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**Submission from**

**Anglicare Tasmania**

**GPO Box 1620**

**Hobart 7000**

**Phone: 6234 3510**

## **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. It currently has a number of disability-related programs which include assistance for job seekers with disabilities and supported accommodation and in home care for people with intellectual disability and people with spinal and/or brain injuries or disabilities.

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.

## **Introduction**

Anglicare Tasmania welcomes the opportunity to participate in the Review of Carer Payment (child).

This submission is based on findings from research conducted by Anglicare's Social Action and Research Centre (SARC). SARC is currently finalising a study of the experiences of families caring for children with disabilities in Tasmania. The study has involved in-depth interviews with 24 families across the state about their daily lives, the additional disability related expenses they face and their experiences of accessing the services that they need. Interviews were conducted from January to March 2007 and covered family's sources of income and their experiences of dealing with Centrelink. Among the research sample there were seven families in receipt of Carers Payment (child) and four families who had applied for the payment but had failed to get it. The research is due to be published in September 2007. This

submission comments on the impact of the caring role and the assessment process for the Carer Payment (child).

## **The Caring Role**

All participants in the research described how acquiring caring responsibilities had had a profound impact on their lives. This impact was both physical in terms of the practical demands on their time and energies and emotional in adjusting to their situation, their child's disability and the caring role. It imposed strains on relationships in the immediate and extended family which impacted on the level of informal support available. It impacted on the health and well being of primary carers and their ability to participate in employment and socially. It also had a profound impact on other non-disabled children in the family.

This submission addresses two major impacts of acquiring a caring role. Firstly the demands of caring and adjusting to a caring role, particularly dealing with the shock of a difficult diagnosis, meant that parents were poorly placed to investigate what services and benefits they might be entitled to. This was especially true for those families who did not already receive Centrelink support. For some parents a considerable period elapsed after the birth or diagnosis of a child with a disability before they found out they might be entitled to Carers Payment. As all parents do, they were looking after their child and did not necessarily even identify themselves as a 'carer'.

*I knew nothing. It was one of Tina's drivers. He said did you get that bonus money when everyone caring got \$1,000 and I went no what are you talking about? I said I'm not a carer and he said yes you are. I came in and rang Centrelink up and they said yes you should be getting this and that. This was only two years ago that all this happened. I relied on people to tell me things and of course they didn't. (Viv caring for Tina aged 16 with a chromosomal disorder)*

*We didn't find out about the carers pension until eight months after. It was a fair while after her birth. We were just talking to someone. (Suzanne and Tony caring for Meg aged 7 and David aged 5 both with multiple disabilities)*

Secondly the financial impact of acquiring caring responsibilities, combined with additional disability related expenses and difficulties in sustaining or accessing employment can be acute.

All families who participated in the research were asked whether, over the last 12 months, they had experienced a series of difficulties due to a shortage of money. The results are listed in the Table. It shows that three quarters of the families had sought financial help from friends and from family and had difficulties in paying power and phone bills on time. One third had delayed payments on their rent or home loan and a third had also had difficulties heating their home appropriately. Over half of those who owned vehicles had difficulties paying the registration and insurance and half also had not sought health care when they needed it due to a shortage of money. Over forty percent had pawned or sold something in the past year to make ends meet. It also shows that those families caring for a child with a disability and in receipt of a Health Care Card were doing considerably worse than Health Care Card holders generally.

<b>Proportion of families reporting experiences of financial hardship in the previous 12 months</b>			
<b>Type of financial difficulty or hardship</b>	<b>% of Families in Sample Reporting Hardship</b>	<b>Tasmanian Population#</b>	
		<b>% HCC Holders</b>	<b>% All population</b>
Unable to pay electricity/phone bills on time	71	25	15
Unable to pay rent/home loan	33	6*	4
Unable to pay car registration/insurance on time	55	20	11
Pawned or sold something	42	20	7
Gone without meals	4	11	4
Unable to heat the home	33	10	4
Sought financial help from friends or family	75	22	14
Did not seek health care when needed	54	20	10
Did not fill a prescription ordered by the doctor	38	14	9

Note: Questions adapted from Household Expenditure Survey

# Figures taken from the Tasmanian Community Survey (Madden & Law, 2005)

\* estimate has relative standard error of between 25% and 50% and should be used with caution

A number of those in the research in receipt of the Carer Payment (child) were doing without, were in debt, were using emergency relief services, borrowing money at high rates of interest and unable to afford reasonable housing or transport. It demonstrates the limited ability of benefits targeted at carers to keep families with children with disabilities out of poverty.

## Assessment Process

Research participants identified three major difficulties with the assessment process. Firstly they expressed concerns about the extent to which the outcome of their application hinged on how well the doctor had completed the medical report. Some families had doctors who understood the process and were good at doing the paperwork. Others were reliant on doctors who failed to detail the extent of care required by the child or the impact of the disability on the carer. These issues can be particularly prevalent when the child does not have a 'recognised disability' or a diagnosis or when the doctor is not well known to the family due to a recent move or change of surgery. This could adversely affect their application for assistance.

*I get the Carers' Payment. Because they are undiagnosed they probably wanted to know a little bit more information but the doctor said to us you will get it. It's probably hard when they are babies to prove but in her doctor's words she let them know that things weren't going to change and it was ongoing and in her medical experience she knew how to word it even though they were undiagnosed. (Suzanne and Tony caring for Meg aged 7 and David aged 5 both with multiple disabilities)*

*I am actually trying to get on the Carers' Payment. The doctor said I should be getting it because she needs full time care. They rejected it because the doctor wrote autistic and not severe autistic and autistic can just mean a little bit. So they said to go back to the doctor. But it's proof that she needs full time care because she's got aides full time at school, so that's proof that she can't be left alone and I can't do certain things. (Marge caring for Rachel aged 5 with severe autism)*

Some doctors can be quite disruptive:

*One problem was our paediatrician who has humming and hawing about doing the paperwork. He had other patients who were worse than Tony. He filled it out and there were no problems at all because he (Tony) fitted every criteria. When we told the doctor he said, "I don't know how you managed that". (Dawn and Gary caring for Tony aged 8 with multiple disabilities)*

Secondly applicants had difficulties with continuous demands for information from Centrelink staff who, although they might have been benefit recipients for years, were unfamiliar with their case. This meant having to constantly repeat the same information about their child's disability which was frustrating and distressing, particularly as it was already available on Centrelink records. This was especially difficult for parents caring for children with life-long, severe disabilities which were not going to change or improve:

*I am fighting to get the carers pension and they want all this information off me. Even though I'm on the books they still want ID off me, still want me to get diagnoses off the doctor. They have it all on the computer. I don't understand. It think it's horrible. They should make that carer's pension*

*easier so you can just ring up and say you already have my details, you know what my child has. You shouldn't have to go through it all because it hurts and it's upsetting. It's finding the time to go and get the doctor and do the paperwork. You have to take the person with you and Centrelink don't understand that. (Michelle caring for Dan aged 10 and Rod aged 2 both with muscular dystrophy)*

Thirdly parents found the eligibility criteria too stringent and this prejudiced their application particularly when the doctor did not emphasise the actual impact of the care regime on the primary carer in the medical report:

*I couldn't get the payment for them because Claire wasn't being fed through a tube in her stomach. That was the difference between Claire's disability and the next step down where they can't eat which makes no sense to me because when you do the food in the stomach bit it's quicker than having to sit down and feed her. It can take half an hour to an hour but anyway that's their criteria. (Jill and David caring for Rosie aged 2 with cerebral palsy and epilepsy and Emma aged 7 with autism)*

## **Recommendations**

Anglicare Tasmania recommends:

- better promotion of the benefits available to those caring for children with disabilities;
- comprehensive disability awareness training annually for all Centrelink staff;
- improvements to Centrelink data storage systems so that those with life-long disabilities which do not change do not have to regularly restate information about the condition or disability; and
- the provision of information to medical practitioners required to complete medical reports about the application process and the importance of highlighting the impact of any disability or condition on primary carers.

## **References**

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

Madden, K., Law, M., 2005. *The Tasmanian Community Survey: Financial Hardship*. Social Action and Research Centre. Anglicare, Tasmania.