

Appendices

Appendix A: Literature search strategy

The literature search strategy initially identified 124 relevant references. Databases were searched for the period 1995–2006. Table A.1 outlines the databases searched and the search terms used. Additional literature was identified through searching the reference lists of the articles that were identified in the initial search.

Table A.1 Databases search strategy

Title of database	Search terms used
Australian Family and Society Abstracts (AFSA)	Carers and effects Disabled and social support networks
Australian Public Affairs Information Service (APAIS)	Carers
Education Resources Information Centre (ERIC)	Caregiver attitudes
Psychinfo (searched 2000 onwards because of amount of references)	Disabled and carers Carers and wellbeing
Sociological index	Carers and wellbeing
Social Services Abstracts and Sociological Abstracts	Carers (and caregivers) and disabled Family relations and caregivers
PubMed	Carers and disabled

Is your participation voluntary?

Your participation in this study is voluntary. Even if you agree now, you can withdraw later if you wish.

Your name and contact details will only be passed on to the interviewers after you have had a chance to consider if you would like to take part.

If you would like further information, need to update your contact details, or do not wish to participate in this study, please call the Department of Families, Community Services and Indigenous Affairs (FaCSIA) on **1800 337 176** (a free call except from mobile and pay phones) by 15 September.

When and how?

If you want to be involved in this valuable study *you do not have to do anything now*. The next step will be if you receive a telephone call to invite you to participate. An interview can be conducted at the time of the telephone call *or* an appointment will be made to call you back at a more convenient time.

If it is difficult for you to take part in a telephone survey, due to language differences, disability or any other reason, please contact the fieldwork agency that has been contracted to conduct the interviews, the Social Research Centre, on **1800 023 040** by 15 September to make other arrangements.

The Families Caring for a Person with a Disability Study

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The Families Caring for a Person with a Disability Study

What is the Families Caring for a Person with a Disability Study?

The *Families Caring for a Person with a Disability Study* is an important new study of Australian families funded by the Australian Government Department of Families, Community Services and Indigenous Affairs. The aim of the study is to get a better understanding of how families care for a person with a disability and how it affects family life.

The study will interview 1,000 primary caregivers of a person with a disability about how families support one another, family relationships, service use, and the impact of caring on the carer's physical and mental health.

The *Families Caring for a Person with a Disability Study* is being conducted by the Australian Institute of Family Studies.

Australian Institute of Family Studies

The Australian Institute of Family Studies is an Australian Government Statutory Authority that was established in 1980. Funded by the Australian Government, the Institute conducts research that aims to promote the understanding of social and economic factors influencing family wellbeing.

Why is this study important?

The results of the *Families Caring for a Person with a Disability Study* will provide a picture of the life of families caring for a person with a disability in Australia today and a description of the services you use for support. The information will be used to better understand how families care for a person with a disability and how caring for the person with a disability affects family relationships and the physical, emotional and economic wellbeing of family members. Your views are really important, and will help us to ensure that we get an accurate picture of what life is like for families caring for a person with a disability.

Why should I help?

For survey results to be accurate, it is important that each person selected takes part in the survey. Otherwise, the survey will not provide a true indication of the circumstances of all families.

What does the study involve?

The study will involve a telephone interview that will take about 25 minutes to complete. At the time of the initial telephone call you can make an appointment for the most convenient time for you to be interviewed.

You will be asked about things such as who cares for the person with the disability, how family members support each other, the impact that caring has had on family relationships, work, finances, and health.

How was your family selected?

Your family was selected as part of a large sample randomly chosen from Centrelink computer records of families with caring responsibilities.

What about my privacy?

It is natural for you to be concerned about how your privacy will be protected. All information collected will be kept *strictly confidential* as required by law.

The ethics committee of the Australian Institute of Family Studies has approved the study. All researchers involved must comply with the Privacy Act 1988.

Personal details that could identify you, or your family, will be removed prior to use by researchers. Personal details that could identify you will not be provided to any government agency or the Australian Institute of Family Studies.

Will my caring payments be affected?

The financial assistance you receive (be it Carer Payment or Carer Allowance or both of these payments) for caring for your relative with a disability will not be affected, whether or you choose to participate in the study or not.