \$5,000 on digital hearing aids rather than \$2,000 on analog hearing aids; this may depend on socio-economic factors and, aggregated to the national level, may also vary between countries;
- the availability of support services (for example, targeted education programs); and
- perhaps most importantly, the extent to which deaf people are accepted and valued in the community.

The NHPC has acknowledged the need for further discussion and consultation around these issues in its 2001 National Report on Health Sector Performance Indicators. In this report the NHPC pointed out that:

The weights assigned to various disabilities are derived from overseas research that attempted to measure the extent to which people were prepared to trade off reductions in mortality against reductions in disability (i.e. years of life with good health against years of life with various disabilities). There may be issues around the acceptability to the Australian community in general and to various disability groups of both the basic trade-off methodology and the specific weights assigned to various disabilities...At the very least, there is a need for discussion within the community as to how well the weights (especially those derived from overseas research) reflect the views of both the people most affected by disability and Australian society as a whole. (NHPC 2002: Glossary)

There clearly needs to be an Australian project to develop 'disability weights' and this should include participation by clients of health services and people with disabilities and their carers as well as the general population. The original international projects were based on the views of health professionals or experts and non-health university graduates. In more recent work the WHO has conducted large population surveys in over 30 countries using

different techniques to the original 'Person Trade-Off' methodology. These include asking a representative sample of the population to rank health states according to severity as well as to indicate on a visual analog scale (a 'barometer' ranging from 0 for the best possible health state to 1 for the worst possible health state) the relative position of the health states considered.

Issues for the National Health Performance Framework

Although this discussion is primarily concerned with issues around the use and limitations of the DALE and DALY measures, the NHPC acknowledges that these issues also have implications for the logical structure and consistency of its National Health Performance Framework, with particular reference to the dimension 'Life expectancy and wellbeing'. Like the DALE and DALY measures, this dimension combines two distinct health service objectives—the reduction of mortality and the reduction of disability. Although often complementary, these two objectives are conceptually separate and their combination in a single measure implies a trade-off between them.

The NHPC has agreed to review its framework after a period of three years. This should provide an opportunity for the issues discussed in this paper to be discussed within the wider Australian community.

