SARC briefs

My Life as a Budget Item:

Disability, budget priorities and poverty in Tasmania

This study explored the circumstances of Tasmanians with disabilities of working age living on low incomes in 2005-06. It was undertaken by the Social Action and Research Centre at Anglicare Tasmania. Information was collated through interviews about the daily lives of 48 people reliant on the Disability Support Pension (DSP) and 20 carers. This summary outlines the main findings and recommendations from the research.

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Key Finding 1: Poverty and Disability

- **The links between poverty and disability.** Lower workforce participation rates, lower incomes and a higher cost of living due to disability related expenses means that many Tasmanians with disabilities live in poverty.

- **Inequity in income support.** Although two people might have very similar needs those who are compensable under insurance schemes have access to significantly better levels of income and support than those who are non-compensable and reliant solely on the DSP.

- **High cost of living.** People with disabilities incur a range of costs which are not faced by non-disabled people to cover basic needs like transport, medical treatment, personal care and aids and equipment. Although some of these additional costs are met through government subsidies and services living with a disability in Tasmania is very expensive.

The Number of People with Disabilities in Tasmania

- Approximately 111,700 people in Tasmania (23.5% of the population) live with a disability (ABS, 2004).
- More than 24,800 people aged 18-64 years rely on the DSP as their main source of income.
- Approximately 22,000 have a profound or severe core activity restriction which means that they sometimes or always require assistance with daily activities in order to live a reasonable lifestyle.
- Advances in medical technology mean more people survive traumatic injury or health problems. The likelihood of disability also increases with age and Tasmania is projected to age more rapidly than other jurisdictions (Productivity Commission, 2005).
- The numbers of people requiring support to live in the community is growing and this means that the State faces a significant increase in demand for services for people with disabilities.

> “*People with disabilities should not have to fight every inch of the way. Society should be able to say okay this is what you need and so that is what we will give you. It should be factored in as part of our daily life. We shouldn’t have to be fighting for basic rights.*
>
> Trish, 50, caring for her son living with quadriplegia”

- **Limited disposable income.** A typical budget for a Tasmanian with a severe disability leaves only $32 per week to spend on all other aspects of their life once basic living costs have been covered.

- **Social exclusion.** Disability commonly leads to a constrained existence where living standards, opportunities and life chances are substantially poorer than for the rest of the population and where many Tasmanians are living in hardship and cutting back on essentials like food, heating and health needs as well as social and community participation.

Key Finding 2: Lack of Access to Services

- **A fragmented service system.** In Tasmania support is currently delivered through a complex maze of organisations with little care planning across disciplinary boundaries to provide a holistic service. People in need of assistance have to approach a number of different agencies to have their basic needs met. The lack of information about how services work or what individuals are entitled to is very confusing for the service user trying to find their way. Under-funding has generated significant unmet needs and long waiting lists for a range of services.

- **Problems with Centrelink.** These are associated with administrative procedures and processes and levels of disability awareness among Centrelink staff. The recent welfare-to-work reforms have also generated concerns among people with disabilities that seeking paid employment could severely jeopardise their income levels.

> “ ***Over time as you have doors and opportunities constantly slammed in your face and denied, coupled with increased feelings of worthlessness and lowered value you simply give up, become compliant and accept your fate. Once this process has taken place it is very difficult to bring about renewed empowerment. This is poverty in all its manifestations.***
>
> Steve, 31, living with blindness ”

> ***This wheelchair cost $18,000 and the most the State Government will give under their funding scheme is $6,000. There is a huge gap and if people don't know where to go and who to talk to how are they expected to find that $12,000 gap. For some people, because of the disability, they might need very specialised equipment which means that they can't afford other things, like groceries.***
> Jack, 47, living with cerebral palsy

- **Inadequate personal care and support services.** Personal support services in Tasmania enable people to remain in their own home and are currently delivered through different programs and a range of providers. Success in accessing support can depend on how a disability was acquired and skills in navigating the system rather than on need. Those who are successful receive a minimum level of service which enables them to remain at home but which does not necessarily provide a good quality of life. There are particular shortfalls in the amount of domestic assistance an individual can get and in the support available to promote social and community participation.

- **Missing out on essential equipment.** Assistive technology is able to revolutionise levels of independence and change people's lives but can be expensive. Assistance available to meet these costs in Tasmania is fragmented and provided by a range of services where eligibility differs according to type of impairment, how it was acquired, age of the applicant, where they live and in what sort of accommodation. There are currently major shortfalls in the assistance available to meet basic needs like mobility, communication and continence.

- **Limited housing options** for people with disabilities are common and have a profound impact on their ability to manage as independently as possible. It can be difficult to find housing which has the modifications that people need and which also has reasonable access to services and transport. At the extreme end of this spectrum are younger people with disabilities and high support needs who have no alternative but to live in nursing homes for elderly people.

- **Barriers to health care** include long waiting lists for acute and specialist health services, high transport costs, a lack of awareness among health service staff about disability issues and an absence of planned discharge procedures from hospital care. People with disabilities also have difficulties in accessing preventative health programs, oral health and complementary therapies, some of which are vital to maintaining reasonable levels of mobility and controlling pain. The additional costs they face in paying for medications and other medical supplies are not adequately met through the Pharmaceutical Benefits Scheme and mean that some people do not get access to the health care they require.

- **Difficulties in accessing employment, education and training.** Tasmanians with disabilities face a number of major obstacles in this area. These include direct discrimination in the case of employment. They also include the additional costs involved particularly with transport, technical aids and personal support which are not effectively or fully met by government subsidies.

- **Social isolation** is the norm rather than the exception for people with disabilities in Tasmania. Overcoming the physical, financial, attitudinal and psychological barriers to participation is a constant battle for many people which drains their energies. There are limited day options and barriers to accessing mainstream recreational and leisure facilities. In addition a lack of affordable transport imposes severe restrictions on people's lives reinforcing the social isolation that so many experience.

“

'You don't go out. You try not to get involved. People invite you somewhere and say bring a plate or bring a bottle of wine which is usually about $20. You can't go anywhere, how can you go anywhere? How can you go to a concert, how can you afford it? People come to your house and expect things. I don't buy milk now unless I know someone is coming because I've cut back on the milk. You can't say to someone bring your own toilet paper and milk when you come. I'm not part of the community, I can't function.

Sarah, 53, living with acquired brain injury

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Key Finding Three: Carers

- **Reliance on informal care.** Home based care relies heavily on the availability of friends and particularly family as carers and the majority of personal care and support for those living at home is provided by informal carers. Informal care is also very important to those living in supported accommodation and improves their quality of life.

- **The high cost of caring.** Acquiring caring responsibilities can bring with it restricted employment options, extra costs, low levels of financial assistance and a high risk of poverty, hardship and poor health both emotionally and physically.

- **Lack of support for carers.** Most carers feel that they need more support in their caring role and many considered that they were unsupported and exploited. They were critical of both the financial support available to them and the lack of a range of respite options to give them a break from caring.

- **The value of carers.** Given the value of their work if it had to be replaced by formal services supporting carers should be a priority for Tasmania. At a time when the number of carers is projected to fall while the working age population of people with disabilities is projected to rise it will become imperative to counter the disincentives to care.

> “*We are saving the Government quite a lot of money by keeping our loved ones at home. There is not enough support. The carer’s allowance is only $90 a fortnight. If you divide that by 24 hours a day and 7 days a week we are only getting around 15 cents an hour to look after our loved ones. It is absolutely ridiculous. More acknowledgement and financial compensation is required. The money we receive for all the different needs including respite is just not fair, it really isn’t.*
>
> Pamela, 61, caring for daughter living with cognitive difficulties and husband living with Parkinsons”

Carers in Tasmania

- There are currently 22,000 primary carers in Tasmania (ABS, 2004) caring for a partner, son or daughter.

- Together with South Australia, Tasmania has the highest percentage of the population living in households providing care (NATSEM, 2006).

- Although demand for care for people with disabilities is anticipated to grow in the next 20 years the caretaker ratio is projected to fall (ABS, 2004) so who will care will become a big issue in Tasmania.

Anglicare recommends

- an immediate injection of funds to provide basic services to people currently on waiting lists;
- a commitment to annual funding increases to Disability Services to meet the projected growth in demand;
- additional funding to improve access to respite, day options, aids and equipment, home modifications, social support, domestic assistance, a range of housing options and affordable transport and to introduce a streamlined service system;
- comprehensive disability awareness training for all those involved in providing disability and other services to people with disabilities conducted by trainers who have disabilities;
- increased incentives for employers to employ people with disabilities and an onus on government and non-government organisations to review their own employment practices to ensure they are non-discriminatory towards disabled people;
- the establishment of a disability support information service using a one stop shop approach to disseminate information about rights and entitlements to support and assistance across the spectrum of services;
- the resourcing of a peak consumer organisation that represents people with all types of disability; and
- the introduction of a universal disability allowance to meet the additional costs associated with disability.

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I get really sick of having to tell my details over and over again to get a basic service. My disability will never go away and if anything it will only get worse but there’s no recognition of any of that stuff. It’s awful to feel you have to beg for everything and that you’re not the priority everybody else is and the fact that you have to wait for everything for so long. I would just sometimes like one thing to be really simple and straightforward.

Mary, 57, living with physical disability

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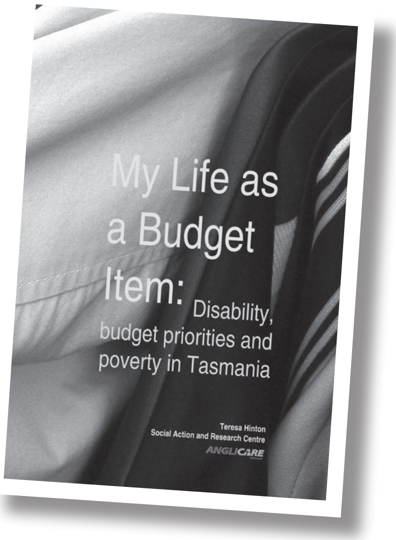
For more information

The full report, *My Life as a Budget Item: Disability, budget priorities and poverty in Tasmania* by Teresa Hinton, is published by the Social Action and Research Centre at Anglicare Tasmania.

It is available by calling **6234 3510** or at **www.anglicare-tas.org.au**.



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Social Action and Research Centre (SARC)

The SARC team work with low income Tasmanians to identify the structural barriers that impact most severely on their lives. The Centre pursues policy change on these issues at a State and Federal level.