

Families with a child with disability

Joblessness, financial hardship and social support

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Supporting children with disability and their carers and families is an important priority for the Australian Government. The recent commitment to establishing a National Disability Insurance Scheme (Macklin, Gillard, & McLucas, 2011), and the appointment of a new Minister for Disability Reform (Macklin, 2011) signals a changing policy environment in relation to providing support for people with disability, their carers and their families. A National Disability Insurance Scheme would support people with disability and allow them to exercise choice and control in their lives and thereby achieve their best in life (McLucas, 2011). While a National Disability Insurance Scheme focuses on providing support to individuals with disability, this support will have important flow-on effects for their families.

Within this context, this chapter provides information about the experiences of families with children with disability. While all families, including those with a child with disability, have a wide range of strengths and capabilities, there is broad recognition that families with a child with disability may experience barriers to full participation in society. On a population level, people with disability experience a range of social disadvantages, including lower participation in education and employment, reduced economic resources, greater financial stress, and fewer opportunities for participation in society (Australian Institute of Health and Welfare [AIHW], 2009; Edwards & Higgins, 2009; Saunders, 2006). When parents are carers of children with disability they also experience barriers to employment and social participation (Australian Bureau of Statistics [ABS], 2009a; Edwards & Gray, 2009; Edwards, Higgins, Gray, Zmijewski, & Kingston, 2008; House of Representatives Standing Committee on Family Housing Community and Youth, 2009), and these disadvantages can then flow on to those children and other children in the family (Emerson & Llewellyn, 2008).

In order to address the barriers that people with disability and their families face, it is essential to understand the nature of these experiences. This chapter therefore focuses on families' experiences of joblessness, financial hardship and accessing social support. This is in recognition that these families may experience not only financial barriers, but also restrictions in accessing different types of social support, including emotional and practical support. The Longitudinal Study of Australian Children (LSAC) collects extensive information, covering a range of topics, about all members of the study child's household, which provides a unique opportunity to explore the broad experiences of families with a child with disability and to directly compare them with families without a child with disability.

This chapter uses data from the B and K cohorts at Waves 2 and 3 to address the following questions:

- How many LSAC study children and siblings had a disability that restricted their everyday activities? How many families had a child with disability at multiple time points?
- Did families with a child with disability experience higher rates of joblessness or a greater number of financial hardships than families without a child with disability?
- Did parents with a child with disability have access to the same level of social support as parents without a child with disability? Did they feel that they were able to get the help/support they needed as often as parents without a child with disability?

There are two commonly used measures of disability in the Australian population, used by both the Australian Bureau of Statistics and the Australian Institute of Health and Welfare. The first measure

defines people with disability as being those with a condition that has lasted or is expected to last at least six months and who experience limitations or restrictions in their performance of an activity or on their participation in society (ABS, 2003, 2009b; AIHW, 2009). The second measure is a subset of the first measure and defines people who experience a severe or profound core activity limitation as being those who sometimes or always need help with mobility, self-care or communication (AIHW, 2009).

Because LSAC is a study of the general population of children and their families, and not a survey of those with disability in particular, the first of these measures (from ABS, 2003) has been used to collect data in LSAC, and is used throughout this chapter. It is possible that the LSAC sample under-represents children with a severe or profound core activity limitation, because this level of disability may have restricted their family's participation in the study.

The questions about disability used in this chapter are taken from the LSAC Household Form, a component of the interview that contains questions asked about every member of the study child's household. Study children and their siblings were defined as having a disability if the respondent (usually the primary parent) answered "yes" to *both* of the following two questions in relation to the study child/sibling:¹

1. Does [person] have any medical conditions or disabilities that have lasted, or are likely to last, for six months or more?
 - a. Sight problems (not corrected by glasses or contact lenses)
 - b. Hearing problems (where communication is restricted, or an aid to assist with or substitute for hearing is used)
 - c. Speech problems
 - d. Blackouts, fits or loss of consciousness
 - e. Difficulty learning or understanding things
 - f. Limited use of arms or fingers
 - g. Difficulty gripping things
 - h. Limited use of legs or feet
 - i. Any condition that restricts physical activity or physical work
 - j. Any disfigurement or deformity
2. Still thinking of conditions lasting six months or more, is [person] restricted in everyday activities because of any of the following?
 - a. Shortness of breath or breathing difficulty
 - b. Chronic or recurring pain
 - c. A nervous or emotional condition (requiring treatment)
 - d. Any mental illness for which help or supervision is required long-term
 - e. Long-term effects as a result of a head injury, stroke or other brain damage
 - f. Any other long-term condition, such as arthritis, asthma, heart disease, Alzheimer's, dementia, etc.
 - g. Any other long-term disease or condition that requires treatment or medication

All references to a "child with disability" in the remainder of this chapter are to those who meet *both* of these criteria. Readers should note that some children were reported as not having a disability but as being restricted in their everyday activities, and vice versa; these children were not defined as having a disability for the purposes of this chapter.

The most important caveat to note when reading this chapter is that it groups a very wide range of disabilities together, including those that may have different effects on carers and families, and those that have different financial implications. While such a grouping is appropriate for a general study of child development, such as LSAC, further insight into the caring and financial implications of having children with particular disabilities is better provided by other research that relates to specific types of disabilities.

¹ Note that there were slight wording differences between Waves 2 and 3 in the lists of conditions for both of these questions (which were presented to respondents on a prompt card); however, these differences were not expected to lead to any substantial variations in results for the two waves.

4.1 Families with a child with disability

Table 4.1 shows the percentages of LSAC families with at least one child with disability who was restricted in their everyday activities. The table shows that between 3% and 5% of LSAC families included at least one child with disability, with the higher percentages being in the K cohort, particularly at age 6–7 years. Because there are more siblings than study children in the sample (i.e., there is only one study child for each family, but potentially multiple siblings per family), families are slightly more likely to have a sibling with disability compared to the study children themselves. For the B cohort, percentages of children with disability remained consistent between Waves 2 and 3 (at 3%), whereas for the K cohort, percentages decreased slightly between the two waves (from 5% to 3%). This may reflect a peak in the percentages of children with disability in the early school years, which has been observed in other data sources (e.g., AIHW, 2009).

Table 4.1 Study children and siblings with disability, B and K cohorts, Waves 1–3				
	Age of B cohort study child		Age of K cohort study child	
	2–3 years	4–5 years	6–7 years	8–9 years
	%		%	
Study child has a disability and is restricted in everyday activities	0.9	1.3	2.1	1.6
At least one sibling has a disability and is restricted in everyday activities	2.0	1.8	2.9	2.0
Total number of families with at least one child with disability who is restricted in everyday activities	2.9	3.0	4.6	3.3
No. of observations	4,606	4,253	4,464	4,196

Table 4.2, which includes only those families who responded at both Wave 2 and Wave 3, shows the number of waves at which at least one child in the family was reported to have a disability and to be restricted in everyday activities. K cohort families were more likely to have a child with disability at one wave (5%) or two waves (2%) compared to the B cohort (4% one wave and 1% two waves). The relatively low percentage of families with a child with disability at multiple waves suggests that in the LSAC sample, many disabilities (or at least the restrictions arising from them) may to some extent have been transitory.

Table 4.2 Waves at which at least one child in family had a disability, B and K cohorts, Waves 1–3		
	B cohort	K cohort
	%	
Neither Wave 2 nor Wave 3	95.0	93.6
One wave (either Wave 2 or Wave 3)	4.2	4.7
Both Wave 2 and Wave 3	0.9	1.7
Totals	100.0	100.0
No. of observations	4,253	4,196

Note: Only includes families who responded at both Waves 2 and 3. Percentages may not total exactly 100.0% due to rounding.

4.2 Families with a child with disability and experience of joblessness and financial hardship

This section investigates the experiences of families with a child with disability (whether the study child or a sibling) in relation to joblessness and financial hardship.

Joblessness

Joblessness affects a family's financial wellbeing and ability to purchase any specialised equipment, medication or services a child with disability may need, as well as having broader effects on the family and children (Reference Group on Welfare Reform, 2000). In this chapter, a two-parent

family is defined as jobless if neither parent was employed, and a lone-parent family is defined as jobless if the lone parent was not employed.²

Table 4.3 shows the association between whether a family had a child with disability and whether the family was jobless. The table shows that in both cohorts, families with a child with disability were more likely to be jobless. In the B cohort (when the study child was 4–5 years old), this difference was not statistically significant. In the K cohort (when the study child was 8–9 years old), the difference was statistically significant.

	B cohort (study child 4–5 years old)		K cohort (study child 8–9 years old)	
	Family includes child with disability	Family does not include child with disability	Family includes child with disability	Family does not include child with disability
	%		%	
Jobless	13.9	10.6	18.3	8.0
At least one job	86.1	89.4	81.7	92.0
Totals	100.0	100.0	100.0	100.0
No. of observations	124	4,127	144	4,051

Note: B cohort: $\chi^2(1, n = 4,251) = 1.4, p = .43$; K cohort: $\chi^2(1, n = 4,195) = 18.7, p < .01$.

Previous analysis using LSAC data has shown that lone-parent families are much more likely to be jobless compared to two-parent families (see Gray & Baxter, 2011). The numbers of families with a child with disability in the LSAC sample are too small to support a separate investigation for lone-parent and two-parent families of the relationship between joblessness and whether the family includes a child with disability. However, Table 4.4 shows that for both cohorts, there was no statistically significant relationship between whether the family was a lone-mother or two-parent family and whether the family included a child with disability; that is, the two groups of families with and without a child with disability comprised similar proportions of lone-mother families and two-parent families. This suggests that the higher rates of joblessness in families with a child with disability are not necessarily because of a greater number of lone-mother families in that group.

	B cohort (study child 4–5 years old)		K cohort (study child 8–9 years old)	
	Family includes child with disability	Family does not include child with disability	Family includes child with disability	Family does not include child with disability
	%		%	
Lone-mother family	18.6	13.4	18.8	15.3
Two-parent family	81.4	86.6	81.2	84.7
Totals	100.0	100.0	100.0	100.0
No. of observations	124	4,118	143	4,012

Note: There were very few lone-father families (less than 1% for each cohort), so these were excluded from analyses comparing different family types. B cohort: $\chi^2(1, n = 4,242) = 2.8, p = .15$; K cohort: $\chi^2(1, n = 4,155) = 1.2, p = .33$.

2 See Chapter 1 for information about how lone-parent families are defined.

Financial hardship

Each study respondent (the study child's primary parent) was asked a series of questions (based on Bray, 2001) to measure the family's experience of financial hardship:

In the last 12 months, have any of these happened to you/any members of the household because you/any of you were short of money:

1. Could not pay gas, electricity or telephone bills on time
2. Could not pay the mortgage or rent payments on time
3. Went without meals
4. Were unable to heat or cool your home
5. Pawned or sold something because you needed cash
6. Sought assistance from a welfare or community organisation

A greater number of hardships experienced indicates greater financial difficulty, such that a family who has experienced two of these will most likely be in greater difficulty than a family who experiences just one. Table 4.5 shows the differences between families with/without a child with disability in terms of the number of financial hardships they experienced. The table shows similar (statistically significant) results for the two cohorts, with families with a child with disability being more likely to experience at least one financial hardship (37% compared to 19–21% of families without a child with disability) and more likely to experience a greater number of financial difficulties.

	B cohort (study child 4–5 years old)		K cohort (study child 8–9 years old)	
	Family includes child with disability	Family does not include child with disability	Family includes child with disability	Family does not include child with disability
	%		%	
No hardships	63.3	79.1	63.2	80.8
One hardship	22.1	13.1	18.6	10.8
Two hardships	8.9	5.4	11.5	5.8
Three or more hardships	5.8	2.4	6.7	2.6
Totals	100.0	100.0	100.0	100.0
No. of observations	124	4,111	143	4,042

Note: B cohort: $\chi^2(3, n = 4,235) = 19.4, p < .01$; K cohort: $\chi^2(3, n = 4,185) = 28.1, p < .01$. Percentages may not total exactly 100.0% due to rounding.

Table 4.6 (on page 38) provides more detail about the specific financial hardships that families experienced. The table shows that B cohort families with a child with disability were statistically more likely to report being unable to pay bills on time, going without meals, and being unable to heat or cool their home, compared to families without a child with disability. For example, 29% of families with a child with disability reported being unable to pay their gas, electricity or telephone bills on time at least once in the previous 12 months, compared to 17% of families without a child with disability. Out of the six financial hardship categories, K cohort families with a child with disability were statistically more likely to report being unable to pay bills and being unable to pay the mortgage or rent payments, compared to families without a child with disability.

Table 4.6 Experience of specific financial hardships in families with and without a child with disability, B and K cohorts, Wave 3				
	B cohort (study child 4–5 years old)		K cohort (study child 8–9 years old)	
	Family includes child with disability	Family does not include child with disability	Family includes child with disability	Family does not include child with disability
	%		%	
Could not pay gas, electricity or telephone bills on time	28.8	16.9 *	29.3	15.7 *
Could not pay the mortgage or rent payments on time	11.5	6.9	15.7	6.9 *
Went without meals	5.5	1.6 *	4.8	1.7
Were unable to heat or cool your home	4.0	0.7 *	2.7	1.4
Pawned or sold something because you needed cash	1.4	3.1	6.3	2.4
Sought assistance from a welfare or community organisation	7.4	3.1	7.9	3.3
No. of observations	124	4,111	143	4,042

Note: * Statistically significant difference between families with/without a child with disability. Could not pay gas, electricity or telephone bills on time: B cohort: $\chi^2(1, n = 4,235) = 12.2, p < .01$; K cohort: $\chi^2(1, n = 4,185) = 18.3, p < .01$. Could not pay the mortgage or rent payments on time: B cohort: $\chi^2(1, n = 4,235) = 3.9, p = .05$; K cohort: $\chi^2(1, n = 4,185) = 15.6, p < .01$. Went without meals: B cohort: $\chi^2(1, n = 4,235) = 11.2, p < .01$; K cohort: $\chi^2(1, n = 4,185) = 6.8, p = .01$. Were unable to heat or cool your home: B cohort: $\chi^2(1, n = 4,235) = 15.9, p < .01$; K cohort: $\chi^2(1, n = 4,185) = 1.42, p = .25$. Pawned or sold something because you needed cash: B cohort: $\chi^2(1, n = 4,235) = 1.3, p = .23$; K cohort: $\chi^2(1, n = 4,185) = 8.0, p = .01$. Sought assistance from a welfare or community organisation: B cohort: $\chi^2(1, n = 4,235) = 7.4, p = .01$; K cohort: $\chi^2(1, n = 4,185) = 8.6, p = .02$.

4.3 Families with a child with disability and access to social support

This section of the chapter looks at whether parents with/without a child with disability have different levels of access to social support. As a measure of social support, both parents were asked a series of questions based on the Social Support Survey (Ware & Sherbourne, 1992), which are summarised into four measures:

People sometimes look to others for companionship, assistance, or other types of support. How often are each of the following kinds of support available to you if you need it?

1. Emotional/informational support:
 - Someone you can count on to listen to you when you need to talk
 - Someone to confide in or talk to about yourself or your problems
 - Someone to share your most private worries and fears with
 - Someone to turn to for suggestions about how to deal with a personal problem
2. Tangible support:
 - Someone to help you if you were confined to bed
 - Someone to take you to the doctor if you needed it
 - Someone to prepare your meals if you were unable to do it yourself
 - Someone to help with daily chores if you were sick

3. Affectionate support:
 - Someone who shows you love and affection
 - Someone to love and make you feel wanted
 - Someone who hugs you
4. Positive social interaction:
 - Someone to have a good time with
 - Someone to get together with for relaxation
 - Someone to do something enjoyable with

Response options: 1 = None of the time, 2 = A little of the time, 3 = Some of the time, 4 = Most of the time, 5 = All of the time.

The items making up each of these four measures were averaged, giving an overall score for each measure, such that higher scores reflected a greater level of social support. A measure of “total social support” was also generated from the average of all items across the four measures. Table 4.7 shows that there was a statistically significant difference between mothers with a child with disability and mothers without a child with disability in the K cohort, with mothers with a child with disability reporting significantly lower levels of access to emotional/informational support, tangible support, positive social interaction and total social support. There were no significant differences between the two groups for B cohort mothers or B and K cohort fathers.

Table 4.7 Mothers' and fathers' access to social support, by whether family includes a child with disability, B and K cohorts, Wave 3				
	Mothers		Fathers	
	Family includes child with disability	Family does not include child with disability	Family includes child with disability	Family does not include child with disability
	Mean score (n)		Mean score (n)	
B cohort (study child 4–5 years old)				
Emotional/informational support	3.85 (104)	3.89 (3,697)	3.53 (72)	3.65 (2,664)
Tangible support	3.59 (103)	3.76 (3,694)	4.24 (72)	4.22 (2,660)
Affectionate support	4.18 (104)	4.21 (3,692)	4.26 (72)	4.27 (2,655)
Positive social interaction	3.94 (104)	4.07 (2,693)	4.15 (72)	4.16 (2,657)
Total social support	3.86 (104)	3.96 (3,697)	4.02 (73)	4.05 (2,666)
K cohort (study child 8–9 years old)				
Emotional/informational support	3.42 (122)	3.90 * (3,595)	3.47 (85)	3.56 (2,608)
Tangible support	3.31 (122)	3.79 * (3,591)	4.08 (85)	4.12 (2,605)
Affectionate support	3.91 (122)	4.19 (3,588)	4.09 (85)	4.15 (2,601)
Positive social interaction	3.69 (122)	4.05 * (3,591)	4.02 (85)	4.09 (2,598)
Total social support	3.55 (122)	3.95 * (3,596)	3.89 (85)	3.96 (2,610)

Note: * Statistically significant difference between families with/without a child with disability. B cohort mothers: $t(271)$: Emotional/informational support = 0.32, $p = .75$; Tangible support = 1.48, $p = .14$; Affectionate support = 0.27, $p = .79$; Positive social interaction = 1.07, $p = .29$; Total social support = 0.98, $p = .33$. B cohort fathers: $t(270)$: Emotional/informational support = 0.89, $p = .37$; Tangible support = -0.16, $p = .87$; Affectionate support = 0.07, $p = .95$; Positive social interaction = 0.12, $p = .91$; Total social support = 0.77, $p = .30$. K cohort mothers: $t(270)$: Emotional/informational support = 3.98, $p < .01$; Tangible support = 3.69, $p < .01$; Affectionate support = 2.40, $p = .02$; Positive social interaction = 3.01, $p < .01$; Total social support = 3.90, $p < .01$. K cohort fathers: $t(269)$: Emotional/informational support = 0.57, $p = .57$; Tangible support = 0.31, $p = .76$; Affectionate support = 0.39, $p = .70$; Positive social interaction = 0.53, $p = .60$; Total social support = 0.54, $p = .59$.

Parents were also asked how often they felt that they needed help/support from someone but were unable to get it. Table 4.8 shows how mothers and fathers with and without a child with disability responded to this question. The table shows a similar pattern for both mothers and fathers for both cohorts. Mothers with a child with disability were more likely to say they were unable to get the help/support they needed “very often” or “often” (B cohort: 24%, K cohort: 25%) compared to mothers without a child with disability (B cohort: 11%, K cohort: 12%). This difference was statistically significant for both cohorts.

Table 4.8 How often mothers/fathers needed help or support but couldn’t get it, by whether family includes a child with disability, B and K cohorts, Wave 3

Needed help or support but couldn’t get it	Mothers		Fathers	
	Family includes child with disability	Family does not include child with disability	Family includes child with disability	Family does not include child with disability
	%		%	
B cohort (study child 4–5 years old)				
Very often	7.4	2.6	0.0	2.1
Often	16.3	8.7	10.7	6.1
Sometimes	52.0	52.8	41.4	41.7
Never	24.3	35.9	47.9	50.1
Total	100.0	100.0	100.0	100.0
No. of observations	90	3,130	71	2,623
K cohort (study child 8–9 years old)				
Very often	9.9	3.1	7.5	2.1
Often	14.8	9.0	7.6	6.3
Sometimes	59.3	49.8	46.3	41.8
Never	16.0	38.1	38.7	49.8
Total	100.0	100.0	100.0	100.0
No. of observations	95	2,843	84	2,540

Note: Questions about support needed were in the two parents’ leave-behind questionnaires, so the sample size is lower than for questions in the main interview. B cohort: Mothers: $\chi^2(3, n = 3,220) = 17.1, p < .01$; Fathers: $\chi^2(3, n = 2,694) = 3.8, p = .36$. K cohort: Mothers: $\chi^2(3, n = 2,938) = 28.2, p < .01$; Fathers: $\chi^2(3, n = 2,624) = 12.4, p = .01$. Percentages may not total exactly 100.0% due to rounding.

The difference between fathers with and without a child with disability was not statistically significant in either cohort, though fathers of a child with disability were slightly more likely to say they were unable to get the support they needed. Fathers in general were less likely than mothers to say that they were unable to get the support they needed. In the B cohort, 11% of fathers of a child with disability said they couldn’t get the support they needed “very often” or “often”, compared to 24% of mothers of a child with disability and, similarly, 8% of fathers in the B cohort without a child with disability said they couldn’t get the support they needed “very often” or “often”, compared to 11% of mothers with a child with disability.

4.4 Summary

This chapter has explored a number of areas in which families with a child with disability may experience barriers to full participation in society. While there are a relatively low number of families with a child with disability participating in LSAC (ranging from 3% to 5% between Waves 2 and 3), this chapter has provided some insight into differences between families with/without a child with disability.

Families with a child with disability were more likely to be jobless, though this difference was significant only for the older cohort. There were similar proportions of lone-mother families within the groups of families with and without a child with disability, which suggests that the higher rates of joblessness in families with a child with disability were not necessarily because of a greater number of lone-mother families in that group.

Similarly, families with a child with disability were more likely to experience financial hardships. Families in the younger cohort with a child with disability were more likely to report (at least once in the previous 12 months) being unable to pay bills on time, going without meals, and being unable to heat or cool their home, compared to families without a child with disability. Families in the older cohort with a child with disability were more likely to report being unable to pay bills and being unable to pay the mortgage or rent payments.

Mothers in the older cohort with a child with disability reported significantly lower levels of access to emotional/information support, tangible support and positive social interaction, compared to mothers without a child with disability. For fathers in the older cohort and both mothers and fathers in the younger cohort, there was no statistically significant difference between mothers and fathers with or without a child with disability in the level of social support they had access to—including emotional/informational support, tangible support, affectionate support, and positive social interaction.

Despite there being few differences in access to support, both mothers and fathers of a child with disability were more likely to report being unable to access help/support when they felt they needed it. These results suggest that families with a child with disability do not necessarily have access to less support than other families, but that they may need more support than parents who do not have a child with disability.

This chapter has therefore provided broad contextual information about the experiences of Australian families with a child with disability in direct comparison to families without a child with disability. The results suggest that while financial support is important for families with a child with disability, additional social support may also be needed, including emotional support and tangible support, or just being able to access help when needed. Further research specific to particular disabilities is needed to elucidate the particular financial and social barriers experienced by families of children with specific disabilities.

4.5 Further reading

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