Health Promotion and the Disabled: Funding Issues

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The disabled have a narrow margin of health. They are, on average, much more likely than non-disabled persons to experience a broad range of secondary disabilities, and experience disability related acute health problems including decubitus ulcers, urinary tract infections, and respiratory tract infections. It has been shown that persons with disabilities experience higher rates of hospitalisation than the general population, largely from preventable conditions, and experience difficulties in access to primary care, and other services: in particular health promoting services.

However, despite the vulnerability of the disabled to these problems, and the wide window of opportunity for health promotion to reduce premature mortality, improve quality of life and lower healthcare costs associated with disability, little research has been conducted to address issues of the funding of health promotion and healthcare for these persons. These issues are of considerable importance, as it is the funding arrangements which largely determine the scope and amount of health promotion received by the disabled, how this is distributed and to whom it is distributed.

This paper attempts to redress this imbalance by providing an overview of issues concerning the funding of health promotion for the disabled. Several areas are considered where improvements in funding could be achieved to reduce barriers in access to appropriate healthcare and health promotion for the disabled. From this review it is clear that there is a need to find models of the finance of care that will avert unnecessary rehospitalisation, respond to the new health needs of the disabled as they get older, offer access to timely health promotion and primary care, focus on the outcomes of health promoting activities, lead to shorter stays in hospital, develop community-based rehabilitation, and encourage the role of carers and volunteers. In the end this requires incentives for providers of care to consider the longer-term needs of the disabled, and the most promising means to achieve this restructuring of funding may be through case-management.

The uncertainty surrounding the future of the current Australian healthcare system, as with systems worldwide, presents the potential for the disabled to either lose their access to health promotion and care further or to capitalise on these changes to ensure that their situation is improved. Either way it is clear that research is urgently required to address the issues raised in this paper in a timely fashion, to ensure that beneficial changes are capitalised upon and the potential for negative impacts are minimised.
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1 Introduction

Participation in health promotion\(^1\) may lead to lower levels of premature mortality, higher quality of life and lower healthcare costs [1]. However important this may be for the general population, it is even more significant for those already with a disability\(^2\), whose quality of life and independence rely critically on their ability to maintain their ‘narrow margin of health’ [2-7].

The disabled are, on average, much more likely than non-disabled persons to experience a broad range of acute health problems including decubitus ulcers, urinary tract infections, and respiratory tract infections [8-10], and be more at risk of, for instance, cardiovascular disease and stroke [11]. These problems often do not surface until after the disabled person has been discharged from care [5,7,10], yet despite the vulnerability of the disabled to these problems, few programs have been developed, and little research conducted, to address issues of care for these persons [4,8,9,12]. Even the basic step of conducting studies to ascertain the health promotion needs of the disabled have been few [13]. This lack of research is even more surprising when one considers the similarity in philosophy of the health promotion and independent living models, which both hold as a central concept that individuals accept responsibility for their own health [14,15].

General health promotion tends to work with a template of normality based on the ‘person-in-the-street’ who, while more or less healthy, has no afflictions that are inaccessible to remedial action [16]. Such activity tends to cover the health of people without disabilities and the prevention of disability, but not the health status of those people whose disability was not prevented. However, there will always be disabled people however much primary prevention of disabilities is sought, and so these activities do not, in the main, overcome these problems. The health promotion perspective should be viewed as encompassing a wide variety of overlapping and interlinking initiatives (including health protection, preventive medicine, health

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\(^1\) See Appendix 1 for definition of Health Promotion as used in this paper.

\(^2\) See Appendix 2 for definition of Disability as used in this paper.
education, public policy and community and individual empowerment [17,18]) in order to maintain and enhance existing levels of health [19] and well-being [20-22] in the disabled.

Important in this wider perspective is the recognition of the health promoting role and responsibility of all health professionals [23]. This is important to the delivery of health promotion for the disabled as: (i) the health services that people with disabilities receive may be delivered with a health promoting focus; (ii) health promotion initiatives targeted at the general population may include components specifically aimed at the disabled; and (iii) specific health promoting projects for people with disabilities may be devised.

However, the development and extension of programs for the prevention of further disability, and the promotion of general health in the disabled population, are hindered by the lack of understanding of the socioeconomic implications of disability within society and mechanisms to address this. These issues are of considerable importance, as it is the funding arrangements which largely determine the scope and amount of health promotion received by the disabled, how this is distributed and to whom it is distributed. The current system of funding for healthcare and health promotion may be seen to contain certain inadequacies. This paper therefore aims to outline the most significant funding issues concerning health promotion for the disabled3, with a view to establishing a longer term research agenda.

1.1 Scope of the Paper

It is impossible to cover all areas of relevance and interest in any single research agenda, and certain judgements have therefore been made concerning what is considered to be both of sufficient priority and also practical to include. It is important to stress, however, that such inclusion and omission only reflect this need to establish boundaries to the scope of analysis, and do not necessarily reflect what may be considered to be definitive priorities. The scope of the review has been limited in five areas.

First, the focus of the paper is not intended to concern prevention of primary disability, but rather on the needs of the already disabled person. This may be, for instance, once their lives have been saved and they have been discharged from immediate rehabilitation4, for those born with a disability, or those acquiring a disability through old age.

Second, this paper will not be considering certain subgroups of the disabled population explicitly. That is, the review will encompass issues relating across the broad spectrum of the physically disabled, and not concentrate on issues specific to, for example, children with disabilities, the elderly or ethnic minorities.

Third, the paper will not be concerned with immediate post-disability care for those becoming disabled by accident, for instance the majority of those with spinal cord injury. This paper is concerned essentially with secondary prevention to reduce further disability, and with measures to improve the quality of life of the disabled, for

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3 Note that we are dealing here with specific issues involved in the funding of care and of health promotion for the disabled. For an excellent discussion of issues with respect to general health promotion funding see Richardson et al[24].

4 Note that we shall be covering long term ongoing rehabilitation needs, for example to prevent secondary disability.
instance by reducing secondary problems, such as urinary-tract infection, and in reducing handicaps resulting from a primary disability.

Fourth, the scope of the disabled under consideration is limited to those with physical disabilities, rather than mental disabilities. Notwithstanding this, many of the arguments and issues raised will apply to a greater or lesser extent to this population.

Fifth, the paper is concerned with all aspects of the disabled persons life which impact on their health status (broadly defined in terms of physical, mental and emotional well-being). Such a broad definition of health encompasses all aspects of the disabled persons life. Thus, reference is made in this paper to the funding of a range of government services for those with a disability, including income maintenance programs, pensions, educational support and mobility. However, primary concern will rest with the financing of the healthcare system and in particular the funding of health promotion for the disabled population.
2 Scope for the Beneficial Impact of Health Promotion in the Disabled Population

In common with all healthcare services, decisions concerning the relative priority of health promotion for the disabled should be based on information relating to three areas: (i) the public health significance or burden of suffering (measured by, for example, mortality, life expectancy and/or cost of illness); (ii) the theoretical preventability (efficacy) and practical preventability (effectiveness) of such health problems (ie that there is the potential to bring about a beneficial change through intervention); and (iii) the relative cost-effectiveness (efficiency) of individual health promotion measures aimed at achieving this potential. Note that cost-effectiveness does not refer specifically to cost-saving. Health promoting activities aiming to create and/or support less dependency and more productive lives for the disabled may lead to reduced health service costs. However, it is not necessarily to reduce costs that we might advocate health promotion initiatives, but also to result in an improvement in the quality of lives of the disabled, even if this increases healthcare costs.

The purpose of this section is to consider the public health significance and the potential beneficial impact of policies targeted at the disabled as background to issues in the financing of health promotion and healthcare for the disabled.

2.1 Epidemiology of Disability

The disabled population in Australia is significant\(^5\). In 1993 the Australian Bureau of Statistics (ABS) estimated that 3.2 million Australians (18% of the total Australian population) were disabled in some way. ‘Disabled’ was, in this case, defined according to whether a person had one or more specific conditions, such as loss of sight, loss of hearing or ‘disfigurement or deformity’, for six or more months. Such a ‘clinical’ view of disability may be seen as too narrow. In this paper the definition adopted is that proposed by the World Health Organisation, where ‘disability’ is seen as a process, moving from pathology (physical characteristic) to impairment (tasks unable to be performed due to pathology) to disability (tasks unable to be performed given the level of societal assistance provided) to handicap (disadvantages suffered as a result of disability). ‘Disability’ is therefore seen as a gap between personal capability and environmental demand and societal assistance. These definitional issues are further discussed in Appendix 2.

Notwithstanding such issues, of the 3.2 million defined as disabled by the ABS, 2.5 million (14.2%) were classified as handicapped (difficulty in performing tasks associated with daily living), of whom 721,000 (4.1%) were classified as severely handicapped (cannot perform one of the tasks of daily living, or requires personal help or supervision to do so). The most frequently reported primary disabling conditions were those of the musculoskeletal system and connective tissue, with 863,000 (4.9%) being disabled by these conditions. The next most frequently reported primary disabling conditions were hearing loss (450,000, 2.6%) and mental disorders (353,500, 2.0%). The most frequent handicap was difficulty in relation to mobility (1.8 million, 10.4%) (making up 68% of the handicapped sub-population). Next most frequent were difficulties in relation to employment (8.5% of the

\(^5\) It is important to note that, although this section is reporting the prevalence of disability, many of those who may be classified as ‘disabled’ according to ABS definitions would not define themselves or their health primarily in terms of their disability [25].
population, 60% of the handicapped subpopulation), self-care (5.7% and 37% respectively), and communication (2.9% and 19% respectively) [26].

Not only is the disabled population significant in size, but is also likely to increase. With advances in medical technology, more and more patients are surviving serious accidents and disease, but are, as a consequence, left permanently disabled. This has contributed to a two-part growth in disability: (i) the disabled as a group are, as a result of such technological progress in medicine, increasing in number; and (ii) with the population steadily aging, the amount of time spent with disabilities associated with old-age is increasing. The disabled represent a significant investment in healthcare resources, both in terms of primary disability and secondary complications and health needs. However, the scope for reduction in these resources, and/or for a more appropriate distribution to meet objectives more efficiently, is potentially large.

In addition, it is worth emphasising that those with disabilities are frequently multably disabled. For instance, ABS data shows that each disabled person has on average 1.6 disabilities. This evidence concurs with professional opinion and observation, as well as intuition, that the disabled population are at increased risk of getting additional disabilities and illness by virtue of their initial disability.

2.2 Resource Implications of Disability

It is worth noting that disability is not inherently a ‘cost’ to society. Disability, as defined above, suggests that each individual has a mix of abilities, requiring a greater or lesser level of support from the state or private sector (ranging from eye glasses to motorised transportation for instance), and involving other resource implications (from a day off for disabling hay-fever, to removal from the workforce due to spinal cord injury). It is likely that at any one time the proportion of the population not requiring some aid, medication or resource use of some kind for a ‘disabling’ event, transient or permanent, treatable or untreatable, will be the minority. However, much ‘disability’ in the sense used in this paper may be socially constructed, for example in ‘wheelchair-unfriendly’ buildings or prejudice of employers against the disabled. In this case much of the resource consequences flowing from the increase in reported prevalence of ‘disability’ may well be avoidable. Bearing this in mind, it is, however, clear that increases in reported disability (whatever the cause) will have resource consequences for society.

For instance, it implies the loss of skill and experience of people who become disabled and leave the workforce, and the consequent need to retrain workers. Disability may in addition have a doubly adverse effect: the disabled person loses his/her income from work, and the need to care for the disabled person may cause his/her spouse or other family members to lose his/her income as well. Disability often reduces the base of active workforce support for national social benefit systems, whilst it increases the expenditures of such systems and the costs of administration of benefits. It was estimated in 1985 that the total Commonwealth contribution to services for the disabled was $5,600 million, including $3,700 million spent on pensions and benefits to the disabled. States contribute about another $800 million to disabled care [27].

There is also a strong correlation between disability and poverty, deriving from a combination of reduced income for the family and the extra costs of disability. Healthcare expenditures are greater amongst the disabled as they have to bear the cost of disability-related expenditures, such as domestic help, transport, heating,
home aides and assistive devices. The level of financial support is often based on the cause of disability rather than level of financial need. Disability perpetuates poverty, but also poverty is a major factor leading to increased disability. In particular, the vicious circle of poverty and disability spirals to compound the primary disability with subsequent secondary health and social problems. For instance, it is estimated that around 62% of handicapped people on benefits have these as their principal source of income, implying a standard of living below or near the poverty line, and that 60% of income units with handicapped people do not have an income earner (compared with 23% of all income units), and that the more severe the handicap the lower the income [28].

The impact on the family is an important area to be considered. The implications of disability for the family and/or carer include increased personal stress and physical and emotional illness, reduced ability to care for children and undertake household tasks, reduced time/energy for work outside and within the home (paid and unpaid), reduced social contributions and interaction and a reduced status of family in the community (stigmatisation). These issues in relation to the role of health promotion are examined in more detail in section 3.6.1.

Perhaps the most compelling intuitive reason that disability will have considerable resource implications for society is the fact that most people live with chronic disabling conditions rather than die from them. Thus there is considerable need to prevent these conditions if possible, but also a need to make living with them as healthy as possible as individuals will have to live with them for a considerable period of time [29]. In addition, as the overall cost of care increases with dependency [30], the need to reduce lifetime dependency levels is also vital.

Much of the resource implications of disability are preventable, or at least reducible. For instance, a recent study showed that eradication of chronic disease with high fatality, such as cancer or heart disease, will lead to an expansion of overall morbidity and associated healthcare resource use [31]. In contrast, reducing conditions causing little or no mortality, but high levels of morbidity, had the potential to contract overall levels of morbidity and thus reduce healthcare resource use. This would suggest that health promotion campaigns aimed at eradicating not only primary disabilities, but also secondary consequences of such disabilities, as well as multiple disabilities, may well be of great overall benefit to society. For instance this would reduce costs in terms of rehospitalisation, reduced carer burden, and improve the workforce participation rate of the disabled person.

Health promotion has a role to play in all these areas through interventions at primary and secondary care levels, population education programs to make less handicap out of disability, and in promoting reform of funding and provision of health services. Of course, it must also be acknowledged that there are going to be costs that cannot be recouped, as the primary disability will never be removed. Although it is feasible that there may be some disability we cannot do anything about, it is likely that there is something we can do about each handicap and about reducing the effect of disability.
3 Healthcare Funding and the Disabled

Barriers\(^6\) preventing access to healthcare, employment, education, transportation and so forth are an important feature of the disabled persons quality of life and overall health status. All too often, however, it is not the disability that is the cause of barriers to these elements of daily living, but the external environment \([1]\). In particular, many of these barriers occur due to the various funding systems of services designed to provide support for the disabled and to finance health services and health promotion. This section considers six major issues in the funding of government services for the disabled, with specific reference to healthcare and health promotion.

3.1 Categorisation of ‘Disabled’ for Funding Purposes

This is perhaps the most critical issue concerning the funding of care for the disabled. Funding for the disabled depends almost exclusively upon them proving that they are disabled. People with disabilities receive compensatory provision on the basis of their disabilities and not their strengths\(^7\). However, for example, of those with a hearing impairment, some may see themselves as belonging to the deaf ‘community’. That is, some individuals may view deafness not as a disability but as constituting membership of a linguistic and cultural group. They may therefore seek community based provision such as support for Auslan as a ‘community-language’, equitable access to communication facilities and increased provision of interpreters. But, however much they may wish to be integrated, the established system of funding means they have a difficult time achieving this. For instance, they are still tied to definitions of disability for their government support and entitlements, and in asserting political action they are required to stress the ‘handicap’ they have in common. This does not promote a positive view of the disabled, but concentrates only on the negative aspects; the person’s weaknesses.

Similarly, outcomes and categorisation which are focussed almost exclusively on the \textit{inability} rather than the \textit{ability} are reflected in the resultant resource allocation decisions. This precludes opportunities, leading the disabled person to become segregated, frustrated and economically dependent. Such definitions tend to create a handicap out of a disability, skewing resources in ineffective directions - for instance, in allocating funding to those who remove themselves from the workforce and not providing allowance to those who remain. However, by assuming ability and disability combined, the resource allocation decision becomes one of altering the environment in order to focus upon maximising the ability side of the equation, rather than minimising the disability side. In aiming to reduce \textit{handicap}, we include both the ‘disabled’ \textit{and} the ‘non-disabled’, with a focus on removing environmental and social barriers in order to promote and enable all individuals more toward achieving their maximum state of well-being.

Although the number of those considered ‘disabled’ is increasing (see section 2.1), the structure of social spending (including government spending on healthcare and

\[^6\] Barriers are defined as perceptions regarding the unavailability, inconvenience or difficulty of a particular health promoting option. They may arise from peoples internal cognition’s, from significant others and from the environment \([1]\). Barriers of particular importance may be convenience of facilities, transportation and lack of information \([1, 32]\).

\[^7\] Defining ‘disability’ as those who attribute their inability to sustain employment to a physical or mental impairment or to a chronic illness will underestimate the prevalence of disability, since many ‘disabled’ hold down paid employment successfully \([16]\).
health promotion) still encourages dependence rather than independence. Programs of income maintenance and disability pensions, for example, can lead to an incentive, or reward, for staying dependent. The focus of the finance of disabled care, and the benefits system, as well as health promotion activities themselves, are therefore key. Ideally, funding for those who are disabled would be based upon the capacity of each individual to make maximum use of his/her abilities. The objective of achieving the optimum degree of independent functioning within societal life (ie integration) is achievable only by programs which foster independence through the removal of barriers to healthcare, education, employment, mobility and social integration.

3.2 Funding Educational Programs

Although much of the problem with access to healthcare and health promotion is physical, such as transportation and physical access to facilities, of equal, or perhaps greater concern, is inadequate provider knowledge [8,33]. Health professionals, particularly General Practitioners (GPs), it has been argued, must make the transition from ‘focussing health promotion on prevention’ and instead ‘should primarily promote the health of their patients, especially those patients with a [disability].’ (P269 [34]). However, in order to do this they must first be aware of the special health needs of the disabled which frequently is not the case. For instance, Burns et al [35], in a Delphi survey of experts on priorities for primary care with respect to the disabled, found that clinician education was a significant barrier to the disabled receiving adequate care.

Not only are doctors generally uninformed about the problems of people with disabilities, but they may also feel threatened by disability as the very personification of medical failure - especially if the disability is due to some medical intervention [35]. There is also a tendency toward ‘diagnostic overshadowing’, whereby the doctor tends to ascribe all abnormalities to the primary diagnosis of disability, ignoring other possible conditions - this is crucial as most disabled persons have multiple disabilities (as illustrated in section 2.1). For example, one study showed that individuals discharged from rehabilitation with spinal cord injury frequently saw their GP, and that the topics of discussion were overwhelmingly about the disability. However, the individuals involved revealed that they desired health promotion services (particularly concerning exercise, stress management and diet) more frequently than disability services (such as pressure sore prevention, bowel program management or bladder problems). This is due in combination largely to the health care providers only focussing on the disability, but also the client being unaware of how to obtain the care they need [36]. The impact of improved education toward the needs of the disabled patient could potentially result in further illness prevention, hospitalisation avoidance, and minimised length of any hospital stay [33].

However, education should not be content merely with ensuring that the health professional is aware of the needs of the disabled individual. There also needs to be an awareness, by the disabled person as well as the health professional, of the role of medicine as potentially iatrogenic and disempowering. The well-known sociological concept of the medical model being centred around the acceptance by the client of the ‘sick role’ has added importance in considering the disabled. In sociological models, the ‘sick’ person receives certain privileges (mainly exemption from normal social activities and responsibilities) but is expected in return to accept the sick state as aberrant and to work towards ‘recovery’ or ‘cure’ by co-operating with the doctor. That is, the role and interaction of doctor and patient is constructed around illness as something that is curable. However, when considering disability
there is a situation where cure is frequently not the endpoint of the exercise, and acceptance of the sick role thus leads the person to regard themselves as permanently deviant and devalued.

The dependency of the sick role removes the incentive for the person to take control of their life. Such a model need not be limited to doctors, but also occurs in other rehabilitative professions - where ‘cure’ is replaced by ‘rehabilitation’. In either case the central feature is that it is assumed that it is the patient who must change to meet an adequate performance in terms of activities in daily living. It is therefore important that health promotion activities are focussed toward educating the health professional and disabled individual away from such an assumption.

An additional problem with the disabled taking on a ‘sick role’ is that this encourages them to see any disability as total - the disabled may need educating about the concept of partial disability and the concept of the self as a mix of varying degrees of ability, rather than disability. Self concept is an important component of education programs for the disabled, as after acute illness, for instance, self concept remains unchanged, but after disability they are aware of change and stigma of society. For professionals often the intent is making sure the patient is independent, but they may not wish to be so [37].

Health promotion, provided with appropriate funding, can play a key role in the education of patient, professional and the general public concerning the health needs of those with a disability [38, 39].

### 3.3 Healthcare Reimbursement Systems

Funding by procedures performed, with no consideration of extra resources for people with special needs, leads to a problem in the treatment of the disabled person. Central funding and the use of prospective payment systems (such as ‘casemix funding’) mean that the cost of care becomes a barrier to the disabled person receiving even the normal level of care that most Australians would expect. As consultations, and any other form of care, can take longer with a disabled person than a non-disabled person, the additional cost is both a disincentive for the disabled themselves to seek care and for the medical industry to provide it. As Evans [40] succinctly states, ‘since [prospective payment system] funding provides incentives for early hospital discharge, rehabilitation programs will need to assess the impact on discharge disposition and the long term outcome of disabled patients’ (P294).

For instance, because of problems the disabled may have in mobility and vision, even a routine medical procedure can take considerable time (even signing a Medicare form can take ten minutes). As no extra allowance is made for this difficulty, people with disabilities are likely to fare particularly badly under systems such as casemix funding that provide funding at a set rate for each procedure. This system provides a financial penalty for hospitals that treat clients with disabilities who require more attention than the ‘average’ patient, and has led to an increased emphasis on streamlining care for such people; a development that does not necessarily lead to improved outcomes.

There are also issues of appropriate funding incentives for general practice, particularly in the provision of health promotion for the disabled. At present in Australia the GP may incorporate some element of health promotion, such as dietary advice, within the traditional ‘6 minute’ consultation. If such advice was likely to take
longer than this, the incentive would not be to provide such advice since consultation reimbursement is fixed. Although certain procedures, such as various forms of screening, do carry a separate financial incentive for the GP to undertake, many health promoting interventions do not. This is particularly so in the case of routine care and treatment that may be delivered in a health promoting way to the disabled. Such potential financial disincentives for the provision of health promotion in general practice are compounded when considered alongside ‘diagnostic overshadowing’ (see section 3.2).

Management of funds for health promotion, it may be argued, should be more flexible. For instance, in making money available to GPs for health promotion as an additional part of a consultation, to enable DRG weighting of disabled treatment to include a health promotion component [38], or a move toward a more appropriate overall system of finance, such as case-management (see section 3.4). Change of this latter sort would likely consist of a community based multidisciplinary team which is client centred and goal oriented. However, the appropriate system of financing will also be dependent upon the current global system of healthcare financing.

3.4 Interdepartmental Cooperation in Financing Services

Few important outcomes can be achieved by the health service working in isolation. For example, in order to minimise the handicap imposed by paraplegia, it is necessary to prevent medical complications and progressive deformity, maintain physical fitness, and be trained in the use of appropriate technical aids. But it is also necessary to live in a house which is accessible and useable by someone in a wheelchair, in a location where there are enough dropped kerbs, buildings with public access and transport facilities to allow disabled persons autonomy in the fulfilment of their personal potential. Rehabilitation would not have been successfully achieved if the disabled person were to become marooned in an inaccessible flat, however good their self-care and wheelchair skills may be. In order for appropriate outcome targets for rehabilitation services to be formulated, it will often be necessary to test the combined effectiveness of health, social and local authorities, including education, housing, transport and employment.

At present, funding of government services, such as healthcare, social services and education, are distinct and separate. Even within healthcare there is financial separation of primary and secondary care, and state and federal responsibilities. With such diversity of budgets, and a financial climate of cost-control, there is little incentive for active cooperation and much incentive for cost-shifting. This creates an extraordinary complexity in the funding and provision of healthcare for the disabled, with both funding and provision coming from a variety of disparate and wholly or partially separate sources. For instance, one carer has been quoted as using 26 phone numbers regularly to coordinate care for her disabled child [38].

One means which has been proposed for reorganising funding and provision is case-management, which has been adopted in a variety of settings, such as the Social Health Maintenance Organisations in the US and private sector initiatives [41-43]. Under this system one individual, the case manager, would have the responsibility for organising, coordinating and (if a budget holder) purchasing all the various services which the disabled individual may require. A variety of models of case-management may be considered, from simple negotiation for care, to being a partial or total budget holder, to the disabled person themselves becoming their own case-manager [44].
However, the appropriateness and efficiency of case-management has not been established unambiguously. Evidence suggests that although case-management may be an effective and efficient organisational mechanism for some clients (principally those with complex needs [43, 45-50]), many clients with low to moderate levels of disability can gain considerable benefits from community services provided without case-management [43, 51-53]. Due to this a range of other approaches has been suggested, including reforms along the British system of purchaser-provider split [43].

These potential means of reform are clearly complex, and will require further research with respect to the disabled population. It is, however, worth noting that policy documents from the Commonwealth [39] have suggested that care should be provided in a coordinated and collaborative fashion (including private sector institutions and employers as well as the public sector) [38].

3.5 Incentives to Avoid Unnecessary Rehospitalisation

Studies indicate that persons with disabilities experience higher rates of hospitalisation than the general population. For instance, DeJong et al [10] found that nearly 40% were rehospitalised within the first year after discharge, and 16% were hospitalised two or more times during that period. Other studies confirm this impression, often with even higher readmission rates (such as 60% or 70% for various conditions) [5,7,54, 55]. One study even estimated that rehospitalisations could account for 60% of all hospital costs [55]. It is important to recognise that the majority of the leading causes of such readmission, such as urinary-tract infection, decubitus ulcers, pressure sores and respiratory tract infection, are all entirely preventable [10, 56-59].

The prevention of these causes of readmission will, however, require an incentive for the various agencies involved to prevent such readmission and a closer cooperation between these providers. Rehabilitation services, for instance, have a wide remit in the promotion of health in the disabled, including prevention of such secondary admissions [60], and funding arrangements need to recognise this role. Importantly, the hospital sector requires an incentive to review admissions to identify potential preventable admissions, and work directly with the community to address the problem [38]. As both previous sections show, there is a great need for a reappraisal of healthcare reimbursement systems for health promotion and the disabled, as well as greater interdepartmental cooperation, and the application of these to rehospitalisations could provide an effective, and profitable, place to begin.

3.6 Non-Healthcare Sector

Much health promoting activity is, and could potentially be, carried out within the non-healthcare sector. This will encompass areas of home and community care and also private sector input. Both of these are considered below.

3.6.1 Home and Community Care
A crucial distinction to be made with respect to home and community care is between those services considered to be ‘informal’ care and those which are ‘formal’ care. Informal caregivers may be distinguished from formal community care as the family and friends of the individual concerned who are unpaid caregivers in the home supporting people of all ages with severe and chronic disabilities [61]. Formal community care would encompass paid agencies such as home-help, community nurse visits and meals-on-wheels, who provide care for these home-based individuals on a paid basis. The balance of each of these sectors in the delivery of care will have important implications for the funding of care, both in structure and overall amount, where care may most effectively and efficiently be delivered, and the effectiveness of delivering a health promoting message to the disabled [62, 63].

In terms of the cost of care incurred by informal and formal community care, several studies have been performed which indicate that informal care services are used more and at a greater imputed cost than formal services [64-67]. For example, one recent study estimated that informal care of the disabled elderly comprised almost 80% of the total cost of (formal and informal) community care [68]. However, not only is the use of informal services great, but varies directly with the severity of disability and level of dependency. In general, the more complex a person’s disability, the more informal carers tend to contribute to their support and the wider the range of different services needed to help solve their problems [69, 70]. Thus, if costs of such care are not accounted for, then by such informal care attracting no funding we are effectively discriminating against those most in need; this will have severe equity implications.

Families and other unpaid caregivers are an important source of support for the disabled [61, 71-74]. It is expected that the burden on informal caregivers will continue to rise as the population ages and becomes more disabled [75, 76], the organisation of care continues to develop and change [77, 78], community care grows [61], and the level of disability for each person increases [79]. Informal care is thus becoming of increasing interest both overseas [80-83] and also in Australia at both a research [84-87] and policy level [88, 89]. In Melbourne, for example, the Victorian Health Promotion Foundation funded a program specifically to promote well-being and prevent ill-health in the informal care giver [61, 90].

In addition to the financial burden, studies have shown that informal carers can suffer from illness brought about by caring [91]. Services for caregivers generally are designed to prevent deterioration in the caregivers health, promote their health, and sustain their capacity to care [92, 93]. For instance, studies which have conducted evaluation of such services for the elderly have provided evidence of their effectiveness in reducing the burden of illness amongst the informal care giver, and improved quality of life [94-96]. However, such services as group support, counselling, respite care and domiciliary services are not often used, largely because the caregivers lack of knowledge about the existence of these services, how to receive them or funding of these services [97, 98].

Overall, informal care is an important aspect of care for the disabled, and the delivery of health promotion to them. They are an important force to be considered in the design and provision of services. An understanding of the role and perspective of informal carers is a vital part of understanding the context and need for health

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There are also non-monetary costs, such as destruction of self-esteem, increased personal and marital stress, reduced ability to care for children and the household, and reduced social interaction.
promotion services for the disabled. It is critical therefore that the funding of such care be recognised in importance and structures put in place to ensure that this important area of care is capitalised upon.

3.6.2 Private Sector

There is a growing interest in the use of health promotion in the workplace, with many large corporations (such as Xerox, AT&T and the Victorian Railway Company (VicRail) [99, 100]) now having their own medical departments or programs established to conduct a range of occupational health initiatives. The philosophy behind this is to promote the employees health, thus increasing productivity, and also to reduce the company’s health care costs by controlling the disability period during which the employee is off work [101, 102].

Employer based health promotion and disability management emphasise the early identification of risk factors, planned management of physical and disability-related symptoms, a willingness to modify jobs, and the establishment of personnel policies that facilitate work return and job retention rather than ‘defacto and premature retirement for chronically ill, injured or disabled workers’ (P218, [100]). Such work based programs tend to encompass both disability management and health promotion activities [99], where ‘disability management’ refers to the active process of minimising the impact that a disability has on the persons ability to function in their work-based role [99], and health promotion refers to the prevention of further disability and promotion of good health habits [99]. Of course there will be a considerable degree of overlap in these two concepts.

Disability management, in identifying employees who are showing signs of chronic illness or disability and providing suitable intervention, is thus an essential part in: (i) developing the individuals own resources through a variety of health promotion initiatives; and (ii) the removal of barriers imposed by the work environment. Health promotion is a critical part of this disability management, as it is designed to prevent further illness and disability, for instance by reducing risk of injury [100]. Such disability management programs often use a ‘case manager’ to coordinate the multiple needs of the disabled employee [102], but also to assess the progress of the disabled person, their work and home environments and care and generally acting as that persons advocate [102].

Such interest by the private sector could be capitalised upon by health promotion policy. For instance, public funds could be used to encourage individuals to demand, and employers provide, health promotion. Secondly, they could be used to finance or subsidise particular activities to make them more accessible [38].
4 Research Agenda

This paper has briefly reviewed six major areas of health promotion and healthcare which need consideration from a funding perspective with respect to the disabled. The recommendations for future research raised in section 3 are more formally established in this section.

4.1 Categorisation of ‘Disabled’

It was argued that the structure of government funding of services for the disabled depends almost exclusively upon them proving that they are disabled. Such a focus on inability rather than ability may result in inappropriate, and inefficient, resource allocation decisions. For instance, in allocating funding to those who remove themselves from the workforce and not providing allowance to those who remain.

Research is therefore required to develop a more appropriate concept of what ‘disabled’ means. Of importance in such a process would be the need to combine ‘ability’ and ‘disability’ along a continuum in order to focus more on peoples ability rather than inability. This would then enable the focus of resource allocation to become one of altering the environment in order to focus upon maximising such ‘ability’, rather than minimising ‘disability’. Such a refocus of the meaning of ability and disability would emphasise removal of environmental and social barriers in order to promote and enable all individuals to achieve their maximum state of well-being.

Ideally, funding for those who are ‘disabled’ (or perhaps in line with a new definition, ‘less-abled’) would be based upon the capacity of each individual to make maximum use of his/her abilities. The objective of achieving the optimum degree of independent functioning within societal life (ie integration) is achievable only by programs which foster independence through the removal of barriers to employment, mobility and social integration.

4.2 Education in the Provision of Healthcare

Critical for the provision of appropriate healthcare for the disabled is the education of health professionals to view the disabled in a sympathetic and empathetic light in order to fully understand and respond to their needs [33-35, 103, 104]. Doctors who are perhaps uninformed about the problems of people with disabilities may have a tendency toward ‘diagnostic overshadowing’. Such a situation is problematical for the disabled person achieving better health since it may be difficult for them to get treatment and advice related to their other health problems [36].

The impact of improved professional education concerning the needs of the disabled patient would be expected to result in the prevention of further illness, avoidance of unnecessary hospitalisation and minimised length of any hospital stay [33]. Health promotion can play a key role in the education of patient, professional and the general public concerning the health needs of those with a disability [38].

4.3 Healthcare Reimbursement Systems
It was argued that funding by procedures performed, with no consideration of extra
resources for people with disabilities, leads to problems in the treatment of the
disabled person. Such prospective payment and casemix based funding means that
the cost of care becomes a barrier to the disabled person receiving even the normal
level of care that most Australians would expect [40]. Infact, such a system provides
a financial penalty for hospitals that treat clients with disabilities who require more
attention than the ‘average’ patient. There therefore needs to be research into a
more appropriate means of funding. For instance, funding made available to GPs for
health promotion as an additional part of a consultation, to enable DRG weighting of
disabled treatment to include a health promotion component, or a move toward a
more appropriate overall system of finance, such as case-management.

4.4 Interdepartmental Cooperation in Financing Services

Combined with all of the above there needs to be consideration of cooperation
between the variety of providers and funders of services for the disabled. Few
important outcomes can be achieved by the health service, community services or
education services working in isolation. This may be achieved, for instance, by
greater emphasis on, or developing a new type of, case-management in organising
funding and provision [38, 39, 44].

4.5 Unnecessary Rehospitalisation

It is clear that persons with disabilities experience higher rates of hospitalisation than
the general population [5, 7, 10, 54, 55], and yet most of the causes are entirely
preventable [10, 56-59]. However, such prevention of rehospitalisation will require
an incentive for the various agencies involved to prevent such readmission and to
engage in closer cooperation. Rehabilitation services, for instance, have a wide
remit including prevention of such secondary admissions [60], yet funding
arrangements do not recognise this role. Importantly, the hospital sector requires an
incentive to review admissions to identify potentially preventable admissions, and
work directly with the community to address the problem [38]. As already mentioned,
a reappraisal of the reimbursement systems for health promotion and the disabled is
required. Greater interdepartmental cooperation, and the application of funding
reforms to rehospitalisations could provide an effective, and profitable, place to
begin.

4.6 Non-Healthcare Sector

Much health promoting activity is, and could potentially be, carried out within the non-
healthcare sector, which encompasses areas of home and community care and also
private sector input. Home and community care (both formal and informal) is an
important input into the delivery of health promotion and healthcare to the disabled,
as well as many other services. Of even more importance, giving the growing
population of those considered to be ‘disabled’, is the balance of such costs between
the formal and informal sectors. Several studies have been performed which
indicate that informal care services are used more, and at a greater imputed cost,
than formal services [64-68]. By such informal care attracting no funding we are
effectively discriminating against those most in need. This will have severe equity
implications.\(^9\)

\(^9\) Note also the non-financial burden [91].
Overall, informal care is an important aspect of care for the disabled, and the delivery of health promotion to them. It is vital therefore that the funding of such care be recognised in importance and structures put in place to ensure that this important area of care is capitalised upon.

The private sector role in health promotion for the disabled is also important. Many companies are seeing the benefits of health promotion for this group of employees, thus increasing productivity and also reducing the company’s health care costs by controlling the disability period during which the employee is off work [101, 102]. Such interest by the private sector could be capitalised upon by health promotion policy. For instance, public funds could be used to encourage individuals to demand, and employers provide, health promotion.
5 Conclusion

This paper has highlighted several key aspects of the current state of care and service provision for the disabled, with emphasis on health promotion. In particular, the paper raised several areas where research and policy should be focussed to improve and restructure funding to reduce barriers in access to appropriate healthcare and health promotion for the disabled. There is a need to find models of finance and delivery of care, as well as specific interventions, that will avert unnecessary rehospitalisation, respond to the new health needs of the disabled as they get older, offer access to timely primary care, focus on the outcomes of such promoting activities, lead to shorter stay in hospital, develop community-based rehabilitation, and encourage the role of carers and volunteers. In the end this requires incentives for providers of care to consider the longer-term needs of the disabled [56]. One of the more promising ways to proceed in the restructuring of health promotion and care for the disabled is potentially the move toward case-management [44].

Although a research strategy was outlined in section 4, there are two other factors which may need to be taken into consideration. First, a lack of information on the impact of health promotion activities for the disabled implies a funding system that should be open to experiment and new ideas, and recognise the need to build up the collection of appropriate data. Second, as the benefits of health promotion for the disabled may be less visible than in other areas, or take longer to accrue, funding will require protecting such that it may be sustained.

A restructuring of funding arrangements in healthcare is not a task to be undertaken quickly. However, changes are already taking place in an attempt to deal with the perceived ‘crisis’ in the funding of healthcare overall (such as a move toward case-mix funding, and managed competition initiatives). There is both potential for the disabled to lose in this general restructuring, or to gain. The danger is that with such restructuring health promotion, particularly for those already disabled, may seem a ‘soft target’ for funding cuts, or that without a voice such restructuring will, as a side-effect, disadvantage the disabled (such as with casemix funding). However, there is also the potential to use the current willingness, even eagerness, to change the structure of funding to promote the health of the disabled. For instance, there is a greater move toward budget-holding and case-management which could be of great benefit to the disabled, as outlined above. Whatever the potential, it is vital that research is undertaken in a timely fashion to capitalise on the changes taking place to ensure both that the potential harm to the disabled is minimised, but also that the changes which will be beneficial are promoted and capitalised upon.


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Definition of Health Promotion

Overall, there is some consensus that “health promotion is the maintenance and enhancement of existing levels of health, through the implementation of effective programs, services and policies.” (p61, [19]). However, the means by which it achieves this are varied and different definitions are open for what may be considered health promoting programs, services and policies. For instance, health promotion may be viewed as a process of disseminating information and teaching skills to help people improve their nutritional habits, stress management techniques, social health and environmental sensitivity, with the goal of enabling the individual to improve their level of “wellness” [13]. Similarly, it is often seen to encompass specific actions associated with client education and informational and emotional support to enable them to become more independent in living [36]. On a broader level health promotion may be defined as “any combination of health education and related organisational, economic and environmental supports for individuals or collective behaviour conducive to health” [105].

This paper takes a broad view of health promotion based on the Ottawa Charter, which describes health promotion as the “process of enabling people to increase control over the determinants of health and thereby to improve their health” [20]. Health promotion is thus a way of working which [106]:

- concerns everybody in the context of their everyday life, rather than just targeting people at risk for specific diseases;
- focuses on the determinants, or causes, of health; including personal, behavioural, social, economic, and environmental factors;
- uses combinations of diverse methods and approaches at both population and individual levels within a range of sectors;
- seeks to involve people in identifying the problem, deciding what needs to be done, and in implementing the action;
- applies across the continuum of health care in the form of primary, secondary and tertiary prevention.

As a consequence of such a broad definition, all health professionals may be considered to have a health promotion responsibility. What contrasts health
promotion, however, against other interventions, such as disease treatment and institutional care, is the type, level and nature of the interventions. It has a strong orientation towards prevention and includes action at a population level as well as with individuals. Such approaches may include personal education, personal health services, mass media information, community action, organisational development, environmental support and public policy measures [21, 22].

In general terms these measures can be distinguished from, for example, preventive drug therapy or surgery, in that they do not provide a specific medical treatment for a diagnostic condition. Instead, health promotion measures involve a range of processes aimed at, for example, protecting people against disease/injury (such as worksafe projects), inducing health behaviour modification (such as exercise), informing and modifying social and professional values and attitudes (by education) and lobbying for changes in the social and political environment in which people live (by legal means to make buildings more wheelchair friendly) [107].

The approach taken in this paper is to view health promotion in this wide public health setting, to include not just patient and public education, but also health protection, preventive medicine, health education, public policy and community empowerment [17]. Health protection concerns enforced regulation of behaviour, such as air pollution, occupational health and safety and radiation protection. Preventive medicine is the use of scientific advances to alter the natural course of disease to prevent the onset or progression of illness, such as immunisation, mammography screening, management of diabetes. Health education is often synonymous with health promotion in that it seeks to provide learning experiences which facilitate the voluntary adoption of healthier behaviour, such as “healthy heart” campaigns, quit smoking and “slip-slop-slap”. Health policy seeks to create a social, economic and physical environment to assist and encourage people to make these healthy choices, such as pricing policies of tobacco, and wheelchair access in public buildings. Community empowerment aims to improve the capacity of a community, or individual, to identify, respond and resolve their problems, which basically seeks to mobilise those with a common interest to act as a cohesive power or pressure group on policy makers [17]. Thus, health promotion and the disabled encompasses all these areas.

The concept of health promotion as outlined above is critical for those with disabilities, because it emphasises self-care rather than expert care, and thus promotes an active, independent attitude toward healthcare. Its orientation to lifestyle management is already in keeping with self care regimens established as part of the disabled persons life [15].
Definition of Disability

The definition of disability influences the reported prevalence of disability, the perceived need for services, associated measurement of economic and social costs, the capability and desire of disabled people to return to employment, and the impact of interventions designed to minimise disability and handicap in society. Unfortunately, there is no easy definition of disability, as the primary distinguishing factor of the population of people with disabilities is their lack of a common characteristic.

In popular terms, disability may be defined according to whether something is curable (disability is seen as incurable) and the extent to which this causes differing (socially defining groups eg those with arthritis feel common identity, but those with bad teeth see themselves as normal people going to the dentist). Generally, 'labels' in everyday life are based on the extent to which the person can be separated from their condition (the extent to which the condition is intrinsic and thus distorting). Common definition of the disabled tends to be based on social and cultural premises which assess the extent to which the individual can be considered as 'abnormal'. This is, however, of little value when attempting to define 'disabled' for use in empirical research.

A more ‘formal’ means of defining disability to enable statistics on the prevalence of disability to be collected has traditionally been based on health conditions. This is largely a clinically based model which views particular disorders as disabling, covering any health impairment provoking restrictions in normal function for an extended time period. For instance, the ABS 1993 survey on disability (see section 2.1) defined a person with a disability as having one or more of the following conditions which had lasted, or were likely to last, for 6 months or more:\footnote{Note that the ABS do not measure pathology directly, but assess what people think of themselves. This makes it impossible to distinguish changes between the way people are and the way they think they are. Such data are therefore difficult to interpret, as changes may be due to an underlying change in prevalence, change in diagnostic techniques, greater willingness to talk about disability and/or greater availability of aids moving more to the mild handicap category. [38].}

\begin{itemize}
  \item loss of sight (even with glasses/lenses)
  \item loss of hearing
  \item speech difficulties in native language
\end{itemize}
- blackouts, fits or loss of consciousness
- slowness at learning or understanding
- incomplete use of arms or fingers
- incomplete use of feet or legs
- long-term treatment for nerves or an emotional condition
- restriction in physical activities or in doing physical work
- disfigurement or deformity
- need for help or supervision because of a mental disability
- long-term treatment or medication (although still restricted in some way by the condition being treated)
- difficulty gripping and holding small objects
- long-term effects of head injury, stroke or any other brain damage
- any other long-term condition resulting in a restriction

A handicapped person was defined as a disabled person aged 5 years or over who was further identified as being limited to some degree in his/her ability to perform tasks in relation to one or more of the following areas: self-care, mobility, verbal communication, schooling, and/or employment.

However, the most comprehensive definition of disability is provided by the World Health Organisation (WHO) [108], who consider ‘disability’ as a process - moving from pathology (characteristics of physical body) to impairment (operations that the person is unable to perform because of those characteristics) to disability (activities that the person is unable to do, given the level of assistance provided in the society they live in, because of that inability) to handicap (the disadvantages they suffer as a consequence). Impairment is seen to be a permanent or transitory psychological, physiological or anatomical loss of body structure or function. Disability by contrast is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being; it may be temporary or permanent, progressive or regressive. However, handicap, which is commonly what is thought of as ‘disabled’ by lay definition described above, is a social disadvantage for an individual resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is considered normal for that individual. Thus one can be impaired without being disabled, and disabled without being handicapped.

The important distinguishing factor here is between intrinsic disability (without personal or equipment assistance) and actual handicap (even with such assistance). ‘Disability’ is therefore not considered a personal characteristic, but is instead a gap between personal capability and environmental demand (thus, for example, being dependent on some assistance to do daily tasks maybe considered to be a disability, but being without that assistance would lead to handicap). According to this definition, policy should therefore focus not only on impairment and disability in the medical sense, but crucially on the prevention of handicap, in the sense of the removal of the gap between personal capability and environmental demand [109]. This definition therefore concentrates on the physical environment as much as on the individual with the impairment.