



**Response to the Inquiry into the Provision of Assistive
Technology and Equipment for People with Disabilities**

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Submission from

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Introduction

Anglicare Tasmania welcomes the opportunity to contribute to the Inquiry into the Provision of Assistive Technology and Equipment for People with Disabilities. The comments expressed in this submission are based on two research projects carried out by the Social Action and Research Centre at Anglicare Tasmania. The projects examined the access that both working age adults with disabilities (Hinton, 2006) and families caring for children with disabilities (Hinton, 2007) have to the aids and equipment they need. The submission makes comments about the Community Equipment Scheme (CES) and its resourcing, effectiveness and consistency. It also comments on the caps for particular items of equipment and the ability of people with disabilities and their families to access funds for equipment and assistive technology in a timely manner.

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 12 years SARC has produced a series of major research reports on these issues including access to health care, unemployment, financial crisis, mental illness and disability.

Background

People's lives can be transformed by having access to appropriate assistive technology and as technology improves it is increasingly able to revolutionise lives and improve both emotional and physical independence. For children with disabilities and developmental delays it can be a particularly important tool in facilitating normal development and helping to approximate the quality of life of children without disabilities. For equipment to promote positive outcomes it needs to be appropriate and provided at the right time, suit the individual and the carer and not be too heavy or cumbersome.

However the costs of assistive technology are increasing and can be a huge expense in limited budgets. This means that although those on low incomes, like the Disability Support Pension, have access to financial subsidies these are cash limited and means tested and commonly do not allow them to meet all their basic needs for aids and equipment and particularly for mobility, continence and communication aids. The absence of appropriate assistive technology may reduce the ability of adults to live a safe and an independent life, require a greater reliance on personal assistance from a support worker and greatly increase expenditure on health and social care in the longer term. For children it can mean a slowing in their development, a limitation in their capacity to participate in everyday activities and a higher risk of developmental delay.

Anglicare recognises the pressures on the current CES in Tasmania. These include advances in technology, the ageing population, increasing demand and the incidence of relationship breakdown and split families with equipment required in each household. There are also growing numbers of ageing carers requiring lighter weight equipment and an increase in body weight requiring an increased weight capacity of equipment. Despite these pressures the overall budget of the CES has not increased for six years beyond occasional top ups. This has limited its ability to meet demand, increase the range and quantity of equipment on offer and to cover the cost of maintenance, repair and replacement of loan equipment. This causes delays in supplying standard equipment and unpredictable waiting times and leads to clinical need being prioritised at the expense of aids to promote community integration and participation.

Research Findings

Participants in Anglicare's research commented on:

- **difficulties in accessing sufficient funding** to pay for large items of equipment like wheelchairs and hoists. While a customised chair can cost up to \$21,000 the Community Equipment Scheme in Tasmania will only fund individual items to a maximum of \$6,000. Powered mobility is often the most appropriate response for a child and allows them to have control over their own mobility and to participate in childhood activities. Yet this commonly costs \$8,000 or more and can be beyond the reach of many low income families.

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)

- **reliance on charitable funding.** Many people are forced into fundraising to close the gap between the subsidies available and the actual cost of basic equipment. They have found this difficult and in some cases demeaning. Parents in particular can be reluctant to use their child to elicit sympathy and to approach charitable bodies for assistance.

It is demeaning to be asked to fundraise. I have met the cost partly through the Community Equipment Scheme and I have also approached individual organisations such as Rotary which has been quite helpful. Even though I can be quite an outspoken person I do feel a bit funny about asking people to help me with money. It is a pride thing I guess. (Mat, 22, living with cerebral palsy)

- **waiting times.** Accessing charitable funding is not necessarily straightforward and it can take up to two years to confirm a contribution, customise a chair and order it. Some charitable organisations do not commit funds more than twelve months ahead or will not release them until there is a commitment from the State to provide matching funding. This delays the supply and involves people with disabilities and service providers in holding procedures which drain energy and resources.
- **the impact on children.** These issues can impact particularly negatively on children. Unlike adults they are growing and their condition may well be changing. This means that equipment like a wheelchair requires constant modification and updating but nevertheless they have to compete in the same funding pool as adults. Inability to access appropriate equipment in a timely fashion can mean delaying their start at school and have a big impact on their cognitive development and ability to participate.

We did a fundraiser for Meg's wheelchair. We couldn't just go in and say we need a wheelchair and they would say right we'll order one and it would be funded. If you tried to do that you could be waiting literally years. When we found out Meg really needed a wheelchair for kindergarten it was October. We were then told that if she was to wait for government funding she could wait 12 months. Well she couldn't wait 12 months because she started school in a few months. We raised nearly \$4,000. There is that initial thing of putting the kids out there. That was the hardest part with Meg. It was difficult because

we have always done everything ourselves. We don't like asking people for money. (Suzanne and Tony caring for Meg aged 7 and David aged 5 with multiple disabilities)

- **using inappropriate equipment.** Waiting times and financial strains typically mean that people with disabilities are using outdated or inappropriate equipment.
- **inconsistency.** Many participants considered it was pure chance whether they had obtained or not obtained the equipment they needed. It was a question of applying at the right time or getting a good occupational therapist who was able to push their case, or shouting louder than anyone else to get priority.

I've got an electric wheelchair now which I've had for the last five years. The government subsidised it. The reason was that I applied at the end of the year and they had a lot of money left over and they looked at the list of people who needed equipment and spent the money by the end of the financial year. I was a lucky one. (Jim, 30, living with cerebral palsy)

- **emotional strain.** High costs, long waits and managing with inadequate equipment impose an additional emotional toll on people with disabilities and their families who are already stressed by the demands of daily care.

Anglicare's research which publicised the funding gaps and long waiting lists for wheelchairs resulted in the establishment of a philanthropic fund with a private donation from the Elphinstone William Adams Group in 2007 to provide new wheelchairs to Tasmanians on the waiting list. The Fund is administered by Anglicare in partnership with the CES and with matching funding from State Government. However resources are one off and although they help to shorten the waiting list for wheelchairs they will not be able to meet future demand.

Meeting Essential Needs

Anglicare's research highlighted shortfalls in the provision of equipment in two essential areas – communication equipment and continence aids.

Communication Equipment

This can be vital to allow people with disabilities to manage their everyday lives and their finances, access services and obtain information. It has a multitude of uses like environmental controls for opening doors and turning on lights and heaters, voice commands

for computers or microwave ovens or special adaptations to mobile phones and other pieces of basic equipment so that people with a disability can use them. It can greatly reduce the need for personal assistance from a carer and allow people to better control their own lives. People with sensory disabilities are particularly dependant on communication technology and it can be life saving. Deaf and Hard of Hearing people may require flashing lights on door bells and telephones, pillow vibrating devices to act as smoke alarms and flashing strobe lights for baby alarms.

However research participants had experienced shortfalls in the subsidies available to help fund communication equipment like communication boards, speech synthesisers and computer software as well as potentially life-saving aids like smoke alarms suitable for deaf and hard of hearing people. In particular the majority of smoke detectors commonly available have audible alarms and cost approximately \$20. Smoke alarms for people with hearing impairments can cost between \$300-400 plus installation costs because they must be fitted professionally. Yet despite the potentially fatal effects of an inappropriate smoke alarm there is no subsidy available to meet this additional cost through the CES or other schemes.

Continence

The CES continence service provides up to \$1,000 in continence supplies per year with the client contributing half the cost. This includes a free assessment by a continence nurse to ensure the right product choice. Some clients, and particularly children with continence needs, have now been transferred to the Commonwealth Continence Aids Assistance Scheme (or CAAS). This provides a lower annual subsidy for continence aids and the provision of supplies is not linked to assessment or to treatment.

Anglicare research showed:

- adult users of the schemes have difficulties in meeting the cost of their continence needs and are finding the subsidies barely meet the expense; as one user said '*CAAS only provides for a quarter of the needs of the fully incontinent*'. Some try to meet the additional costs by applying to Disability Services for one off funding but few are successful.
- a lack of awareness of subsidies available means that some families continue, sometimes for years, with no additional support for continence needs.

- families have considerable difficulties in meeting the continence needs of their disabled children which often present as a huge financial cost to the family. For fully incontinent children it can cost over \$100 per month in nappies. This means that the current subsidy of \$471 available from the CAAS runs out in under five months leaving the family to meet the full cost for the rest of the year. Costs can also increase with particular conditions including diabetes, irritable bowel syndrome and autism. Costs of \$100 per month represent 10% of carer payment (child) and 51% of the fortnightly carer allowance (child). Some research participants were in the hands of debt collectors through unpaid nappy bills and lived with high levels of perceived threat because of the debt collection process.
- the impact of inadequate continence support is significant and affects all aspects of daily life and particularly social and community participation. People report economising by not changing as regularly, by not eating or drinking in public and by finding it easier not to go out at all.
- the additional costs of purchasing continence accessories and medications which are not scripted can be high. These include nappy bleach, wipes, washing powder, additional wear and tear on clothing, delivery charges and supplements like cranberries to assist with bowel function.

As one family said:

I personally think that if your child is incontinent and I'm not talking about just wetting the bed at night, I'm talking about severe incontinence like my child has then I feel the government should back us up and at least give us the money to buy the nappies for the year because that is so hard. If you haven't got the funds to go out and buy the nappies, what are you going to do? You are going to cut back, you are going to start not changing the child, or you're going to change them once in a blue moon. Just give us the money for the nappies. It annoys me so much because that to me is basic health for someone therefore it should be provided without any questions. (Doreen caring for Chloe aged 16 with severe autism)

Recommendations

The research clearly indicates that people are currently going without necessary equipment for extended periods in their lives leading to reported deteriorations in their health, wellbeing, safety and social and economic participation. What people with disabilities and their carers

want to see is an increase in the range and level of assistance available to acquire necessary aids and equipment and an improvement in consistency and waiting times. This requires urgent attention.

Anglicare would like to see:

- provision of **subsidies to enable Deaf and Hard of Hearing Tasmanians to purchase visual and tactile smoke alarms** at the cost of a standard house smoke alarm.
- **adequate assistance with continence needs.** Provision of nappies and other continence aids is a basic and essential health need and should be fully funded. The Australian and State Governments should commit to fully funding the cost of disposable nappies and associated continence aids for Pension Concession Card and Health Care Card holders over the age of four years.
- Australians with disabilities able to claim **the expense of essential equipment like mobility and communication aids under the Medicare Scheme less other funding sources** like those available to eligible people under the CES. This would enable an increase in the funding caps on large items of equipment like wheelchairs and hoists.
- **an increase in the general level of funding in the CES scheme** to address unmet equipment needs, improve the timeliness of supply and ensure that community integration and social participation does not always take second place to the risk of institutionalisation or hospitalisation.

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. *Forgotten Families. Raising children with disabilities in Tasmania*. Social Action and Research Centre. Anglicare Tasmania.