

Response to the Inquiry into the Operation and Effectiveness of Patient Assisted Travel Schemes (PATS)

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Submission from

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Introduction

Anglicare Tasmania welcomes the opportunity to respond to the Inquiry about Patient Assisted Travel Schemes or PATS.

This submission is based on findings from Anglicare research and particularly from two research studies conducted by the Social Action and Research Centre at Anglicare. These studies (Hinton, 2006 and Hinton forthcoming) explored the experiences of Tasmanians reliant on the Disability Support Pension and the experiences of families caring for children with disabilities.

Anglicare would like to express concerns about the inadequacy of the current Tasmanian PATS and how this has a differential and negative impact on low income and disadvantaged households. In particular Anglicare would like to comment on:

- the procedures used to determine eligibility for travel schemes;
- the level and forms of assistance provided;
- the feasibility and desirability of extending patient assisted travel schemes to all treatments including allied health and dental treatment.

About Anglicare

Anglicare Tasmania is a non-government organisation that has been working for the Tasmanian community for the past 20 years. Since its establishment it has grown into a state-wide service responding to issues faced by Tasmanians such as financial crisis, homelessness, unemployment, the adverse health, social and economic consequences of alcohol and other drug use, and the challenges faced by people with physical and intellectual disabilities or mental health problems.

Part of Anglicare's mission is to speak out against poverty and injustice and to offer alternatives to decision-makers to help build a more just society. Anglicare practices this advocacy through its Social Action and Research Centre (SARC) established in 1995 to work with low income earners to identify the issues that affect them, and then carry these concerns to Government.

Over the past eight years SARC has produced a series of major research reports on issues affecting low income Tasmanians including access to health care, unemployment, financial crisis and mental illness.

Research Evidence

Anglicare's research has consistently demonstrated the difficulties low income Tasmanians face in accessing affordable transport (Madden, 2005). These include difficulties in maintaining private vehicles and in paying petrol costs as well as being reliant on scarce and inaccessible public transport. These problems with transport mean there is no equitable access to health services for low income and disadvantaged households and they are particularly acute in Tasmania where a dispersed population with medical services concentrated in major population centres can mean travelling considerable distances to receive medical services. Indeed accessing the health services that people need can cause severe financial hardship. Although access to PATS can meet some of the transport and other costs people face Anglicare has a number of concerns about the operation of the scheme.

Level and Form of Assistance

For those with significant health needs but reliant on low incomes the level of assistance available from PATS is inadequate. The Tasmanian scheme currently offers 10 cents a kilometre towards petrol costs and \$30 per night to pay for accommodation. Many people with disabilities and families caring for children with disabilities find the accommodation and petrol allowance does not begin to meet their costs. Although those accompanying patients for hospital stays are able to access subsidised accommodation through Ronald McDonald House if the patient is a child aged under 18 years, this is not available to adults and those attending day time clinics or appointments. Research participants commented on difficulties in finding cheap accommodation and on meeting the costs of other living expenses like meals. There were also the more hidden costs of maintaining a household in Tasmania while a child with a parent escort is treated in Melbourne or in Hobart.

He goes every six months to Melbourne to his orthopaedic surgeon. When we go it costs me a fortune. I have to have somewhere near to stay to the hospital and I can't get anything under \$80 a night. That's all my pension gone and I can't get any help there. They apologise but they can't do anything. They pay the air fares and the taxi fare if I have the chit, so that's good. They did say they would pay a certain amount of the accommodation and I've kept all my receipts but the only way they will pay all the costs is if you stay in Ronald McDonald but they only like people to stay there if their child's having operations. They think he's just having a consultation one day but it's too much for me so I have to stay some where. If I've got an appointment to be there 8 in the morning I have to get there the night before. If they had the surgeons here it would save all that money and we wouldn't have to go. (Grandmother caring for 6 year old grandson with multiple disabilities)

We have had to relocate to Burnie to be near dialysis and have also had a few trips to Hobart. It has probably been fairly hard with extra costs. We have had accommodation paid for but of course there are meals out to pay for. Then there are fuel costs as well even though we are 10 cents a kilometre but it all adds up (54 year old man caring for his wife with renal failure)

We had five trips to Melbourne this year and it's the worst year he's had. They pay for the trips but it still costs us money. They pay for our air fares and accommodation and we pay for the meals and each time you go you're out of pocket. We really felt it this year. (Grandparents caring for their grandson living with multiple disabilities).

We've been to Melbourne once. We were there for a week, my husband and I and Declan. It didn't cover food and you have to still run your house at home for everyone and cover the cost of that. It cost us a bit of money going over there and having to buy the food and everything, the phone bills, trams. (Parents caring for eight year old son with multiple disabilities)

For families using private vehicles parking costs could be a major expense:

We stay at Ronald McDonald House so that's covered through the transport system. We drive down. We used to take the bus and we paid our bus fares and then put the tickets in and they would reimburse but the last couple of times he's got worse with his pain and the doctors suggested an ambulance ride or take the car down. So we've managed to save a bit of money and put that in the petrol to drive down. The subsidy for the petrol is not much. We were down there for four days once and we left the car in the park and by the time we left it cost us \$50 in parking tickets. (Parents caring for 15 year old son with Spina Bifida).

Eligibility Criteria

PATS will subsidise the cost of accessing specialist medical services more than 75 kilometres from the normal place of residence. However the lives of people with disabilities and especially of families caring for children with disabilities are often dominated by a round of medical appointments, therapy appointments, developmental checks and so on. The majority of these appointments are within the 75 kilometre radius which excludes people from access to the PATS but which can mean significant transport costs:

They paid for me to go to Hobart and back but otherwise we don't fit in because we're not far enough away from Burnie. It's about twenty kilometres. We go into Burnie three or four times a week. Fuel is a huge thing and the time in the car when you're tired. When we had Sue in hospital for three weeks it cost us over \$2,000 just with fuel. David was coming home, it was the middle of winter, it was three trips a day. He was buying a lot of take-aways because he was too busy to do any cooking. The teacher at the school enquired about the cost and got us \$200 from the Sunshine Foundation which was really nice. (Jill, caring for her two year old daughter with severe cerebral palsy)

Some families only just lose out when they fall out of the 75 mile radius and this imposes a very heavy financial burden because they then receive no financial assistance.

I used to go every week to the orthopaedic clinic where he was having the plaster changed here at Launceston General Hospital and they wouldn't give the patient scheme to me because I'm about two kilometres out of the map. Even the doctor tried to get it for me and they said we can't because the map finishes. So every week there was 80 kilometres I was doing there and back. And then he would have to go to his therapy and there was nothing there for that. The only time we can get reimbursement is if it's for the speech therapy. (Grandmother caring for 6 year old grandson with multiple disabilities)

PATS will usually only pay for one parent to accompany a child under 18 years. In exceptional circumstance approval may be given for financial assistance for more than once escort. This was an issue for some families where both parents were involved in meeting the care needs of their child and both wanted to accompany their child when accessing medical services:

We have been told that if he does go to Melbourne the government will help one parent go and then we have to find our own money. Well we have kids here to look after as well. Its all right to pack up and go to Melbourne but your doing double living, you have to buy food in Melbourne or Hobart and still have food here for the ones who stay here and a family friend or relative staying in the house to look after the house and the animals. We've managed but it's been a burden as well. It's something we had to do so we've done it. . (Parents caring for 15 year old son with Spina Bifida).

Recommendations

Improving the transport infrastructure is crucial to improving health outcomes for low income and disadvantaged households. It is vital to ensure that patients are not barred from the services they need by an inability to access affordable transport.

Anglicare recommends:

- that PATS ensures that concessionary rates and subsidies for patient transport are based on real economic modelling relative to the incomes of concession eligible users. This will entail increasing funding to PATS to meet the actual cost of transport, accommodation and living expenses such as meals. This will go some way to assist with the invisible costs of supporting two households during in-patient stays.
- an extension to the current PATS scheme so that

- Health Care Card and Pension Concession Card holders can access transport and accommodation subsidies to specialist medical services within the 75 kilometre boundary
- the scheme covers both access to specialist medical services and access to allied health practitioners when referred by a medical specialist.

References

Hinton T 2006 *My Life as a Budget Item: Disability, budget priorities and poverty in Tasmania.* Social Action and Research Centre, Anglicare Tasmania

Hinton T 2007. Forthcoming. *Families Caring for Children with Disabilities in Tasmania*. Social Action and Research Centre, Anglicare Tasmania.

Madden, K 2005. *Transport Issues Paper*. Social Action and Research Centre, Anglicare Tasmania.