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Paper title: **Forgotten needs, creative responses: Systemic transport issues for people with dementia**

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Abstract (200 words):

A significant and growing population in our community are transport disadvantaged due to their cognitive impairment resulting from dementia. Despite this, government services in particular have failed to recognise the special needs of persons with dementia. This is illustrated through the personal story of John Mitchell, in this instance, whose safety was put at risk through the lack of suitable transport provision. Reliance on taxis poses some risks, especially for those with significant mental confusion. Both the Passenger Transport Act and Disability Discrimination Act indicate requirements to be met, both of which are defaulted in this situation. The lack of transport provisions for people with dementia has been of long standing in its impact on quality of life, and a range of examples are given. A brief history of Access Cabs and subsidised transport demonstrates the focus on physical disabilities and the resulting inequities for those with cognitive impairment. Frequent reviews have indicated requirements for change but policy inertia has resulted. A systemic approach is required to meet the varying needs of this group and potential ways ahead are indicated. The responsibility of government to take action to overcome barriers and achieve creative responses to the current inequities is outlined.

Introduction

This paper will address the relationship between dementia and transport. It will provide a consumer viewpoint to the issue and indicate some future research directions. We consider that this paper will give a strong message to transport planners and researchers about a neglected area of research and policy.

Dementia is a progressive and disabling condition, primarily of older persons that causes irreversible brain damage. In 2002, more than 160,000 Australians had dementia with the condition affecting one in three people over the age of 80 (Access Economics, 2003, 32). The prevalence of dementia has increased 62% in the last decade (Access Economics, 2003, 43). Despite this, health, aged care, transport and other government services have failed to recognise the special needs of persons with dementia and in many cases, have thereby failed to provide adequate or appropriate services to this increasingly large group of people.

This will be illustrated through a personal story about my late father. The failure to provide appropriate transport services to people with dementia not only limits their quality of life and participation in the community, but can, in cases like my father's, actually place dementia sufferers at serious personal risk. I am sure my father's experience was not unique, but is reflective of a general failure by transport systems to equally recognise cognitively impaired persons, with physically impaired persons, as being transport disadvantaged, with special transport needs.

Whilst there has been progress in providing transport services for the physically impaired, this paper will illustrate that little or no progress has been achieved to date in providing transport arrangements for the intellectually impaired, such as those suffering dementia in South Australia. The second part of this paper from the Alzheimer's Association in SA will look at some preliminary results from a literature review and survey of community transport, indicating future research and policy imperatives.

Some facts about dementia

As a result of the ageing population, the number of people in the community with dementia is rapidly increasing at a rate which has been described as the *dementia epidemic*. It is predicted that in 2040, half a million Australians will have dementia (Access Economics, 2003, iv) and that it will be the number one cause of disability for our aging baby boomer population ahead of cardiovascular disease, cancer and depression (Access Economics, 2003, 80). It is set to become the number one health concern and has significant socio-economic impacts. Dementia is the most expensive mental health item in Australia, costing \$3.2 billion in 2002, mainly comprising residential care costs of \$2.9 billion. By the end of the decade these costs are expected to nearly double (Access Economics, 2003, iv).

Those of you who have some personal knowledge and experience of dementia, I am sure will agree that it is a terrible condition. Not only does it dramatically affect the quality of life of the person with the condition, but it is also traumatic for family members to witness the progressive decline and degradation of the person they once knew.

Dementia is a condition caused by a number of diseases which can impair memory, thinking, orientation, comprehension, language, judgement, emotional control and social behaviour. The most common are Alzheimer's Disease, vascular dementia, often associated with multiple strokes, dementia with lewy bodies and fronto-temporal dementia. The progression of dementia is categorised as *mild* in the early stages, *moderate* during the middle stage and *advanced* during the late stage before the person dies. The symptoms of dementia vary, depending on the part of the brain affected and the characteristics of the individual. They include, problems with memory, difficulty finding words, finishing thoughts or following directions, difficulty performing familiar tasks or learning new ones, a failure to recognise objects or people despite having knowledge of their characteristics, neglect of self, including hygiene and eating. There can be psychiatric and behavioural features which include depression, delusions, hallucinations (visual and auditory) and behaviours such as wandering, incessant walking or agitation, repetition, following and socially inappropriate behaviour. (Access Economics, 2003, 1).

In the early stages of dementia there is short term memory loss and mild cognitive difficulties, but the person is still able to maintain activities. In the middle stage the person is usually physically active but there is significant impairment in judgement and decision making, requiring assistance and often supervision. Difficulties are evident with simple and routine tasks such as shopping, cooking, driving or handling money. In the later stage the person becomes incontinent, there is global memory loss and they completely lose the ability to care for themselves. They are unable to perform basic tasks such as dressing, eating, and bathing, and eventually become immobile and require nursing care (Alzheimers Association ,1999, 1).

John Mitchell's experience

My late father, John Mitchell, suffered dementia. He was a World War II veteran who died in September last year aged 78 years.

In January, 2003 my father collapsed at home and was admitted to the Daw Park Repatriation General Hospital where he underwent major surgery for facial cancer. This resulted in the loss of an eye and a substantial part of the right side of his face and was followed by an extensive course of radiotherapy.

My father's dementia was classified as advanced. He was permanently disorientated as to time and place – put simply he didn't know what day it was, the date, time or where he was. He was often highly agitated and completely unaware of his circumstances and medical condition, having no short term memory. He was acutely confused about every aspect of his life, including where he lived and was unaware of his placement into nursing home care. At times he suffered hallucinations. He was transferred from hospital to a secure dementia unit of a nursing home in May 2003, where he spent 3 months prior to his death. However, during the period of time that he was in nursing home care, he was required to attend a range of medical appointments at the Repatriation General Hospital and the Adelaide Radiotherapy Centre at Flinders Private.

Owing to his war service with the Royal Australian Navy, my father was a Gold Card Holder, which meant he was entitled to receive a range of health care services, which included transport and travel assistance to obtain health care. To provide transport services for veterans, the Department of Veterans Affairs rely on general taxis, or ambulance if the

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medical circumstances necessitate ambulance travel. My father did not qualify for ambulance transport and general taxis were the only mode of transport available to convey him to medical appointments.

On learning this, given my father's mental state, I immediately became alarmed at the potential risks associated with taxi transport and made enquiries of Veterans Affairs to determine if there were other more suitable modes of transport available for persons with dementia. I was advised that there were no other forms of transport available and that transport for dementia sufferers had not been specifically considered. I pointed out that given my father's confused state, it was highly likely that he could re-direct a taxi driver to his old home address, or some other place, as he was unaware of where he lived. Veterans Affairs assured me that this could not happen. They explained that the Department of Veterans Affairs has Agreements with a range of taxi providers, and that taxi drivers are required to transport veterans to the destination specified at the time of the booking.

This did not allay my fears and I subsequently searched vainly for other options.

I ascertained that my father was ineligible to utilise Red Cross Courtesy Cars because he was a Gold Card Holder and eligible for Veterans Affairs transport services. S A Ambulance confirmed that he would not qualify for non-emergency transport as his medical circumstances did not necessitate ambulance transport i.e. he did not require treatment, such as the administration of oxygen en route to medical appointments, nor did he require stretcher transport owing to immobility. He was also not eligible to utilise Access Cabs as this scheme is exclusively for persons suffering severe and permanent physical impairments. I also established that in accordance with the specified care and services outlined under the Residential Care Manual, nursing homes are only required to make transport arrangements and are not obliged to provide transport services.

I was therefore reluctantly forced to rely on general taxis as the only means of transport available through Veterans Affairs.

From the safety of a secure dementia unit, where he had no access to the outside world, my father, unaccompanied and in a permanently confused, agitated and disoriented state, was transported by general taxi to a medical appointment at Flinders Private one winter's afternoon in July last year. Arrangements for his return to the nursing home were made by reception staff at Flinders Private and he was subsequently collected by taxi for the return journey. However, rather than being taken to the nursing home as specified by Flinders Private, my father, as predicted, re-directed the taxi driver to his old home address, unaware that he no longer lived there. This re-direction was queried at the time by the taxi driver with the radio room, however as passengers are legally entitled under Regulation 59(2) of the Passenger Transport (General) Regulations 1994 to re-direct a taxi driver during the course of their journey, the radio room advised that the re-direction could stand as long as my father paid for the travel to the new destination. My father agreed to pay the re-directed fare, despite the fact he was unaware he had no money with him.

He was therefore taken to his old home address where he had lived for 48 years. It was unoccupied, secure and in darkness. When my father was unable to pay the fare, after some 10 minutes neighbours were alerted to the problem and came to his aid. They paid the fare, took my father inside and contacted me.

This re-direction by my father could have had life threatening consequences had it not been for the neighbours who assisted him. The taxi driver took him to premises that were no longer occupied. It was dark and cold and being disorientated and confused, he could have wandered off and become lost. Given the weather conditions at the time and the fact that he was frail and terminally ill, had he become lost for any period of time, realistically he may not have survived the night. I subsequently learnt in follow-up discussions with the Department of Veterans Affairs, that this is not the first occasion that the Department have experienced difficulties with the transport of persons with dementia by general taxi – I was informed that apparently on another occasion, a dementia sufferer had actually gone missing, necessitating police involvement.

Despite Agreements between Veterans Affairs and taxi providers, my late father's experience demonstrates that reliance by Veterans Affairs upon general taxis to transport persons with dementia is, depending on the degree of the person's dementia, inappropriate and careless. Despite the Department's verbal assurances that my father could not re-direct a driver during the course of a journey, this did occur. I subsequently lodged a complaint with the Passenger Transport Board who conducted an investigation into the matter. In their formal advice to me, they indicated no wrong doing by the taxi driver, owing to the legal right of passengers to change their destination during the course of a journey. They also advised that it is Department of Veterans Affairs' practise to permit re-directions, however the passenger must bear the cost of the fare to the new destination.

The suitability of general taxi transport for dementia sufferers

Given the progressive and degenerative effects of dementia, sufferers eventually become almost totally reliant upon taxi services when they are no longer permitted to drive vehicles and are unable to safely access other forms of public transport, such as buses and trains etc.

However, general taxis cannot always provide a safe and reliable means of transport when persons with dementia eventually lack the mental capacity to make decisions for themselves. Such transport places them at a high degree of personal risk and imposes an unreasonable burden of care upon taxi drivers. This is because:

- general taxi services cater for the general public and do not take account of the special needs of groups in the community, such as those suffering dementia
- drivers are usually unaware of a passenger's mental impairment as currently there is no system to identify mentally impaired passengers and their special requirements, nor a dedicated transport service for persons suffering mental impairments
- the current Passenger Transport (General) Regulations 1994, which govern the operation of taxi services, assume all passengers have the mental capacity to make decisions for themselves and passengers are therefore entitled to re-direct a driver during the course of their journey. Currently drivers must comply with this requirement, even though re-direction to an alternative destination could place the personal safety of a mentally impaired passenger at risk
- as taxi services do not cater for special needs groups, there is no system to make drivers aware of the safety requirements of persons suffering dementia and drivers are

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therefore not required to provide extra services to this group, such as escorting a passenger to a contact point at their destination and leaving them in the care of a responsible person. Whether such a request was accommodated by a driver would currently depend upon the goodwill of the individual driver. Many persons with dementia, for reasons of personal safety, cannot unlike other passengers, be dropped at their destination, but require extra assistance to ensure they are handed over into the care of others

- taxi drivers are currently not equipped to respond to sudden and unpredictable behaviour by acutely confused and disoriented persons who suffer dementia, such as attempting to alight from a moving taxi.

Persons with dementia require a public transport system which specifically caters for persons with a declared mental disability. They need an accountable transport service, staffed by responsible persons who will ensure that passengers are:

- *transported safely to the required destination, and*
- *if necessary, physically escorted to an appropriate contact point and left in the care of a responsible person.*

The currently anomaly under the Passenger Transport Act 1994, which prevents persons with a mental incapacity from utilising Access Cabs, therefore needs to be rectified as a matter of urgency. The use of an appropriate, safe, subsidised taxi service is a necessity for dementia sufferers and their families.

Transport services, discrimination and dementia – the legal framework

It must be recognised that cognitively and physically impaired persons are equally transport disadvantaged and that mentally impaired persons, such as those with dementia, are also entitled to a safe, accessible, supportive and affordable means of public transport. Current legal requirements support this. The Disability Discrimination Act 1992 seeks to eliminate discrimination against people with disabilities, both physical and mental. Public transport is a service covered under the Act and the definition of disability includes persons suffering dementia. The Act places an onus on transport service providers to ensure that they examine their transport services with a view to ensuring that those services, including access to those services, does not discriminate against persons on the basis of their physical or mental disability.

In addition, the objects of the Passenger Transport Act 1994, are to benefit the public of South Australia through the creation of a transport network that:-

‘provides accessibility to needed services, especially for the transport disadvantaged and promotes social justice.’

(Passenger Transport Act 1994, 3)

Further, the Disability Standards for Accessible Public Transport 2002 extend to taxis and specify how public transport is to be made accessible to persons with a disability, as defined by the Disability Discrimination Act, which as indicated, includes both intellectual and physical disabilities.

Currently in this state, it can be said that the objects of the Passenger Transport Act 1994 are not being met as they apply to intellectually impaired persons, nor do current transport services for this group meet the spirit and intent of the Disability Discrimination Act 1992 or the Disability Standards for Accessible Public Transport 2002.

Responsibility

There are a number of government service providers who must share responsibility for what happened to my late father.

Firstly, Veterans Affairs have apparently failed to consider the specific transport needs of veterans with dementia for whom general taxi services may not be safe or appropriate;

Secondly, SA Ambulance's criteria for Non-Emergency Transport on the basis of 'medical need' currently excludes persons with mental incapacity;

Thirdly, the nursing home made an error of judgement and failed in their duty of care by allowing my father to attend medical appointments via general taxi, unaccompanied;

Finally, transport systems failed to provide an appropriate and safe taxi service which could accommodate my father's needs, given his acute confusion and disorientation as a result of dementia.

The challenges in overcoming the current inequities of the transport system for persons with dementia and what needs to be done, will now be outlined by the Alzheimers Association in the second part to this paper.

Systemic issues

Alzheimer's Australia SA has been vocal on behalf of people with early dementia about the current restrictive eligibility criteria for the South Australian Taxi Subsidy Scheme (SATSS) and the failure of the Passenger Transport Board over a number of years, to address the inequities that currently exist in these provisions.

We have heard John Mitchell's story; here are some further examples:

Comments from carers

- *"My husband is in a nursing home with severe dementia. I'm unable to take him on public transport because of his behaviour, in particular, his sexual aggression toward me. However, I could more easily transport him via cab with staff or family member. He needs regular access to transport for visits to hospital, specialist appointments, and the community centre. Taxis cost quite a lot and we are pensioners. We are unable to rely on friends. We have few friends in Adelaide, as we're from the country. The friends we do have are in the same situation; i.e. they are either carers with a partner*

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in a nursing home or caring for person living at home. Our application to the SATSS has been rejected.”

- *“My husband has dementia and recently failed his driving assessment. I do not drive, and am now reliant on friends and family and public transport. The main difficulty is when we need to go across country on Saturday or Sunday when there is reduced transport or long waits between buses, or going into the city at night. We are reluctant to seek help frequently from family and friends and would benefit greatly by having taxi vouchers. We are pensioners and live modestly.”*
- *“My friend cannot catch a bus on her own as she gets lost. She is not familiar with public transport as she used to have her own car. She no longer has a car as she used to forget where she left it and would walk home. She is handicapped by not being able to go out. She is able to go out only when someone can take her or get a taxi which is a cost burden for a pensioner. It is important that at least she can go to appointments in a cab for medical and hair appointments, and shopping to maintain some independence.”*
- *“My Aunt who has dementia is living at home with the support of a Community Aged Care Package. There are no other family members. I work full-time, have family commitments and no time available to drive her to appointments etc. She needs to visit the GP, Specialists, other appointments on a regular basis and only way of attending is on the bus or by taxi. Both are inappropriate options because of her confused state. The safest option would be for her to use Access Cabs where the driver has some familiarity with people with special needs. Access to transport would support her to continue to live at home.”*

Comments from service providers

- *“We operate a respite service in a country town. We try to be very creative with use of available transport, but in one situation we were not able to come up with any other solutions other than the regular taxi service. For this particular client, who had middle stage dementia and lived out of the town, the return taxi fare was \$60 per day. This was not within her budget and so she was unable to attend the respite program. She applied, with our assistance, to SATSS and was refused membership to the scheme based on her physical abilities. This client was not able to access the respite program, which left her socially isolated and unable to participate in skill maintaining activities.*
- *“We encounter many situations where the carer does not drive and the person with dementia was the driver formerly. Bus travel for the couple is frequently difficult because of person with dementia’s behaviours and taxis on a regular basis are too expensive.”*
- *“All clients with dementia we have referred to SATSS have been refused membership over the past years. Often their spouses cannot drive and they comment that full taxi fares are very expensive and frequently bus travel often leads to agitation.”*
- *‘Although a carer may be physically fit and able to access public transport, it’s often too hard to get the person they care for on to public transport, due to any number of reasons: fear, inability to follow directions, mental frailty, challenging behaviours.’*
- *“Funding guidelines for transport are changing. This means that a number of programs are no longer able to offer transport as part of their service.”*

A brief history of Access Cabs and subsidised transport

Access Cabs and subsidised transport for people with disabilities developed in the context of the disability rights movement in the 70's, where the rights of people with disabilities were acknowledged not as legal rights but as 'certain principles of morality or social justice' (Bidmeade, 1987, 3). The United Nations Declaration as to the Rights of Mentally Retarded and of Disabled Persons symbolised these rights in stating that 'persons with disabilities should have the right to an equal opportunity with others to enjoy a normal a life as possible' (1971).

In South Australia the development of such a service was liberating to many people in wheel chairs experiencing frustrations in mobility. The SA Transport Subsidy Scheme (SATSS), introduced in 1987, provided subsidised taxi vouchers to those South Australians 'whose disabilities preclude them from using public transport' (Passenger Transport Board, 1996).

There were two rates of subsidy - 50% for those able to use ordinary taxis and 75% for those who needed the special vehicles of Access Cabs. The five criteria used to determine eligibility to this program were –

- *Permanent dependence on a wheelchair*
- *Severe permanent ambulatory problems necessitating the use of large complex walking aids*
- *Permanent inability to negotiate 3 steps, 350mm high*
- *Permanent inability to sit in public transport without restraint*
- *Inability to walk more than 100 metres without rest.*

However, the focus on physical criteria for eligibility to this service was an ongoing source of frustration for those excluded from this service. Minutes from the Disability Transport Action Group in 1992, show representatives met from a range of disability consumer groups and covered areas such as age discrimination and eligibility issues in regard to Access Cabs, and also queried the charter and consumer representation of Access Cabs and its Board (CAPSA Disability Action, 1992).

Advocacy by the Alzheimer's Association in June 1992 on behalf of two individuals unable to gain entry to the program, received the following reply from the government medical officer of the Office of Transport Policy and Planning: 'The Transport Subsidy Scheme was implemented to provide those people who are confined to wheelchairs, or suffer from other muscular/skeletal problems, the opportunity of recreational mobility. Applicants who suffer from Alzheimer's Disease only (and other intellectual and psychological disabilities) do not at present fall within the entry guidelines' (Office of Transport Policy and Planning, 1992).

A subsequent meeting between officers of the Department and members of the Alzheimer's Association Access Cabs Task Group, confirmed that 'the Access Cabs Policy Division is well aware of the large number of people with intellectual disability and psychiatric disorders, for instance, who are not eligible for the subsidy. Their view is that the financial cost would be prohibitive should the guidelines be expanded, but that this was a 'political issue' ' (Alzheimer's Association Access Cabs Task Group, 1992).

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This area of dissatisfaction was not the only one voiced at his time, with other consumer groups concerned about exclusions to the program, and some with eligibility who were discontented with operational issues of the program (CAPSA Disability Action, 1992). Such a range of dissatisfactions had resulted in the program undergoing six reviews in its first nine years of operation! (Passenger Transport Board, 1996).

In December 1996 the Passenger Transport Board convened a Consultative Committee to look at the issue of those with disabilities excluded from the scheme, following the reviews by Tissato (1995) and Radbone (1995), which raised significant concerns about the program. While consultations occurred with a range of consumer groups, no changes to the criteria for eligibility occurred.

Ongoing attempts to progress this policy issue by the Association, and independent petitions by regional consumer dementia support groups have failed to shift current policy and funding inertia.

Two more departmental reviews have since occurred, one on operational issues (Kowalick, 2001). An Inquiry Into the Passenger Transport Board by the Parliamentary Statutory Authorities Review Committee, in 2002 (Parliament of SA, 2002/03) acknowledged issues of ineligibility and gave the following recommendation: 'That the Minister and Transport SA resolves the issues raised in relation to SATSS to ensure the desired interpretation of eligibility criteria and to take account of the service gaps raised by the Alzheimer's Association and others'. At this point in time the situation is that despite constant reviews, referring to inequities in eligibility, no serious attempt has been made by the Dept of Transport to address these issues. A meeting with the CEO of the Dept of Transport, and a subsequent meeting with the Minister of Transport in May 2004, had not, at the time of writing, resulted in a change of policy.

Provisions in other states

Other states have responded to this issue, for example, the NSW Taxi Transport Subsidy scheme has much broader eligibility criteria. It is open to people who are unable to use public transport because of a qualifying severe and permanent disability. These qualifying disabilities include physical disability, total or severe vision impairment, epilepsy, intellectual disability causing behavioural or socially unacceptable behavioural problems or requiring constant assistance of another person, and also severe communication difficulties.

Given the mandate of the Passenger Transport Board to provide for those who are transport disadvantaged, and of the State government's statements of 'the right of every Australian to enjoy full citizenship... irrespective of age or frailty' and to ensure that 'affordable, accessible transport services will be available to older people', the current situation is a sad indictment of the governments and bureaucracy over this time (SA Government, 1996, 3).

Both State and Commonwealth plans on ageing policy focus on the importance of maintaining participation in community activities, and seek to provide compensatory supports for the effects of disability and increasing dependency. This principle of citizenship is an important one as our society ages. However, schemes that have focused on observable physical impairment only have led to increased risks of hardship, isolation and reduced participation for people with dementia, reducing their status as citizens.

Varying needs for transport

The need of people with dementia for transport assistance in order to continue participation in community and health activities, varies with the stage of the illness, individual responses and co-morbidities. For the latter, other physical diseases, acute infections, surgery, negative drug reactions and stressful changes in environment can cause significant short-term or chronic confusion for a person with impaired cognition. The symptoms that characterise those people in the late stage of dementia are those of physical impairment and thus the need for transport is usually accommodated under the current Access Cabs guidelines.

Greater public and medical awareness is now resulting in many people with early stage dementia being often diagnosed very early and these individuals are generally capable of maintaining their regular activities for a limited period of time, including the cognitive capacity to drive, or use public transport. A percentage of these people may choose voluntarily to cease driving because of the diagnosis.

There are also those individuals who are in transition between early and middle stage dementia, who have little physical disability but clearly have cognitive limitations that would affect their capacity to drive with confidence and safety, thereby putting themselves and others at risk. There is generally fluctuation or lack of insight into their cognitive performance and it is within this group that some individuals are very resistant to stop driving, while others may cease driving due to a lack of confidence or initiative. These individuals also lack the cognitive performance to negotiate public transport without the support of another person and they may well have behaviours that are difficult to manage and may be socially inappropriate.

At present, if a person with dementia relinquishes their licence or voluntarily stops driving, there is no other alternative except for using taxis at full cost. When a person has their licence removed involuntarily, these additional practical and financial difficulties enhance their grief, frustration and confusion about inability to drive.

Family members provide the majority of all care in the community to people with dementia and carer burden has been well identified in literature. Lack of transport options increase the burden on carers, as illustrated by some of the stories heard in this paper.

Expanded affordable transport options would contribute to an increased quality of life through participation and mobility and would lessen stress for their carers.

People with dementia, their carers and advocates are asking for a safe, accessible, supportive and affordable means of transport. This request seems to fit the objects and functions of the Passenger Transport Board, but evidence to date indicates a system that does not deliver these outcomes for people with dementia.

Creative options

Given the varying needs of people with dementia in the early/middle stages, then a range of transport options need to be available to match.

The use of taxis are seen by many families and service providers as a needed transport option. As public transport ceases to be an option for the individual with dementia there is increased reliance on the goodwill of others to assist with transport and reliance on taxis. Based on the comments compiled over many years, the cost of using taxis on a regular basis creates additional hardship for many families. Clearly cost plays a significant part in caring for a person with dementia in the community, and thus an extension of the SATSS guidelines to cater for those with cognitive impairment due to dementia is required.

For those people with dementia and acute confusion, who need to attend essential medical appointments or respite services, general taxis may be unsuitable to ensure that the person travelling with dementia reaches the required destination safely, without wandering away. For this group with special needs, safer options will need to be created.

For instance, the SA Ambulance Service can provide for Non-emergency Ambulance Transport when authorised by the treating medical practitioner, on the basis of 'medical need'. This means that the primary reason for the transport is medical and that the person is being transported to, or from, a facility where they are to receive medical treatment (S A Ambulance Service, 2003). This would have been a safer and more desirable option for John Mitchell, who was, however, not considered to fit the eligibility criteria because he did not require medical treatment en route and did not have any physical impairment which necessitated stretcher transport.

The remaining significant gap remains that of transport of people with dementia to respite centre and medical facilities, when their confusional state places them at risk of using taxis.

People with dementia who:

- Have relinquished their licence or had it removed
 - Are unable to use public transport
 - Cannot safely use or afford to pay the cost of taxis
 - Have to rely on the goodwill and care of others to be transported to essential appointments
- Are without a doubt, 'transport disadvantaged'.

The Association advocates for the funding of an exploratory study to recommend realistic ways ahead for this group of citizens with dementia who, under all relevant State policies, have valid transport needs equivalent to any other persons disadvantaged by disability.

Research indications

At present, some people with dementia qualify as users of Access Cabs and others at a more advanced stage require transportation in ambulances. We do not have numerical data on either of these categories at present. Nor do we have data on people with dementia who are unable to access private or public transport and who fail to fit in the above two categories. The situation is complicated by the fact that behavioural and medical factors may impact on a person's ability to utilise public transport, in a variable way. There is a need for a scoping study which provides this data; examines national and international models of transport support, and assesses community transport options, particularly in relationship to its effectiveness for users and relative cost. In addition to broadening the criteria for access cabs/transport eligibility, other national and international models of transport support need to

be examined, in particular, community transport, in relation to cost and effectiveness for users.

Literature review

An initial scan of available literature in this area indicates large gaps in research and policy work. A specialist focus on dementia and transport is missing, despite the growing size of this group in an ageing population internationally. Most relevant material occurs in general texts on 'transport disadvantage'. An emerging trend, such as in the US, shows a growth in the use of community buses to aid mobility in the areas of daily living (eg shopping) and access to medical appointments. Many of these programs are funded under health and human services portfolios, with contracting of the service component to transport authorities (United States General Accounting Office, 2003).

Preliminary research

Preliminary data has been gathered on the availability of community transport in metropolitan Adelaide (Alzheimer's Australia SA, 2004) for people with dementia. Of the nineteen councils surveyed, wide variability was apparent in

- Eligibility/restrictions
- Type of service available.
- Funding sources (some services were funded through Home and Community Care Programme
- User costs ranged from low costs (\$3.00 a trip) or donation/no cost.

This preliminary survey demonstrated inequities regionally for people with dementia, as evidenced by the following examples of those suburbs where one would be most assisted or least assisted by community transport if transport disadvantaged.

Most assisted:

- Prospect- A free community bus door to door (shopping) with no restrictions, and a free short-term service to attend doctor's appointments.
- Marion- A community bus for shopping and library (\$3.20) and a free volunteer car service for medical appointments
- West Torrens- A community bus/volunteer car for shopping and doctor's appointments.

Suburbs least supportive in the study were:

- Tree Tea Gully- will not take people with dementia shopping
- Burnside- one way trip only to medical appointments, person with dementia needs to be accompanied by a carer on the community bus.
- Adelaide- a bus to the market, person with dementia needs to be accompanied by a carer on the community bus.

The conclusions from this preliminary research is that some regions have improved mobility for those disadvantaged from dementia through the utilisation of Home and Community Care funding for community transport.

Developing creative options

Apart from community transport options, other possible strategies that deserve exploration include:

Improving the safety of taxi use:

- providing a card to the taxi driver conveying important information about the individual's memory loss and clear instructions for safe handover, however this would rely on a care-giver being present at the commencement of the journey. However, as seen in the case of John Mitchell, the symptoms of dementia were not understood by those liaising with and operating the taxi service, and thus important information was not conveyed.
- universal taxi booking systems could be developed which identify and categorise passengers who are at risk and/or who require special assistance. This information would be conveyed to drivers with any specific instructions for safe transport. Such a system should be known by and utilised by residential care centres, respite centres, medical centres, hospitals and other care providers when arranging taxi transport for passengers with cognitive impairments.
- for some people with dementia, general taxis may not be appropriate and Access Cabs may need to be used, with drivers receiving some training in this area.
- where taxis are used regularly by a respite centre, strong relationships could be built up to ensure vital information is conveyed, with safety a primary consideration.

Considering a 'safety net' of transport options:

- expansion of the current criteria for S A Ambulance Non-Emergency Ambulance Transport should be considered to enable ambulances to be used to transport to medical facilities, very confused people with dementia who pose a safety risk to themselves or others.
- volunteer schemes may need to be established when someone needs accompanying for safety, without adding further demands on the primary carer.
- provisions under the Home and Community Care Scheme, designed to help those frail aged and disabled living in the community, also need to be reassessed to provide an equitable safety net for this disadvantaged group.
- Linkages and partnerships with existing community transport services, such as Red Cross Courtesy Cars should be explored.

Conclusions

People with dementia, as a growing group, have been disregarded in the current system of transport provision for those physically disadvantaged. Such neglect has created hardship for individuals, risked their safety, and affected their ability to participate in their usual activities, impinging on their quality of life. There has been gross policy neglect by successive governments to rectify this situation. This has been highlighted by Disability Discrimination legislation and consumer advocacy groups.

With the changing demographics and epidemiology of the older population, government must take responsibility to make provision for affordable, timely, safe and supportive transport options for people with dementia, and this will require creative and collaborative endeavour.

As our overview has indicated, there are both qualitative and quantitative research gaps. The impact of poor or limited access to social and community services because of inadequate transport has yet to be fully addressed anywhere for people with dementia. The variability in approach to transport subsidies and community transport provision across Australia reflects both a broad lack of understanding by Funding Authorities and transport providers of the physical, mental and emotional issues associated with dementia and the impact of deteriorating levels of functionality on mobility. It is clear that a combination of transport options is required to meet the needs of people with dementia and that research to determine the relative costs and benefits to people with dementia, carers and the community is urgently required.

We hope that this paper has brought a human face to an emerging transport dilemma so that this issue can be addressed before the cost in human suffering becomes overwhelming for those facing multiple disadvantages within our community.

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