SARC briefs

Forgotten Families:

Raising children with disabilities in Tasmania

This study explored the circumstances and experiences of Tasmanian families caring for children with disabilities aged 0-16 years. It was undertaken by the Social Action and Research Centre at Anglicare Tasmania. Information was collated from 24 low income families across the State about their daily lives and from service providers. This summary outlines the main findings and recommendations from the report.

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Key Finding 1: Poverty and Disability

- there is a **strong association between childhood disability and low family income** due to additional disability related expenses, sustained periods on government benefits and barriers to entering or retaining employment. The birth or diagnosis of a disabled child is a trigger event for family poverty (AIHW, 2004).

- **high cost of living.** Families incur a range of additional disability related costs. They may need to spend more on heating, on housing in order to fund the modifications they need and to be nearer to services and on travel because they are unable to use public transport. They may also have to buy special clothing and equipment for their child. On average children with disabilities cost three times as much as non-disabled children (Dobson and Middleton, 1998) and costs are particularly high when the disability is severe or profound.

> *The government wants you to look after children like this. If you put Simon into full time care and then tell me how much it's going to cost to look after him. I heard it was something like $300,000 a year. But we are expected to bring him up on minimum amounts. You give your life up and you can't do nothing.*
>
> Sheila and Des caring for Simon
> aged 15 with multiple disabilities

The Number of Children with Disabilities in Tasmania

- There are approximately 8,300 children with disabilities aged 0-14 years living in Tasmania (ABS, 2006) and 99% live with their family (AIHW, 2005).

- 4,800 have levels of impairment classified as severe or profound (ABS, 2006). This means that they sometimes or always require assistance with daily activities (beyond that required by all young children) in order to live a reasonable lifestyle. It is this group who have the biggest need for services.

- 62% of primary carers of disabled children, usually parents, are reliant on government pensions or benefits as their principal source of income (AIHW, 2004). This means that there are approximately 5,000 low income families caring for children with disabilities in the state.

- The proportion of children with profound or severe impairments is highest among those from low income households. Those in the lowest income quintile are over four times more likely to have a profound disability than those in the highest income quintile (AIHW, 2005).

- **inability to meet basic health needs** due to a lack of income causes anguish among families. In particular:
  - families coping with incontinence find the annual subsidy (of approximately $500) inadequate to meet the costs of nappies and other accessories which can total up to $100 a month or more. Some families find their debts for nappies passed to debt collectors by suppliers of continence aids.
  - the realisation that the latest therapies, experts or medication are not available to them because they are unable to pay means that families often live with an overwhelming sense of having failed their child.

- **living in hardship.** Low incomes and high costs mean that many families have difficulties in making ends meet and some are forced to cut back on essentials like food and heating. The rising cost of living in Tasmania is making it harder for them to manage. Over 70% of research participants said they had been unable to pay bills on time and three quarters (75%) had sought financial help from friends or family in the last 12 months.

Key Finding 2: Difficulties in Accessing Services

- **Fragmented services**. Despite many policies and initiatives across different sectors which impact on children with disabilities and the families who support them there is no overarching framework within which to address the issues they face. This means fragmented services, inconsistencies across the state and difficulties in linking services together to provide a coordinated package of support.

- **Information.** A common experience for families is having to engage in a constant battle to find out what is available to them, how to access it and to get agencies and professionals to understand their needs. This is at a time when they face enormous pressures and stresses adapting to their child's disability and meeting often onerous caring responsibilities. It leaves families confused and frustrated, without the support they need and can bring them to the point of collapse.

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The links between agencies aren't there and you hear about it from other parents, other people. Every now and again you come across a good person but generally you've no idea what's out there unless you go out and make 100 phone calls. There needs to be some sort of central coordination.

Angela caring for Dean aged 7 with autism

If your child is incontinent and I'm not talking about just wetting the bed at night 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? 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

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> “*When you say ‘at risk’ people think of abuse and neglect but families are at risk with children who have 24/7 additional needs and those families may not ever come to anyone’s attention that they are struggling until a crisis hits and then suddenly everyone is in on them. A lot of parents have a hidden fear that if they admitted to anyone that they are struggling or they admitted to anybody that things are tough they would be worried that it would be seen as a bad reflection on their ability as a parent rather than a reflection on the additional parenting resources they have to find to support their children.*
>
> Gerry caring for three children
> with autism aged 8, 7 and 6 years”

- **Support in the community.** Families need on-going reliable support with their child’s day-to-day care. Services which assist them to look after their child and which give them a break from the constant demands of caring are essential in allowing them to continue to care. However families reported struggling to access adequate levels of assistance with support hours, respite care, childcare and holiday programs. There are also unknown numbers who do not ask for assistance – not because they do not need it but because they anticipate being turned away or have concerns about the quality or appropriateness of the support. Although most families are able to stay on top of their situation despite low levels of support, they are very aware of how easily things can spiral out of control.

- **Aids and equipment** can be very important in supporting a child’s functioning and development, improving independence and reducing the risk of injury to carers. However many families experience difficulties in getting access to the equipment they need and particularly to mobility, communication and continence aids. Those who are unable to pay face long waits and emotional strain as they try to find their way through complex schemes and fluctuations in available funding. For some it can mean the ignominy of charity or just doing without. For others it can mean falling into the hands of debt collectors.

- **Education.** Many services for children are delivered through the education system and Tasmania has adopted the principle of inclusion. Most people, including parents, are supportive of the idea of inclusion but the research demonstrated that its implementation has been inconsistent so that some families have very good experiences and others negative experiences. Families were concerned about the lack of a range of options to fit the spectrum of educational needs, a shortage of trained teacher aides able to provide high quality support and not just care, and shortfalls in funding that lead to an annual battle to secure support and a planned transition into adult life.

- **Centrelink.** It can be several years after the birth or diagnosis of a child with a disability before a family finds out they may be entitled to Carer Allowance or Carer Payment. Eligibility for benefits may also be dependent on a medical report from a doctor and some doctors do not understand how to complete the doctor's report which can prejudice a parent's application for assistance.

- **Employment.** There are difficulties in accessing and maintaining employment while caring for a disabled child and it can be very dependant on having understanding employers, flexible hours and inclusive and affordable childcare. The absence of these supports means that some parents have to abandon work to care for their child. Families wanted to see options available to them to combine caring with participation in employment, study and volunteer work rather than being condemned to a full time caring role and living on benefits for years to come.

- **Essential services:**
  - **Housing.** Families were struggling to access and maintain affordable housing which met the needs of their disabled child and it could require a crisis to make families eligible for public housing. The cost of home modifications for home owners and those in private rental accommodation was daunting.

  - **Transport.** This was a major issue for many research participants. They described inadequate subsidies for health related travel through the Patient Transport Access Scheme, a lack of assistance with buying and modifying vehicles and a reliance on charitable funding to maintain private vehicles which are so necessary for many families.

  - **Health care.** Families feel they have to push for their children to get the health and therapy services they need and there are few certainties or final solutions. Instead there is always the promise of a second opinion, more effective therapy, better medication or a more experienced specialist to tempt families. However these options often come at a considerable cost which is beyond the reach of those who are already struggling to survive financially. Families also commented on the lack of coordination between acute health services and supports in the community and an absence of assistance in coping with behavioural difficulties and challenging behaviour which left them struggling alone.

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> ***If you're going to put all these children who are very high maintenance and require round the clock care in the mainstream you have to have a back up plan and without the specialised teachers will he succeed, no he won't. He is just slipping through the system. The educational system is letting him down miserably because they just don't know what to do with him. You have to push and it is hard, pushing every day for something better for him and getting the school to recognise it and schools don't. It's a form of abuse really and neglect on the government's part in not giving children what they need. I feel they have failed him terribly.***
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> Liz caring for Sean aged 12 with multiple disability
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- **Social isolation.** The multiple demands placed on parents by the care needs of disabled children mean the whole family is placed under unrelenting stress and although most do cope there is a heavy cost in terms of the quality of family life. It leads to strains in relationships, deterioration in the health of primary carers and a negative impact on the other children in the family. Families can find themselves excluded from social activities outside the home due to general fatigue, financial barriers and difficult behaviours and they described the loneliness and isolation of their situation.

> “*It’s a very lonely life. You don’t tend to make many friends. If you do have friends that come round they spend their time looking at him. So you tend to become very isolated and I’m sure a lot of people with disabled children will tell you the same thing. It’s very isolating, lonely. The only people you have anything really to do with are people associated with his care, medical professionals or other parents with disabled children. That’s about it and most of those parents you don’t do a lot of socialising because they are all very busy and no one has energy.*
> Dawn and Gary caring for Tony aged 8 with multiple disabilities”

Best Practice Model – Local Area Coordination

The research demonstrated how access to effective and coordinated community support is vital in order to assist families with disabled children and to prevent the escalation of situations into a crisis. Families require information about the kind of service they can expect, how to access it and one point of contact with services. This should be available from the point of diagnosis, injury or identification of a developmental delay.

Anglicare would like to see the piloting of Local Area Coordination (or LACs) in Tasmania. This has been successfully developed in Western Australia and adopted in Queensland, the ACT and Scotland for people aged 0-64 years living with disabilities. There is currently a campaign to adopt this model in New South Wales.

Each coordinator works in a defined geographical area corresponding to a known number of people with a disability and providing one point of contact with services. Coordinators have a proactive role in contacting families, giving them information, assisting in managing packages of support and boosting the capacity of informal support networks. They continue to provide information and support as the person ages and the nature of the impairment alters or as entitlements change and have access to a small budget to meet additional disability related costs.

This service costs $2,427 per year for each service user (Disability Services Commission, 2006). Numerous evaluations have shown that it provides value for money and very positive outcomes with more people using services, with people getting coordinated support and with high rates of satisfaction among service users (Bartnik & Psaila-Savona, 2003).

Anglicare recommends:

- an immediate injection of funds to support those families waiting for essential services – personal care and support, aids and equipment, respite, therapy, childcare and holiday provision.
- a commitment to annual funding increases to Disability Services to meet the projected growth in demand and to improve access to and the quality of essential community supports, a range of housing options and affordable transport.
- a Tasmanian policy framework for specialist support to children with disabilities and developmental delays and their families from birth through to adulthood.
- immediate attention to developing a streamlined service system facilitated by local area coordinators, access to information and one point of entry to services.

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> ***I don't think the government is doing enough for kids with disabilities. It's very slack on that. They spend millions of dollars on a football club thing, millions of dollars on the Elwick Showgrounds. They build the new hospital but they just don't think of disability people so they get shoved to the side.***
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> Jane and Mike caring for Lisa aged 4 with cerebral palsy
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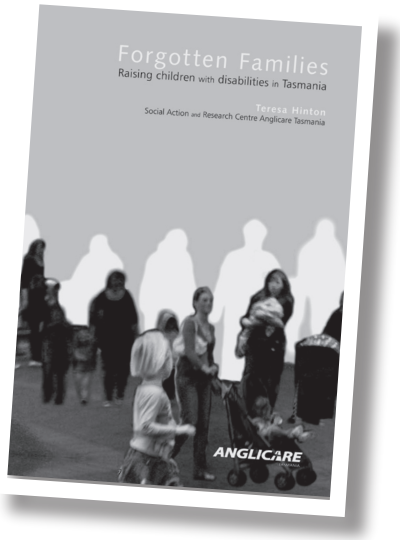
For more information

The full report, *Forgotten Families: Raising children with disabilities in Tasmania* by Teresa Hinton, is published by the Social Action and Research Centre at Anglicare Tasmania.

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



Social Action and Research Centre (SARC)

Anglicare's 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.

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[1] These figures are estimates only and some regions will differ from predictions because of local effects that are not captured by the calculations. This means that they should be used in conjunction with an understanding of local area characteristics and their quality limitations.