ANGLICARE
TASMANIA

Response to Clinical Services Plan Issues Paper

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Submission from

Anglicare Tasmania
GPO Box 1620
Hobart 7000
Phone: 6234 3510

Introduction

Anglicare Tasmania would like to thank the Department of Health and Human Services for the opportunity to consider and comment on the development of the Tasmanian public health care system. We fully acknowledge the complexities of providing services to a small and distributed population together with the changes in demographics, health status and health care which are outlined in the Issues Paper and which are driving this consultation.

This submission does not address the configuration of particular services on individual sites across the state or whether any new clinical services should be introduced. However it does comment on:

- the principles proposed as a basis for the Clinical Services Plan (Question 1);
- factors inhibiting implementation of service models and principles (Question 4); and
- service planning principles particularly in the North West (Question 6).

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 five 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.

Key Concerns

Anglicare's key concern is how any developments will impact on low income Tasmanians and whether they will help to ensure better health outcomes for low income and disadvantaged people. In this context Anglicare supports the design principles proposed for the public hospital system in the Clinical Services Plan Issues Paper. However Anglicare would also like to raise concerns about the Plan's impact on the access that low income households have to a public health service system which is increasingly centralised. These concerns are:

- the current lack of accessible and affordable transport to and from health and other services and especially specialist centres
- the interface between the public health system and community based services

Transport

Anglicare's research has continually demonstrated the difficulties low income Tasmanians face in accessing affordable transport (Madden, 2005). In the course of research into poverty, mental illness, unemployment, housing, disability and financial crisis, the difficulties caused by a lack of access to affordable transport have been a common concern. Anglicare's research has explored in detail the access that two particularly disadvantaged groups have to health services and to transport. These are people with disabilities (Hinton, 2006) and people with severe mental health problems (Cameron & Flanagan, 2004). Anglicare's research shows:

- the costs of running a private vehicle can be a major concern for low income earners and particularly among those with the additional disadvantage of poor health or disability. The high cost of private transport is beyond the resources of many people. This is compounded by inequities in the assistance available to low income people to run motor vehicles whereby Health Care Card holders who are the State's lowest income earners are ineligible for many private vehicle concessions.
- a range of difficulties for low income earners attempting to access public transport services in rural and regional areas and even in outer suburban areas. These include no or very limited bus services, difficulties with the frequency and timing of bus services and the cost.

- limited access to specialised transport services designed to assist people with disabilities who are unable to access public and private transport options. These include financial subsidies for the cost of transport and improving the accessibility of services. In particular:
    - although Metro are progressively making their entire fleet fully accessible by 2020 there are currently only 38 fully accessible buses running on routes at scheduled times during the day.
    - assessment procedures for the Transport Access Scheme which subsidises the costs of taxis can prioritise people with physical mobility impairments over clients with psychiatric disabilities (Cameron & Flanagan, 2004). Despite the subsidy high costs put taxi use out of the reach of many living on the Disability Support Pension.
    - HACC funded community transport services designed to provide access to community facilities like day centres, shopping and so on are increasingly being used to access non emergency medical services in the absence of other medical transport. The service is also very dependant on volunteer driver and vehicle availability and there is no evening or weekend provision.
    - Wheelchair Accessible Taxis are now available in the main urban centres but not in regional areas.

    These difficulties can be particularly acute on the NW Coast. As one respondent commented:

    The bus service runs at really obscure times. It only runs once a day and so if you want to make an appointment you've got about an hour before it comes back so if you are reliant on public transport you have to make arrangements to stay overnight because there are not too many people can get to their doctor, see their doctor out and get back on the bus within an hour. There's the community bus that takes people up for the day and brings them back for $20 which is okay but you have to have a disability. You have to be on a disability pension to use that bus (Loretta, 39, bipolar disorder, North West Region)

There are two services which specifically aim to facilitate access to health services by subsidising the cost. These are:

- the Patient Transport Access Scheme providing assistance with costs to all Tasmanian patients who have to travel more than 75 kilometres intra or

interstate to access public health facilities. Levels of assistance are determined by distance, type of travel and whether accommodation is required and costs are subsidised for the patient and one carer to accompany them. Pension concession card holders are required to contribute $15 to the cost of each return journey with the maximum contribution being $120 in any one year. Travel in a private vehicle is subsidised at 10 cents per kilometre and there is a maximum of $30 per night for accommodation per person. Applications must be lodged before the date of departure through forms provided by GPs or specialists. Reimbursement is claimed on the return home.

- the Red Cross provide transport to and from medical appointments for people with disabilities and the elderly for a small fee of $5. However routes are limited and the service does not cover all areas. Neither do they have any wheelchair accessible vehicles.

Anglicare research has clearly demonstrated the inadequacy of both schemes in meeting the transport needs of low income Tasmanians. For someone with a severe disability and in receipt of a pension concession card the contribution of $15 per return journey represents half their total weekly disposable income:

> *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 paid 10 cents a kilometre but it all adds up. (Laurie, 54, caring for his wife with renal failure)*

> *I don't have any transport. I can't get to hospital for physiotherapy. I should have it twice a week. I only have enough money to get a taxi one way but I don't have the strength to walk back. My leg has deteriorated something shocking (North West Coast)*

Shortcomings in transport infrastructure have been recognised by the Government and the Department of Infrastructure, Energy and Resources is undertaking a review of regular core passenger services in Tasmania to improve their delivery. The Issues Paper also acknowledges the need to ensure efficient patient transport services are provided and that 'current transport in the North West is unreliable because of the remoteness of some communities'.

Overall the current lack of access to affordable transport is a significant barrier for many low income Tasmanians in getting the health care they need. The increasing pattern of centralising key government and community services therefore risks compounding disadvantage and having a negative impact on the health and well being of the population and particularly those in more rural areas.

The inter face between the public health system and community based services

Many people with disabilities as well as being reliant on specialist health care also require an extensive range of health and other support services in the community to maintain a reasonable quality of life. Effective links between acute and community based services can be key in ensuring people have access to the information and support they need in the community. Yet Anglicare research has shown that there are major gaps in the links between acute and community sectors. This is due to:

- the under-funding and paucity of community based services. This can mean extended stays in hospital:

When I had my hand operated on I stayed in hospital for three weeks not because I needed to but because I couldn't get the personal care and I couldn't go to the toilet because I couldn't use my hand (Mary, 57 living with physical disability)

- Inconsistencies in planned hospital discharge which should incorporate a full assessment of needs. The absence of planned discharge was routinely noted by interviewees who had left hospital with little information about what might be available to them and meant that many were left stranded by the discharge process. Non-governmental organisations representing the interests of people with particular kinds of disability continually expressed concerns about not being notified about individuals being discharged from hospital. They were keen to disseminate information before discharge about their services but it was difficult to establish this and it was not occurring on a regular basis. They described the continual turnover among hospital social work staff as a major obstacle to getting information out to those who needed it. This effectively excluded numbers of people from services which could have provided support. In the absence of specific discharge protocols whether

someone received information of not can be a question of luck or encountering the right member of staff:

When I was admitted to hospital the social worker came around and introduced herself and said I will be back to have a chat with you later on and I never saw her again, not at all. So it's been extremely difficult. I have always said that the day you leave hospital, somebody from Centrelink should be there to say you are going to have this or that problem for a while so we will organise your payments or whatever. (Diana, 54, living with ABI)

- reliance on carers to provide the care and medication regime of those with disabilities and/or chronic conditions once in the acute care system. Families find themselves involved in providing basic nursing care because they are the only ones who fully understand the daily care needs. This places a heavy burden on carers and has cost implications for the whole family the further away from home acute services are located.

Going to the hospital is a very scary experience. They have no idea that his arms and legs are out of control. They put him onto narrow trolleys and they leave him on a hard surface oblivious to sores on his legs or feet. This can all lead to months spent flat on his back thereafter. We never leave him at the hospital because of this. The problem with spinal injuries is they don't see enough of it (Trish, 52, caring for her son living with quadriplegia)

As acute and specialist services move further away from the community they serve it becomes increasingly difficult to maintain effective links with community based services in order to facilitate effective discharge planning and support in the community. This means that unless there are proactive strategies to promote coordination any further centralisation of services will lessen links with vital community services and fuel concerns that people will be less likely to get the community support they require.

Outcomes for Patients

With a small and dispersed community there are clearly difficult decisions to be made about how to ensure quality health care is available to all on an equitable basis. However it is clear that given the already significant difficulties many low income and disadvantaged Tasmanians face in gaining access to health care services any

centralisation of services without significant investment in transport facilities and other patient support will mean deteriorating outcomes for patients and their families.

The table below outlines a typical budget for someone with a severe disability living in the community and reliant solely on DSP. It uses average rents in public housing, average expenditure on medication and assumes the receipt of HACC funded personal support capped at $10 per week. It demonstrates the inability of the DSP to cover anything more than the very basic costs of living leaving recipients with little or no discretionary funds at all: a total of $32 a week to spend on all other aspects of their life. Costs are likely to be higher for those surviving in the private rental market.

Fortnightly income and essential expenditure for person with severe disability	
Income	$499
Rent	$200
Fuel/food*	$190
Personal Care	$20
Medication	$25
Balance	**$64**

* Calculated from ABS Household Expenditure Survey (HES) average expenditure by Tasmanian households in lowest income quintile on domestic fuel and power, food and non-alcoholic beverages.

The Australian Bureau of Statistics Household Expenditure Survey data shows that Tasmanians in the lowest income quintiles on average spend $200 a fortnight on the following essential goods and services: clothing, personal care products, health and transport. This level of expenditure is not affordable to people with the budget outlined above. Neither does it take into account any additional expenditure on maintaining a telephone, having a social life or accessing health services at some distance from the home.

Recommendation

Access to medical care is listed in the UN Declaration on Human Rights as a fundamental entitlement for all people (Article 25). However for many Tasmanians on low incomes access to health care services both in the acute sector and in the community is already restricted by distance, by the lack of accessible and affordable transport and by less than optimal coordination of services. Indeed accessing the health services that people need can cause severe financial hardship.

The Clinical Services Plan acknowledges that although local access should be available wherever possible if services have to be centralised to assure safety,

effectiveness or efficiency, patient access may need to be facilitated in other ways through '*service coordination, transport assistance and other appropriate patient support'*. Anglicare recommends that the Clinical Services Plan:

- acknowledge transport as a major contributor to the health of communities which should be physically and financially accessible to all Tasmanians;
- commit to ensuring that concessionary rates and subsidies for patient transport are based on real economic modelling relative to the incomes of concession eligible users;
- ensure mechanisms are in place to promote service coordination and partnership working between acute and community based services;
- ensure that any improvements to transport facilities or to the coordination of acute and community based services run parallel to the relocation of medical services in order to prevent any serious negative impact on the health and well being of low income patients.

References

Cameron P and Flanagan J 2004 *Thin Ice: Living with serious mental illness and poverty in Tasmania.* Social Action and Research Centre, Anglicare Tasmania

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

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