



Australian Social Trends

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Article: Families with a young child with a disability

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Families with a young child with a disability

In 2003, 13% of families in Australia with children aged 0–14 years had a child with a disability, including 7% with a child with a profound/severe disability.

The majority of children with a disability live and are cared for in their own family home. Family members take on caring responsibilities and have differing degrees of access to more formal types of support.¹

The impact of having a child with a disability varies across families. The type of disability, family structure and dynamics, as well as individual characteristics and socioeconomic circumstances of the family, all influence the nature of stress which families may experience, and the coping mechanisms they may have for dealing with this stress.²

Children with a disability

In 2003, almost 320,000 children aged 0–14 years had a disability. Almost all (99.7%) of these children lived in family households, as opposed to institutions. Around 4% of all children aged 0–14 years had a profound/severe disability. These children needed assistance all or most of the time with self-care, communication or mobility.

Children may have more than one type of disability. In 2003, the most common types of disability among children were intellectual disabilities (59% of children with a profound/severe disability) and sensory/speech disabilities (53%).

Data sources and definitions

Data in this article are drawn from the ABS 2003 Survey of Disability, Ageing and Carers (SDAC) and refer to families with children aged 0–14 years.

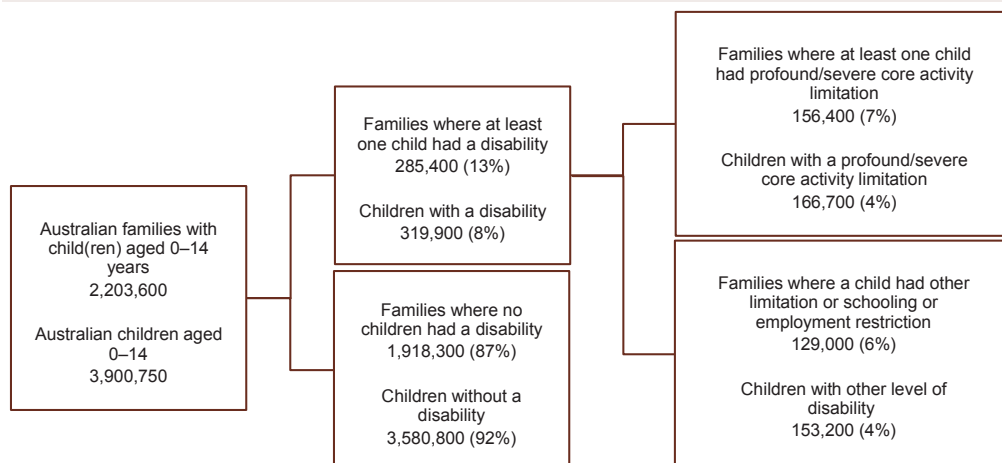
Disability as defined in SDAC refers to a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activity.³ This definition is consistent with the International Classification of Functioning, Disability and Health, which defines disability as an umbrella term for impairments, activity limitations and participation restrictions. *Core activities* include self-care such as bathing and eating, mobility and communication. With a *profound/severe* disability the person always or sometimes needs help with core activities. With a *moderate/mild* disability the person needs no help or supervision but has difficulty with a core activity task, or the person uses aids and equipment but needs no help with a core activity task. For further details, see 'Disability, Ageing and Carers: Summary of Findings', 2003 (ABS cat. no. 4430.0).

The *Primary carers* in this article are those who are parents of a child aged 0–14 years with a disability, who live with that child, and assist them with core activities on an ongoing basis.

The *Socio-Economic Indexes for Areas (SEIFA) Index of Disadvantage* summarises various attributes (such as low income and unemployment) of an area in which a population lives to provide a measure of the level of social and economic disadvantage in that area.

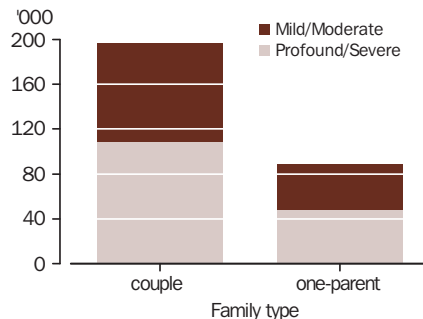
Equivalised family income is a measure of income which is adjusted to account for the different size and composition of families.

Families with child(ren) aged 0–14: child's disability status — 2003



Source: ABS 2003 Survey of Disability, Ageing and Carers.

Families with a child with a disability — 2003



Source: ABS 2003 Survey of Disability, Ageing and Carers.

Families with a child with a disability

In 2003, there were around 2.2 million families in Australia with children aged 0–14 years. One in eight of these families (13% or 285,000) had a child with a disability, similar to the rate in 1998 (12%). In 2003, 7% of families had a child with a profound/severe disability.

In 2003, of all families with at least one child with a disability, 69% were couple families and 31% were one-parent families. One-parent families, irrespective of whether or not they have a child with a disability, are considered to be at higher risk of disadvantage, for example in income, housing and employment.⁴ One-parent families that have a child with a disability may be at increased risk of disadvantage.

Families with a child with a disability were generally larger than were families without a child with a disability. In 2003, there were on average 2.3 children aged 0–14 years in couple families with a child with a disability compared with 1.8 children in couple families without a child with a disability. Similarly, for one-parent families the average number of children of this age was 2.1 and 1.6, respectively.

In 2003, a much higher proportion of one-parent families had a child with a disability compared with couple families. About one in five one-parent families with children aged 0–14 years (19%) had a child with a disability, and 10% had a child with a profound/severe disability. Correspondingly, about one in nine couple families with children of this age (11%) had a child with a disability and 6% had a child with a profound/severe disability.

In 2003, there were 438,000 families (20%) with children aged 0–14 years where one or both parents had a disability. The proportion of families who had a child with a disability was higher in these families than in families where a parent did not have a disability.

Couple families where at least one parent had a disability were more than twice as likely to have a child with a disability as those couple families where a parent did not have a disability (22% and 9% respectively).

Similarly, one-parent families where the parent had a disability were more than twice as likely to have a child with a disability (32%) as those where the parent did not have a disability (15%).

Socioeconomic status

The relationship between disability and socioeconomic status is complex.

Disadvantage may contribute to and precede disability through exposure to environmental risks, inadequate nutrition, or maternal risk factors.¹ Alternatively, disadvantage may be the result of having a child with a disability, reflecting reduced opportunities to engage in paid employment and the greater costs of caring for a child with a disability.

Furthermore, families with a larger number of young children generally have lower levels of labour force participation by parents, and therefore of income, than do families with fewer children. Since families with a child with a disability have more children on average than do families without a child with a disability, some of the differences in socioeconomic circumstances may be due to family size.

In 2003, families with a child with a disability were more likely to be living in areas of greater socioeconomic disadvantage, as identified by the Socio-Economic Index for Areas (SEIFA) Index of Disadvantage. Almost one-fifth (18%) of families living in areas of greatest socioeconomic disadvantage (the first decile) had a child with a disability, compared with 13% of all families.

...educational attainment of parents

The educational status of parents is also associated with disability. Among couple families where at least one parent had completed secondary school, 10% had a child with a disability, whereas in couples where neither parent had completed secondary school, the proportion was 15%. In one-parent families, 11% of parents who had completed secondary school had a child with a disability compared with 23% of lone parents who had not completed secondary school.

Couple families where neither parent had completed secondary school, were almost twice as likely as other couple families to have a child with a profound/severe disability (9% compared with 5%).

Families(a): labour force status of parents — 2003

Selected labour force status of parents	At least one child had a disability	No children had a disability
	%	%
<i>Couple families</i>		
Both employed	50.9	61.4
One employed	40.0	33.3
Neither employed	9.1	5.3
Total	100.0	100.0
<i>One-parent families</i>		
Employed	38.1	52.1
Not employed	61.9	47.9
Total	100.0	100.0
	'000	'000
Total families	285.4	1 918.3

(a) With children aged 0–14 years.

Source: ABS 2003 Survey of Disability, Ageing and Carers.

Labour force participation

One of the indirect costs of having a child with a disability can be the reduced opportunity for parents to work. This may be related to the availability of specialised care for the child, as well as the inability of the parents to find employment with flexible

arrangements.¹ While many parents continue on in employment, some parents may have ceased working after their child acquired or was diagnosed with their disability, and others may not have been working to begin with.

In 2003, around 51% of couple families who had a child with a disability had both parents employed, compared with 61% of couple families where no child had a disability. If the child's disability was profound/severe, the proportion having both parents employed was lower (42%).

Over one-third (38%) of lone parents who had a child with a disability were employed, compared with around one-half (52%) of lone parents who did not have a child with a disability. The proportion employed dropped to 29% where the child's disability was profound/severe.

After adjusting to account for differences in family size between families with and families without a child with a disability, the gap between the labour force participation of parents was reduced. The standardised proportion of couple families with a child with a disability in which both parents were working was 56% (compared with the unadjusted rate of 51%) while the corresponding proportion for couple families without a child with a disability was 61% (the same as the unadjusted rate). Standardisation made less difference to the relative rates of labour force participation between lone parents with and without a child with a disability.

Families(a): disability status and gross equivalised family income per week(b) — 2003

Equivalised gross family income quintiles(c)	At least one child had a disability	No children had a disability
	%	%
Lowest quintile	32.6	20.5
Second quintile	27.3	21.7
Third quintile	20.3	23.3
Fourth quintile	10.2	20.6
Highest quintile	9.7	14.1
Total	100.0	100.0
	\$	\$
Mean weekly equivalised gross family income	501.3	605.0
	'000	'000
Total families(d)	246.2	1 603.3

(a) With children aged 0–14 years.

(b) Regular cash income before tax and the Medicare levy, adjusted for the number of adults and children in the family.

(c) Those in the lowest quintile have the lowest income, those in the highest quintile have the highest income.

(d) Excludes families who did not report their income.

Source: ABS 2003 Survey of Disability, Ageing and Carers.

Income

An income quintile is derived by ranking the population from lowest to highest income, and dividing it into five equal groups. The lowest quintile is made up of the 20% of the population with the lowest incomes.

Reflecting in part the differences in employment by parents, the incomes of families with a child with a disability were generally lower than were incomes of families without a child with a disability. In 2003, over half (60%) of families with a child with a disability were in the two lowest quintiles for gross equivalised family income (that is, income adjusted for the size and composition of the family) and 10% were in the highest quintile. This is in contrast to families with no children with a disability, of whom 42% were in the lowest two quintiles and 14% were in the highest quintile.

In 2003, the mean gross equivalised family income for families with a child with a disability (\$501 per week) was 83% of the corresponding mean income of families where no child had a disability (\$605 per week).

Families with a child with a disability may be affected not only by reduced income but also by the increased costs associated with the child, such as health care, special diets and equipment needed for their care.¹

Housing tenure

Buying, renting or owning one's home are each associated with different costs and different levels of security of tenure. For families with a child with a disability, renting may also be associated with a reduced ability to modify their house to better accommodate their child's disability (by installing hand rails, ramps, hoists etc). On the other hand, renting may enable some families to live closer to treatment facilities.

In 2003, 41% of all families with a child with a disability, and 47% of families who had a child with a profound/severe disability, rented their accommodation compared with 28% of other families.

Primary carers

A primary carer provides most of the informal help for their child, assisting with mobility, communication or self-care. In 2003, the majority of parents who were primary carers, living with and caring for their child aged 0–14 years with a disability, were mothers (92%).

Children with a disability may require many more hours of care than other children. While many parents of very young children would expect to spend 40 hours or more per week caring for their child, this time usually decreases when the child starts school and becomes more independent. However, for children with a disability, the need for care may not reduce as they get older. Among primary carers, over half (58%) who were caring for children aged 5–9 years and 52% who were caring for children aged 10–14 years were still spending more than 40 hours a week providing care for their child.

...assistance

Many primary carers have someone with whom they can share some of their caring responsibilities, or who can offer them assistance. In 2003, assistance was most often provided by a spouse or partner (40%), a parent (10%), or a formal provider (15%). However, around one-third (31%) of primary carers reported that they had no assistance, and one-third (32%) reported that they needed assistance or needed more assistance than they received.

...respite care

Respite care services provide alternative care arrangements for children with a disability so that parents can take a short-term break from their caring role. Such services may be used on a regular basis or in an emergency. Respite care may have waiting lists, access criteria, and may not be available locally.⁵

Emotional effects of caring role on primary carers(a)(b) — 2003

	%
Need more support, or an improvement in situation to aid role as carer	51.3
Weary or lacks energy due to caring role	50.5
Frequently worried or depressed due to caring role	34.1
Often feels angry or frustrated due to caring role	17.6
Has been diagnosed with stress-related illness due to caring role	17.8

(a) Primary carers of children aged 0–14 years with a disability.

(b) Components do not add to total as emotional effects are not mutually exclusive.

Source: ABS 2003 Survey of Disability, Ageing and Carers.

Of the parents identified as primary carers in 2003, 29% had used a formal respite care service for their child at some time in the past, and 17% had done so within the previous three months. About two-fifths (38%) felt they needed more respite care than they received. Over half (55%) of primary carers of children aged less than 15 years had never accessed respite care and felt they did not need it. A further 16% had never received respite care, but felt they needed it.

...emotional effect of caring

Caring for a child with a disability can be emotionally challenging.¹ One of the significant factors influencing how well carers cope is the emotional support and friendship they receive from family and friends.¹

Around half (51%) of all primary carers of children aged less than 15 years felt they needed more support, and half (50%) felt weary or lacking in energy. Some carers reported feeling worried or depressed (34%) and angry or frustrated (18%) due to their caring role; and almost one-fifth (18%) had been diagnosed with a stress-related illness.

...effect of caring role on relationships

In 2003, almost half (47%) of parents who were primary carers for their co-resident child reported that their relationship with the child was not affected by performance of the primary carer role. Where the relationship had changed, the result was more likely to have been an improved relationship with the main care recipient (42% of all primary carers) than placing a strain on that relationship (11%).

While many parents' relationships with their child with a disability became closer as a consequence of providing primary care, relationships with partners and other co-resident family members such as their other children were more often subject to strain. One-third (33%) of these carers reported that their caring role had placed strains on their relationship with their spouse or partner, or that they lacked time alone together. Around half (52%) of the primary carers reported that they were losing touch/lacking time with other co-resident family members. In addition, around one-quarter (26%) of parents who were primary carers reported losing touch with existing friends due to their caring role.

Conclusion

Families who care for a young child with a disability have a variety of different experiences and circumstances. While around 13% of all

families with children aged up to 14 years had at least one child with a disability, this proportion was higher for one parent families and families where one or both parents also had a disability.

Because families with at least one child with a disability tend to have more children than other families with young children, some of the differences between these families may be related to family size. Families with at least one child with a disability tended to have lower socioeconomic status, labour force participation and income when compared with other families with young children aged up to 14 years. In addition, families with a child with a disability were more likely to be renting than either owning or paying off their own home.

Endnotes

- 1 Australian Institute of Health and Welfare 2004, *Children with disabilities in Australia*, cat. no. DIS 38, AIHW, Canberra.
- 2 Floyd, F and Gallagher, E 1997, 'Parental Stress, Care Demands and Use of Support Services for School-Ages Children With Disabilities and Behaviour Problems', *Family Relations*, vol. 46.
- 3 Australian Bureau of Statistics 2003, *Disability, Ageing and Carers: summary of findings*, cat. no. 4430.0, ABS, Canberra.
- 4 Australian Bureau of Statistics 2007, *Australian Social Trends*, 'One-parent families', cat. no. 4102.0, ABS, Canberra.
- 5 Senate Standing Committee on Community Affairs 2007, *Funding and operation of the Commonwealth State/territory Disability Agreement*. Viewed 12 December 2007, <http://www.aph.gov.au/senate/committee/clac_ctte/cstda/report/index.htm>.

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