

Foreword by Professor Alan Hayes



While central to family life, caring can be invisible to those beyond the home. This can especially be the case in families caring for a member with a disability. In order to frame effective policies, research is needed on the extent of caring within families and the impacts that it can have, both within and beyond the family. The current report does this by analysing the results of a survey undertaken in late 2006 of over 1,000 carers receiving government payments. The report shows the impacts of caring for a family member with a disability on both physical and mental health. Caring is shown to have physical, emotional and relational impacts, as well as broader effects on finances and engagement in paid employment. These impacts are amplified in families caring for more than one person with a disability and with other dependent members. As such, the report makes a very valuable contribution to our understanding of the informal care provided by Australian families

I am particularly pleased that this has been a first, very fruitful, collaboration involving staff of the Department of Families, Community Services and Indigenous Affairs (now the Department of Families, Housing, Community Services and Indigenous Affairs) and the Institute. As members of the research team from the department, Dr Norbert Zmijewski and Marcia Kingston wrote and contributed to chapters of the report, provided the sample frame for the study, contributed to the interview schedule and assisted in the training of interviewers. I congratulate the authors on an excellent report that is the product of a most successful joint venture. Of course, a survey of this scope could not have been undertaken without the generous assistance of the many participants who were willing to share their insights and experiences.

Thank you!

A handwritten signature in cursive script that reads "Alan Hayes".

Professor Alan Hayes
Director
Australian Institute of Family Studies

Foreword by Dr Jeff Harmer



Family carers make an invaluable contribution to the care and wellbeing of people who need assistance due to disability, severe medical conditions or ageing. This contribution also provides enormous benefits for the Australian community.

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) acknowledges the importance of a strong evidence base in underpinning good policy development. This report provides valuable new information about family perceptions of the impact of caring for a person with a disability on a significant group of informal carers: those receiving Australian Government payments in recognition of their caring responsibilities.

This research will also provide valuable input to FaHCSIA's review of support for pensioners and carers, which is part of the Government's review of Australia's tax system.

The study is based on a survey of a random sample of people receiving Carer Payment and/or Carer Allowance, which are the major payments available for people who provide informal care for family members or friends. The major findings in the report illustrate the enormous personal sacrifices carers make through their selflessness and hard work.

I would like to express appreciation to the carers who willingly and enthusiastically gave their time to participate in this study. These carers provided important insights into the family impact of caring for a person with a disability, including physical, emotional, social and financial impacts, and the effects on family relationships and labour force participation.

FaHCSIA is pleased to have collaborated with the Australian Institute of Family Studies on this highly worthwhile project.

A handwritten signature in black ink, appearing to read 'J Harmer' with a stylized flourish at the end.

Dr Jeff Harmer
Secretary
Department of Families, Housing,
Community Services and Indigenous Affairs

About the authors

Dr Ben Edwards is a Research Fellow at the Australian Institute of Family Studies (AIFS). He joined the Institute in 2004. His PhD focused on the psychological impact of a cancer diagnosis with patients and families and was supported by a scholarship from the National Health and Medical Research Council. Since joining the Institute, Ben's research has focused on how neighbourhoods and communities influence children and their families, as well as how ill health such as disability and cancer affects families. Ben also has expertise in the statistical analysis of complex data, including longitudinal and family data, and provides statistical advice to other researchers at the Institute.

Dr Daryl Higgins is a General Manager (Research) at the Australian Institute of Family Studies. Dr Higgins is a registered psychologist. Before joining the Institute in 2004, he was a Senior Lecturer in Psychology at Deakin University. He completed his PhD in 1998 on the topic of "multi-type maltreatment", looking at overlap in the occurrence of the various forms of child abuse and neglect and their relationship to psychological adjustment problems in the immediate and long-term. He has responsibility for overseeing the management of a range of projects at the Institute, including the National Child Protection Clearinghouse, the Australian Centre for the Study of Sexual Assault, projects contributing to the national evaluation of the Stronger Families and Community Strategy, and a variety of projects focused on child protection, childcare, children and parenting, family life, caring for a family member with a disability, and research utilisation in the child and family welfare sector. He is also responsible for an evaluation of the Family Court of Australia's Magellan case management system for responding to serious allegations of sexual abuse or physical abuse of children that are raised in parenting matters. Dr Higgins has a strong research background in qualitative and quantitative evaluation. He has recently completed projects evaluating community development initiatives in Indigenous communities, and a series of national consultations to examine how to enhance out-of-home care for Indigenous children and young people, as well as examining the child protection systems in Australia, out-of-home care research, child protection research and organisational risk factors for child maltreatment.

Dr Matthew Gray was appointed Deputy Director (Research) at the Australian Institute of Family Studies in 2005. He is also the Executive Project Manager of *Growing Up in Australia: the Longitudinal Study of Australian Children*. Dr Gray has published widely on economic and social policy issues, including the determinants of labour force status, welfare reform in the United States, economic consequences of divorce, work and family, and changes in the living arrangements of Australian children since 1946. He has also worked on economic and social policy issues related to Indigenous Australians. Dr Gray was a member of the Ministerial Taskforce on Child Support.

Dr Norbert Zmijewski was, until recently, the Section Manager, Research and Data Section, Disability Policy and Coordination Branch in the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). Dr Zmijewski had been a manager in FaHCSIA since 2000. His areas of responsibility included undertaking research and data analysis that contribute to building an evidence base, and supporting development and evaluation of policies for people with a disability and their carers. He is now Research Manager, Business Regulation Benchmarking, at the Productivity Commission.

Marcia Kingston is acting Section Manager, Special Projects Unit, Carers Branch, in the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs. At the time she worked on this report, she was Assistant Section Manager, Research and Data Section, Disability and Carers Branch in FaHCSIA. Ms Kingston has extensive knowledge of carers' issues, having worked on policy development, program management, data analysis and research in the carers area of FaHCSIA since 1998.

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The interview schedule was developed through extensive consultations with FaHCSIA staff. Other parties were also consulted during the development process:

- Associate Professor Garry Robbins, Reader, and Dr Dean Lusher, Research Fellow, Social Network Laboratory, Department of Psychology, School of Behavioural Science, Faculty of Medicine, Dentistry & Health Sciences, University of Melbourne—experts in the measurement and analysis of social networks;
- Gill Pierce, Carers Victoria, and all of the policy officers from Carers Australia’s National Policy Working Group;
- research staff from the Functioning and Disability section of the Australian Institute of Health and Welfare;
- AIFS staff with experience in conducting CATI interviews and/or expertise in the area of disability;
- Dr Erin Wilson, Research Coordinator, Scope Victoria, an organisation that provides disability services; and
- researchers from the university sector with relevant expertise—Dr Sally Savage, School of Health and Social Development, Deakin University; and Dr Valerie Clarke, School of Psychology, Deakin University.

This report was reviewed by Professor Robert Cummins, School of Psychology, Deakin University, and Professor Sidney Bloch, Department of Psychiatry, University of Melbourne. We thank them for their insightful comments and suggestions, which were incorporated into the final version of the report. Expert editing was provided by Lan Wang.

And, finally, our greatest appreciation goes to the carers who participated—for their wisdom, insight, enthusiasm, and willingness to share their stories and their time.