



13
Number 13 May 2014

The Wesley Report

**Giving disability
carers a break**



‘Do all the good you can, by all the means you can, in all the ways you can, in all the places you can, at all the times you can, to all the people you can, as long as ever you can.’

Mission

Continuing the work of Jesus Christ in Word and deed

Acknowledgements

Wesley Mission and Urbis would like to express our gratitude to everyone who took part in the study. It was a privilege to have participants tell their stories and we acknowledge that sharing personal experiences is not always easy.

Media enquiries about this report should be directed to the Public Affairs Manager, Wesley Mission, on (02) 9263 5350.

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Foreword

Carers of people with disability have an enormous responsibility, and the relentless nature of their role cannot be underestimated. The constant nature of caring can have significant impacts on the health and wellbeing of carers, as they attempt to juggle the complex demands of looking after someone with disability rather than themselves.

Wesley Mission has a wealth of experience in the disability sector and this study takes us to the heart of one of the current challenges the sector faces: how best to support the extended network of people with disability.

Our aim in this latest Wesley Report was to hear from carers themselves about what it is like to care for someone with disability. This led us to conduct surveys and interviews with the carers of some of our clients of Wesley Disability Services. We were able to build a snapshot of life as a carer of someone with disability; the commitment, the concerns, the joys, and the challenges. The reality is that this role is hugely taxing and takes its toll on even the most robust, loving people.

We discovered that carers of people with disability are incredibly compassionate and resilient. Their capacity to overcome adversity and rise to continual challenges is remarkable. The overwhelming message that came through from carers is that they do what they do out of love.

An area of interest for Wesley Mission—and one where wider research is scant—is the impact that disability services have on carers. We know that clients themselves benefit enormously from the range of services provided by Wesley Mission and other organisations, but we were curious to delve deeper and find out how carers' lives were impacted. We also posed the question: what if these services didn't exist? What would life be like for carers if they were no longer provided with support?

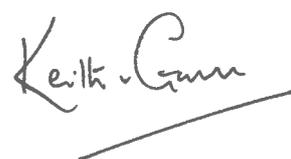
What is evident from our study is just how crucial services are for carers and the important part they play in their emotional, mental and social wellbeing. Carers live with enormous stress and are dealing with multiple issues in relation to those they care for. It is vital that they are able to easily access suitable services that can provide them with the respite they need. For many carers these services are not just an optional extra, they are a lifeline.

While much has been done in recent years to address the needs of people with disability, there is still some way to go in creating an inclusive, robust system of care in Australia that will enable people with disability and their carers to fully enjoy meaningful and productive lives in the community. In partnership with government and other service providers, Wesley Mission embraces the challenge to build stronger, more sustainable services for people with disability and their carers.

I would like to thank all those who took part in the surveys, interviews and policy forums which helped Wesley Mission define some of the key issues for disability carers and the concrete recommendations that flow from this research. It is these recommendations that can inform direction and provide insights for both government and disability service providers.

If this report can go some way towards raising awareness of the vital role that carers of people with disability play in our community—and shed light on some of the key issues that affect them—then it will have achieved its purpose.

Carers are the backbone of support for people with disability. All my life as a Christian minister I have felt the need to care for the whole person, and Wesley Mission is driven to find solutions that will sustain carers for the long-term. It is imperative that we do not regard people with disability in isolation but consider their carers, their family members and other support networks, and develop services that address their broader, and often unmet, needs. My hope is that this report will encourage such a response.



The Rev Dr Keith V Garner
CEO/Superintendent
Wesley Mission



Executive summary

The reality for those who care for someone with disability is that life is complex, draining and rewarding. Having a family member or loved one with disability affects the entire household. For many carers there are no breaks and, even when there are, they find it impossible to ‘switch off’ from their caring responsibility. In order to learn more about life as a carer—and to find out how the disability services they access impact their lives—Wesley Mission conducted surveys and interviews with a broad range of people who care for someone with disability.

Disability in Australia

Disability care is an issue of national significance. One-third of all Australian households include a person with disability and within the Australian population as a whole, a total of 4.2 million Australians were classified as having disability (Australian Bureau of Statistics, 2012a). To meet the needs of people with disability and their families, there are 2,277 Australian agencies providing disability support services under the National Disability Insurance Agency (NDIA) (AIHW, 2013). In 2012 there were 2.7 million informal carers of people with disability in Australia, of which 29 per cent were primary carers.

Key findings

The reality of caring for someone with disability

In our discussions with carers a number of key themes emerged:

- **life is extremely complex and stressful**—almost all carers interviewed were caring for a number of individuals, and had personal health issues, relationship concerns and/or mental health complications. Carers are exposed to a range of stressors across a number of areas, leaving them highly susceptible to breakdown
- **any sense of self is compressed**—the lifestyle of carers is completely focused on and dedicated to the wellbeing of those they care for, resulting in them putting themselves in ‘second place’
- **there’s not enough time**—the complexity of combining caring responsibilities with non-caring responsibilities, and the challenge of fitting work commitments around caring, left carers feeling there was limited time in the day to do all they needed to

- **they are concerned for the future of those in their care**—carers expressed high levels of concerns in relation to the future, particularly in regard to securing a meaningful and safe future for those they care for
- **despite all the stress, carers are very resilient**—while stress, strain and sacrifice are all part of caring for someone with disability, carers showed a determination to provide the best care they could.

The impact of receiving disability services

One of the core aims of this study was to provide insight into the impacts that receiving disability services has on carers and the broader family unit, and we discovered that disability services play a crucial role for all those involved. We asked carers to consider the impact if the services they receive were not there. Across all aspects measured (social, emotional and financial), carers indicated that they would be considerably less satisfied without the provision of care services.

Significantly, 82 per cent of respondents in the survey indicated that their level of satisfaction with their mental health would decline without the provision of care services. A similar proportion indicated that the level of stress in their lives would worsen if the provision of services was reduced (71 per cent). More than half of all those surveyed indicated that they would be less satisfied with their physical health if services were not provided, and 67 per cent said that they would be dissatisfied with the impact on their personal time if services were not provided.

Policy and practice recommendations

The outcomes of our research have led to four recommendations for disability service providers and policy makers:

- Wesley Mission recommends clear information about resources for disability services that are easy to access, given that many carers find it difficult to understand the pathways to services and, indeed, which services they should be using
- while recognising the value of client-directed services, we recommend that primary carers are taken into account in service provision models, and that their needs are also considered in supporting the person with disability
- it would be of great benefit to carers for disability service providers to facilitate peer support groups where carers could come together to share concerns, information and stories. Such groups would also help provide vital support to otherwise isolated and potentially vulnerable carers
- we recommend enhancing community understanding and appreciation of the value that carers bring to society by advocating on their behalf and providing them with support systems that enable them to carry out their caring roles sustainably and meaningfully.

“You have to be a strong advocate for your child. I’m not sure how much longer they are going to be around for, so I endeavour to make sure that they have the fullest life possible and can experience as many things as possible.”



Background

In the last 30 years significant reforms to disability policies, legislation and service delivery in Australia have been made. Over this time the focus has shifted from an institutional approach through to a community-oriented approach and person-centred care, leading to the recent introduction of the National Disability Insurance Scheme (NDIS), as a part of the National Disability Strategy.

Within this shifting context, Wesley Mission and other service providers play an important part in assisting people with disability and their carers to understand how new models of service delivery impact their everyday life and the services they receive.

Wesley Disability Services aims to support people with disability and their carers to live full and productive lives in the community through the provision of services which include:

- **Wesley Disability Accommodation**— providing a range of residential support
- **Wesley Respite**—supporting the relationship between the family and the person with disability by providing regular away-from-home care
- **Wesley Community Living**—supporting people with disability to live independently in their own homes and to actively engage with the local community
- **Wesley LifeSkills**—supporting young people with disability to learn, grow and socialise
- **Wesley Disability Employment**—providing employment and training opportunities.

To continue to enhance the provision of disability services in Australia, Wesley Mission commissioned Urbis to undertake research that would provide insight into the impact that using disability services has on people with disability and their carers. The research focuses on four key areas:

- economic impact
- emotional impact
- broader family unit impact
- impact on the wider community.

The research also aims to understand the negative impact of not having access to services which are currently being used by people with disability and their carers. The crucial question was posed: what would happen if services were not there to provide support and assistance?

The data-gathering process

This study comprised four separate stages:

Stage one

A review of relevant literature on the impacts of caring for people with disability and the benefits of specialist disability assistance for the individual and their family.

Stage two

Quantitative research with carers of people with disability who use Wesley Disability Services.

Stage three

In-depth interviews with a small number of carers of people with disability who use Wesley Disability Services.

Stage four

A policy and practice workshop with staff from the disability services sector.

The data-gathering process is discussed in detail in Appendix B.

A note about the data

It is important to note that this research is not intended to be a comprehensive evaluation of the impacts of disability service access and support provision; neither the sample size nor construction of the sample is robust enough to be considered representative of the carer population as a whole.

This research is designed to provide the broad service sector with some preliminary insights needed to better understand the impact on families and people with disability. In many ways this research is the starting point for further discussions. It aims to provide a preliminary evidence base and a sound context to anecdotal feedback and comment in relation to service access.

It should also be noted that the main target group for this study is primary carers of people with disability and not people with disability themselves. As a result, the focus of the study and report is on the actual impact of receiving disability support services for the carer and family and the perceived impact of receiving services for the person with disability (as reported by carers). This is not a direct study of people with disability and, as such, caution should be taken when interpreting carer comments in relation to the person they care for.

Defining disability

While the term ‘disability’ is often used in a reductionist manner (to classify and segment an audience), disability itself is a complex and multifaceted issue. This complexity is underpinned by the multidimensional nature of the concept: disability is not simply the presence or absence of key criteria.

Aspects such as length of experience, severity and the degree of restriction or limitation all have a role to play in how disability may be defined and, as a result, the context of disability policy and service provision.

The International Classification of Functioning, Disability and Health (ICF) reinforces the multifaceted nature of disability, outlining that:

- anyone could find themselves living with disability to some degree
- disability is a multidimensional concept, with interaction between the nature of the impairment and the impact on function
- there are key facilitators and barriers that enhance or repress experience and performance (ie environmental factors)

(Source: PriceWaterhouseCoopers (PWC), 2011: 32)

A multidimensional approach to disability places an emphasis on the experiences of the individual in relation to what having disability actually entails for them, and the range of limitations and restrictions disability causes for an individual.

For the purpose of this study, we utilise a multidimensional approach to defining disability in line with the Australian Bureau of Statistics (ABS):

‘Disability can be defined as “any limitation, restriction or impairment which restricts everyday activities and has lasted, or is likely to last, for at least six months”. Examples range from loss of sight that is not corrected by glasses, to arthritis which causes difficulty dressing, to advanced dementia that requires constant help and supervision.’ (ABS, 2009: 3)

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Daily devotion

Penny rushes out of work each day at three o'clock to get home in time for the school bus to drop off her 17-year-old son, Will. He is blind with cerebral palsy and is bound to a wheelchair. Every day Penny feeds Will, changes him and bathes him. Will also has sleep apnoea, so Penny is constantly up through the night to make sure he is breathing and to reposition him.

Will stays in Wesley Mission's respite accommodation every Thursday and two weekends each quarter. This is Penny's time out. It should be a time where she can relax, unwind and totally switch off from her caring role.

Easier said than done.

"The adrenalin is always pumping," as Penny explains regarding the non-stop, 24/7 life of a carer. "If I lie down on the couch and read a book I feel like a fraud. I feel like it's not my life. Every woman I know in this situation is manic. You can't be normal doing this."

Stress is something that has pervaded every aspect of Penny's life since she had Will. She also has two older sons, aged 25 and 20. The constant stress on their family life was a key factor in the breakdown of her marriage, with her ex-husband now working overseas.

When Will's brothers were younger, Penny used to worry that they would someday resent her for spending more time with Will than she did with them. She recalls sitting them down when they were children, telling them she was doing the best she could, and asking if they were angry with her.

"They said they would never resent me and kissed me but how do I really know what they feel? Even now they never really say much about it.

"I thought caring for Will would bring us together as a family. It's frustrating because you want to be a tight family unit but you can't."

Penny has recently recovered from breast cancer. This involved 10 months of surgery and treatment and now requires her to take chemotherapy for the next five to 10 years. Penny is sure that stress caused the cancer to develop. Her illness has brought home to Penny just how fragile life is and how unknown the future is. Penny is deeply concerned for her son.

"I'm very aware now of my own mortality and not being there for Will. That is a huge stress."

Permanent residential care for people with Will's level of disability does exist; however, the waiting list is extremely long and places are very limited. The stark reality of disability support services frustrates Penny.

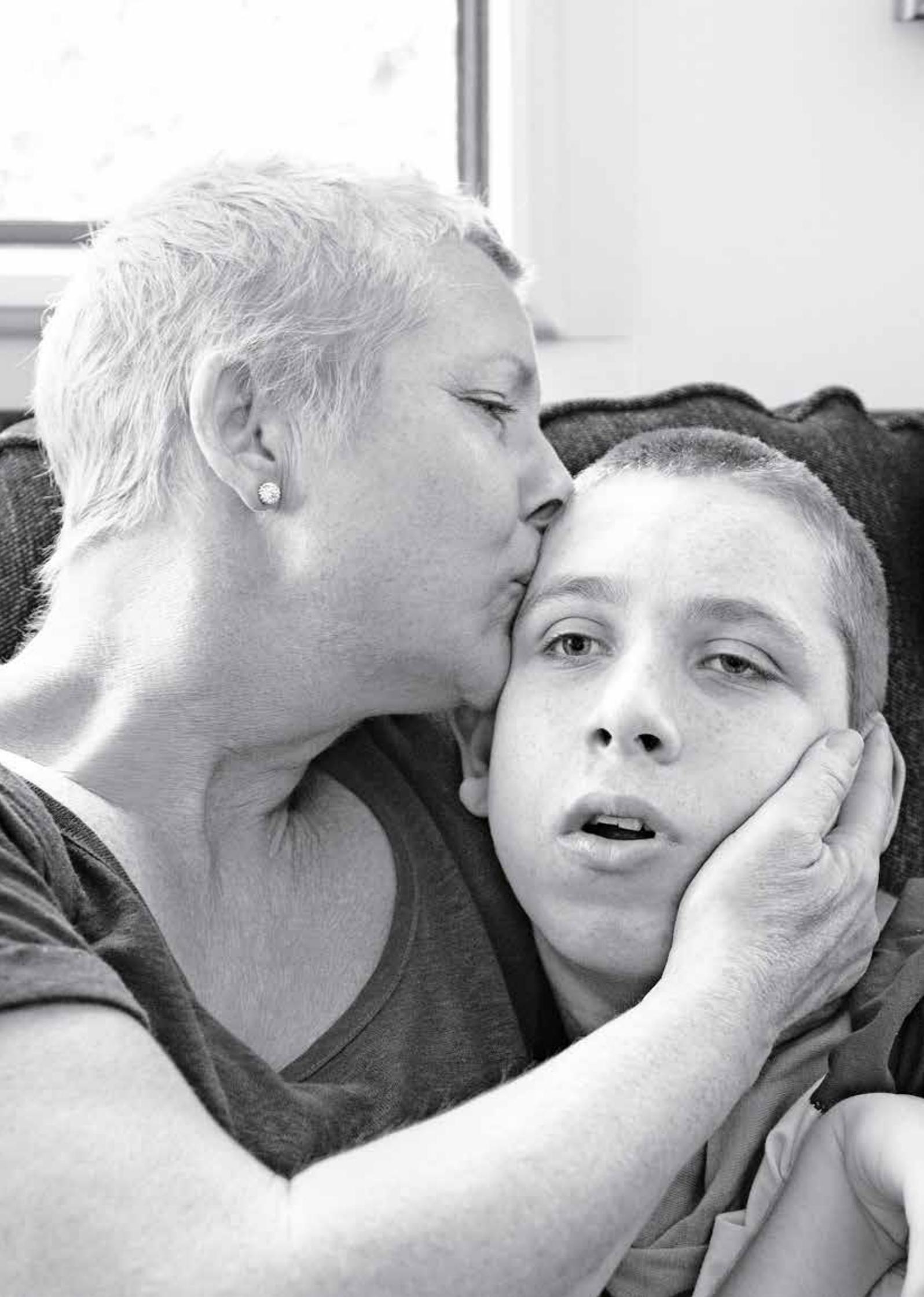
"In Holland and so many other countries there are fantastic facilities and programs for these kids—but not here," Penny laments.

Because she heads home from work early each day and takes six weeks' leave each year, Penny earns less than she normally would. This means she has limited funds to take care of the family each week and she worries about her long-term financial situation.

"You get to the point as a carer where you know you cannot make enough for your retirement. I've accepted it."

There are a lot of things that Penny has had to accept about her life. Many of these things have been tough, but the courage and determination she shows is remarkable. When she was having radiotherapy people would ask her how she continued to work and care for Will.

"I would run over a river full of crocs for Will—but stopping is not optional."



Disability in Australia

In order to understand how access to services may have an impact on people with disability and their families, it is important to take a step back and to understand the context of disability service provision in Australia. The following section provides a brief outline of recent changes and how they affect people with disability and their carers. It also takes a look at how many Australians are living with disability and how their needs are met.

A snapshot of disability in Australia

Disability care is an issue of national significance. One-third of all Australian households (36 per cent, or 3.1 million households) include a person with disability and within the Australian population as a whole, a total of 4.2 million Australians were classified as having disability, representing nearly one-fifth (19 per cent) of the total population (ABS, 2012a).

The 2012 Survey of Disability, Ageing and Carers (SDAC) conducted by the ABS provides a more granular insight into disability within Australia, with the study finding that:

- a majority (88 per cent) reported a specific limitation or restriction that limited them in self-care, mobility, communication, schooling or employment
- 81 per cent reported a physical condition as their main condition. Around one in five (19 per cent) identified a cognitive or behavioural disorder as their main condition
- 60 per cent needed everyday assistance with at least one daily activity, with 1.4 million individuals aged 65 years or older needing this form of assistance
- assistance is most likely needed in relation to healthcare or property maintenance
- in addition, the 2009 SDAC data showed that Aboriginal and Torres Strait Islander people are almost twice as likely as non-Indigenous people to be living with disability (ABS, 2012b)

(Source: ABS, 2012a; ABS 2012b)

Cost to government

- the Australian governments spent \$6.9 billion on disability support in 2011–12
- the costs for people residing in hospitals due to limited community support or unsuitable accommodation is estimated at between \$38 million and \$84 million per year.

(Source: Australian Government Productivity Commission, 2013; Australian Government Productivity Commission, 2011 cited in: NDS, 2013)

Labour-force participation

- participation in the workforce of people with disability and their carers is significantly lower than of the general population
- in 2009, just over half (54 per cent) of all people with disability at working age (15–64 years) participated in the labour force
- in 2009, 69 per cent of all carers had paid employment
- these numbers were considerably lower compared to 83 per cent of the general workforce participation rate.

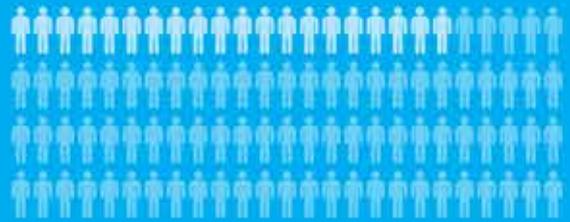
(Source: ABS, 2012 in: NDS, 2013)



Over 1/3 of Australian households include a person with disability.



That's 36 per cent or 3.1 million households



4.2 million Australians live with disability

Equivalent to nearly one-fifth (19 per cent) of the total population

60% need assistance

with at least one daily activity



There are 2.7 million informal carers of people with disability in Australia

- 29 per cent are primary carers
- 70 per cent are female
- 30 per cent are male
- most are between 55–64 years old
- 40 per cent of primary carers spend 40 hours or more a week providing care



\$6.9 billion spent

by the Australian governments on disability support in 2011–12



Giving disability carers a break

Meeting the needs

To meet the needs of people with disability and their families, there are 2,277 Australian agencies providing disability support services under the NDA (AIHW, 2013):

- accommodation services are most often provided, followed by community support and community access services
- around one in 70 people (317,616 people in total) used disability support services in 2012, with the most commonly used services being community support and employment support
- demand for service provision is increasing: between 2007–08 and 2011–12, an increase of 29 per cent in the number of service users was observed, particularly in relation to employment services, with an increase of 48 per cent being seen since 2007–08
- critically, given the aims of this research, while almost all people with disability received some formal assistance (98 per cent), more than one-third of respondents to the 2012 SDAC survey (ABS, 2012a) reported not receiving the full amount of assistance needed (39 per cent).

Who meets the unmet need?

The provision of 'informal care' outside the service system is crucial for the health and wellbeing of people living with disability, given the evidence that some do not receive all the formal assistance they need. Within this context, family members and other relatives play an important role. Family are often seen as the primary support source, particularly when the person with disability does not have access to all the required formal assistance and support they require.

While there is a wealth of literature in relation to individuals who provide informal care to people with disability, reflecting the complexity of disability more generally, there is no single definition of a carer in this context. Definitions of carers differ as a result of

a distinction between a 'carer' and a 'primary carer' (based on level of responsibility) and the fact that many people who provide informal care do not see themselves as carers, simply because they consider their caring role as part of family responsibilities. For this reason, it is fair to say that research and literature on carers might exclude a considerable group of carers, and also that professional support and assistance for carers only reaches a subgroup of carers (AIHW, 2011: 210).

With this in mind, in 2012 there were 2.7 million informal carers of people with disability in Australia, of which 29 per cent were primary carers (ABS, 2012a). Primary carers of people with disability were most likely to care for a child, parent or partner (ABS 2012a; Australian Institute of Health and Welfare (AIHW), 2013; Carers Australia 2008), and according to the 2012 SDAC survey they were:

- more likely to be female than male (70 per cent versus 30 per cent)
- more likely to be aged 55–64 years
- likely to indicate that the main reason they took up the role of a primary carer was because of 'a sense of family responsibility', followed by 'the feeling they could provide better care than anybody else' and 'a feeling of emotional obligation to undertake the role'
- likely to spend a considerable amount of their week caring for the individual, with 40 per cent of primary carers spending 40 hours or more a week providing care. (ABS, 2012a)

A growing body of literature provides insight into the impacts that caring for someone with disability has on the individual and family (see Commonwealth of Australia, 2009; Edwards et al, 2008; Gill et al, 2008; Mental Health Council of Australia, 2012). The general consensus is that caring for someone with disability has considerable impacts on the physical and mental wellbeing of the carer, as demonstrated in The Wesley Report, 11: *Keeping minds well: Caring till it hurts* (2012) which explored issues faced by carers for people with mental health issues.

Ultimately, more than one-third of people with disability do not receive the formal care needs they require—their needs remain unmet. (ABS, 2012a)

As a result, the provision of services to people with disability and their carers is critical in reducing the overall care burden not only on the individual carer, but the broader family group and Australian society as a whole.

The changing landscape of disability care

In the last few years there have been a number of important reforms to disability policy in Australia. Recent changes to disability service provision and policy settings have been guided by the National Disability Strategy, which provides a national, whole-of-government blueprint to ensure unified service provision designed to improve the lives of people with disability (Council of Australian Governments, 2011).

The strategy recognises that not all people with disability are alike and that people have specific needs depending upon their unique circumstances, including their ethnic or cultural background. Within this context, the strategy comprises six outcome areas:

- inclusive and accessible communities
- rights protection, justice and legislation
- economic security
- personal and community support
- learning and skills
- health and wellbeing.

Introduction of the National Disability Insurance Scheme

Although the Australian government has committed to enhancing the quality of life for people with disability, there remains a significant level of unmet need and Australia still faces considerable challenges in relation to increasing the economic and social participation for people with disability. Key challenges include:

- the inequitable, underfunded and fragmented nature of the disability system—with complex policy, practice and funding arrangements across the state, federal and non-government sectors
- a reliance on an informal workforce—while people with disability access government-funded services and care, the majority of support is unpaid and provided by families and friends
- the increasing demands on the disability services system over time—the population of Australians with disability will grow while the number of unpaid carers willing and able to provide support is expected to decrease. (National Disability Services (NDS), 2013; PriceWaterhouseCoopers (PWC), 2011)

It was, in part, recognition of these challenges that led to the introduction of the NDIS in 2013. A central tenet of the NDIS is the facilitation of increased control and greater choice for people with disability over what services and support they would like to help them achieve their goals.

The NDIS is still very much in its infancy. Policy makers, service providers and the NDIA are still coming to terms with complications associated with eligibility criteria, levels of benefit, volume and the interface between the disability, aged and healthcare sectors. Not surprisingly, these nuanced issues also impact on users of the services—people with disability and their carers.

Despite the NDIS being in its early stages, what is clear is that the provision of a person-centred approach and enhanced choice is dependent on a strong service sector. Access to a range of disability support services will continue to be critical for individuals with disability and their families.

Delivery of disability services in Australia

Under the current service structure, the majority of service providers are charity (not-for-profit) organisations, funded by the government under the National Disability Agreement (NDA). Service providers can be grouped into seven main categories, based on their core objectives and the type of support they offer.

These categories are comparable with the support Wesley Disability Services offers to clients and, for reference, the table in Appendix A provides an outline of the key forms of disability services currently operating within Australia.

While the implementation of the NDIS and a renewed focus on person-centred care is designed to better tailor services to the needs of the individual, the provision of disability support outside the NDIS is still essential to assist both carers of people with disability and the individuals themselves.

Understanding the impacts of disability service access for individuals and their families is critical to ensuring that services meet needs and remain relevant within the changed landscape of disability service provision.



Till death do us part

Melissa is only 46 years old but she already has a picture of her retirement years. There will be no overseas cruises or caravan trips around Australia. The days won't be spent sitting by the poolside, reading a book and sipping lemonade. She will not be able to take up a new hobby or follow a long-held dream. She will, of course, share her retirement with her husband, Darren. And her daughter, Jade.

Jade is in her mid-20s and has a moderate intellectual disability. She will never live independently or have a job. Jade is completely dependent on Melissa and Darren for her livelihood and her wellbeing.

"I'm not unrealistic about my future," Melissa confesses. "I know Jade will be with me until I die."

Jade can speak, write her name and read at an elementary level but finds it difficult to process or respond to instructions from others. Melissa knows that holding down a job is just not a reality for Jade.

"If she worked in a restaurant and was asked a question by a customer, she may not know what to say and would simply walk off."

And it is not only Melissa who is concerned about Jade's future. She also has two teenage daughters, Briannan (15) and Courtney (14), who are well aware that Jade's care is a family affair. Briannan is very supportive of her sister but is already talking about the large part Jade will play in her future.

"I know I'll end up taking care of Jade," she states, as though her future was already mapped out.

Melissa desperately wishes this was something that Briannan didn't have to worry about.

"It breaks my heart to think about it. She will need the most understanding husband."

During the week Jade attends a community participation program funded by Macarthur Disability Services. Every six weeks she spends a week or weekend at a respite centre run by Wesley Disability Services. The profound impact that this respite has on the broader family unit cannot be underestimated, Melissa believes.

"Without respite I would be divorced. Taking care of Jade has already put a lot of strain on the marriage.

"If our marriage ended in divorce, we couldn't continue to live in this house and my daughters wouldn't have their father around. And I would resent Jade."

Jade does not have challenging behaviours but Melissa constantly has to check if Jade has properly washed or is eating the right things.

"When Jade is in respite, it is such a relief not to have to worry about all the little things that so easily accumulate."

The respite care that Jade receives also means that the rest of the family can take a weekend away without constantly worrying about Jade. It also makes it so much easier for Melissa and Darren to have time to themselves or get together with friends for dinner.

"If Jade is with us and we get invited to dinner at friends' places, we need to take her," Melissa says. "My friends go out of their way to assure me it's OK, but I feel guilty about my friends feeding the three of us."

These precious times of respite provide the breathing space for this family to cope with what can be a very intense home life. When the family tensions get too much, Jade will often pack a bag and say she is moving out. Melissa knows that Jade would love to live away from home—if she could manage independently.

Melissa has considered that Jade would qualify for public housing but does not think she would cope on her own.

"She doesn't make friends easily. She would be so isolated in Department of Housing accommodation and have no-one to support her."

Jade understands enough to know that she does not have the same kinds of friendships that her sisters have. She often refers to respite as 'going to see my friends'. Jade gets jealous when her sisters are invited to their friends' places or have friends for a sleep-over. As a mother who would dearly love her daughter to have all the things that a young woman desires, this is hard for Melissa to watch.

"I need to spend a lot of time soothing her. I tell her she will see her friends soon."



The reality of caring for someone with disability

One of the core aims of this study is to provide the broad service sector with insight into the impact of accessing disability support for the individual and the family. Before reviewing the impacts, it is important to understand how caring for someone with disability affects the family and individual, as many of the impacts of service provision are directly related to the sustainability of the caring experience. This section takes a look at what life is like for someone who is a carer of a person with disability.

Discussions with carers and comments provided in the questionnaire clearly demonstrate that the life of someone who cares for an individual with disability is complex, dynamic, unpredictable, draining and rewarding. Caring for someone with disability pulls the carer in many directions as a result of multiple responsibilities, competing priorities and pressing commitments.

Key summary:

- life is extremely complex—the demands of caring for someone with disability often result in a compression of any sense of self and a restriction in the ability to engage in activities beyond those focused on caring
- carers of people with disability perform multiple caring roles—research shows that nearly one-third of carers of people with disability were parents of at least one other child outside their caring role and 13 per cent care for more than one person with disability (Edwards et al, 2008)
- carers are hyper-vigilant and have difficulty switching off from their caring role despite opportunities to access services which are designed to assist carers with aspects beyond their caring role.



Health and wellbeing risks for carers

Individuals with disability often depend heavily on the help and support they receive from their carers and families, which can result in carers' lives being completely centred on the person they care for. Time for the carer is limited and time spent away from the person they care for is often accompanied by a sense of guilt and an inability to switch off.

As a result, carers often indicate that caring for an individual with disability negatively impacts their own wellbeing and quality of life, including their health, financial security, employment opportunities and career progression, social participation and family life.

In reviewing the available literature and the findings from the discussions with carers of people with disability, it is clear that the caring role has a significant impact on the health and wellbeing of carers across a range of dimensions.

Life is extremely complex and stressful

Almost all carers interviewed as part of this research were caring for multiple individuals, and had personal health issues, relationship concerns and/or mental health complications. Carers of people with disability had multiple points of vulnerability in their lives and were exposed to a range of stressors across a number of aspects, of which time pressure is a key challenge. As a result, they reported considerable social, emotional and financial impacts as a result of these complexities and the caring role that they perform.

Participants described how they felt their lives were far from normal and often too complex for others to understand. They felt it was hard for others to come to grips with what it really meant to be a carer of someone with disability and the impacts that this role had on them and their family.

"You know it's pretty much, psychologically, it's a difficult thing. I don't think that anyone understands it, when you care for someone."

"I'm one person with two people [brother and sister] and sometimes people just don't realise. 'Oh you don't do much,' 'Oh you're only a carer.'"

Much of the complexity of life stems from a requirement to balance the role of a carer with other roles. Carers in the research were also parents, partners, employees, sons and daughters, and as a result were performing other social roles in addition to caring for someone with disability. Given the

complexity of caring for someone with disability, carers often reported struggling to adjust their lives around the care the person with the disability needed.

"Well, it's about trying to maintain some semblance of normal life. He's got a disability, but he's still a seven-year-old boy. I'm still a person who wants to work, my partner is still a person, and my other son is still a person in his own right. Most families, when you have two working parents, your child will go to after-school care or day care. It really is about that semblance of normal family life and access to the same type of services that everyone else gets, and it's not always that straightforward, unfortunately."

A wealth of literature describes the high levels of stress carers experience as a result of the complexity of their caring role. Evidence indicates that stressors are not only directly derived from the carer responsibilities for the individual, but also from 'secondary' stressors stemming from other roles and responsibilities in life, such as family relationships, employment and financial security (Zarit, 2006).

Research (Edwards et al, 2008) involving 1,000 Australian carers found that nearly one-third of all carers were parents of at least one child outside of their caring role for the person with the disability. In addition, more than one-tenth of all carers (13 per cent) cared for two or three people with disability. This reinforces the findings from discussions with carers who use Wesley Mission services, where factors outside the caring role were a considerable source of concern, worry and stress.

While these descriptors, complexities and impacts may seem obvious to those who work in the sector or those who care for someone with disability, they provide critical insight into the experiences, needs and stressors of caring. Importantly, they provide clear direction in relation to the ways in which disability service provision is of benefit to the individual and family.

Giving disability carers a break

Any sense of self is compressed

Another aspect that affects the health and wellbeing of those looking after someone with disability is living a life which revolves around someone else. Participants described a lifestyle completely focused, and dedicated to the wellbeing of the person they cared for, which resulted in them putting themselves in second place. Within this context, any sense of self for a carer is compressed as a result of:

- being unable to take a break from the carer role
- constantly struggling with combining carer and non-carer responsibilities
- continuously thinking ahead to secure the wellbeing and safety of the person in the near future.

Also, because of the significant demand placed upon them, carers are in a constant state of hyper-vigilance, resulting in a reduction in care that they would give to themselves or their family. Participants often felt they were constantly performing the caring role—every day and all the time. During discussions with carers it was clear that many felt that they could not allow themselves to be distanced from their caring responsibilities, even when an opportunity presented itself (for example, at work or in respite). Caring for someone with disability resulted in a constant state of hyper-vigilance and concern.

“Even when I’m at work, I’m thinking, ‘Where is he today, do I have to pick him up or is he getting dropped home?’ And even if I go out to the shops I think, ‘Will I be home for lunchtime?’”

“I have the time in between when I drop him off and I pick him up, though it’s still full time in my brain—it never leaves you.”

These comments from our research are supported by the SDAC 2012 (ABS 2012a) data, which shows that while almost all carers (97 per cent) participated in a social activity away from home in the three months prior to the survey, only 72 per cent had done so without the person they cared for. This would indicate

that despite the opportunity for a break from caring responsibilities presenting itself, many carers do not (or cannot) engage in these activities without continuing to perform the carer role.

That said, having access to disability services was seen to provide carers with the ability to address some of the stressors in their life. In essence, these services could provide the time and space to take stock and address underlying concerns and unattended issues in a carer’s life. A similar outcome is shown in Wesley Mission’s recent study (The Wesley Report, 12, 2013) into homelessness support, recognising that the provision of homelessness support enables recipients to take the time to stop and pause.

There’s not enough time

Not being able to switch off from a caring role was also a result of the complexity of combining carer responsibilities with non-caring responsibilities. In particular, employed participants often described the challenge of fitting their work commitments around being a carer. As a result, they commonly felt there was limited time every day to make everything work.

“My day entails getting up at 5.30 every day to organise communication books, taxi vouchers, lunch, breakfast, et cetera, for my daughter. Two of those days I drive her to her supported employment, the other days I make sure that she can be picked up by the taxi service that picks her up to go to her program. So it’s not a matter of get up in the morning, get dressed, have a cup of coffee, get the train into work—I spend at least an hour or more organising her.”

“I was always rushing to get there and rushing to pick him up and all of that process I found very stressful. So although I quite liked the teaching I didn’t like the package of it: to be rushing after school and after-school traffic. I’ve given that away because I’m so stressed.”

With the complexity of their situation, the overriding stress, the compression of any sense of self, and the limited time available to them, so much of the freedom and options that many people enjoy in life all but disappear for carers.



Life is extremely complex and stressful

Carers of people with disability have multiple points of vulnerability in their lives and are exposed to a range of stressors

Any sense of self is compressed

Carers are completely dedicated to the wellbeing of the person they care for; they put themselves in 'second place'



There is not enough time

Juggling work and other non-caring responsibilities with caring leaves carers feeling exhausted and time poor



Worried about the future

Carers are concerned for the future of the person they care for, particularly regarding what will happen when they can no longer carry out their caring role



Despite all the stress, carers are resilient

Stress, strain and sacrifice are all part of caring for someone with disability, yet carers are determined to provide the best care they can



Giving disability carers a break

“There is very rarely a day that I don’t get a call from her—my daughter—or a call from where she is, that I have to sort out or something while I’m at work.”

The findings from Edwards et al (2008) show how all-encompassing the carer role can be, with 60 per cent of those surveyed providing more than 100 hours of care per week, including the time associated with being on call to monitor the person with disability. While being ‘on call’ does not necessarily represent direct care, it highlights the need for carers to juggle a range of responsibilities within a limited time—including engaging in social life and employment—beyond the caring role.

Research by Ashworth & Baker (2000) also highlights the impact of care demands, with carers indicating that caring for someone with disability prevented them from doing general daily activities, such as ‘doing the weekly shop’ or ‘getting the place together’.

Securing a future for those in their care

Participants in this study also described their high levels of concern and stress related to future plans, often expressing fears and concerns about securing a meaningful and safe future for the person they cared for.

Carers of people with disability focused on short-term fears and concerns, which were often accentuated by important life events for the person they were caring for (for example, starting high school or turning 18).

“My son has got one more year before he leaves school and we don’t know what care he’s going to get, we don’t know about post-school options, we don’t know how much I’m going to be able to work. That’s the next stress.”

“And it’s only going to get worse; as I said, I’m dreading puberty. And then, when he leaves school, what am I going to do with him? I mean, am I still going to be able to work? I don’t know.”

Coupled with these short-term, sporadic stressors, carers of people with disability expressed concern about the ability for the service system to care for their loved one if something should happen to them personally (this was particularly an issue for parents caring for a child with disability). Participants’ fears and concerns were reinforced by a lack of understanding and awareness of where to go to find the help they might need in the service system.

“It’s kind of being cruel, and I hope in some ways that it [not outliving her child] doesn’t happen that way but, you know, we have to be real here. I’m not getting any younger and who knows what tomorrow brings? It doesn’t matter how old you are.”

“Unfortunately, I’m not going to live to be 200 years of age, and she [daughter] has to go somewhere, because there is no way to even consider that that [living on her own] is an option. She would starve. Her name is down, her name has been accepted, so they tell me, but there is nowhere for her to go.”

Despite all the stress, carers are resilient

While stress, strain and sacrifice are all part of caring for someone with disability, it is important to note that in spite of the difficulties, both the findings from the quantitative survey and discussions with carers reinforce the resilience of carers and the desire for carers to perform this role to the best of their abilities. These findings resonate with the research findings from Wesley Mission’s previous study that explored issues faced by carers for people with mental health issues (The Wesley Report, 11, 2012).

Resilience is a characteristic that was clearly evident among the interview participants in the qualitative element of this study. As already noted, carers who were interviewed as part of the research cited many examples of how their quality of life was limited by their caring role.

Alongside these examples, however, they expressed a determination to make the best of the situation they were in, and recognition of the positive aspects of their lives, including their love for the person they cared for.

“I’ve been looking after my brother and sister since my mum died and that’s been about 20 odd years now, so as far as my career goes, that was my career: looking after them. I don’t see them as hard work, but I do it through love because I felt that the rest of my family just didn’t give a damn.”

“I can hear myself become more cheery as I talk about it [Wesley LifeSkills], because I’m just so thankful for their commitment and how they have been with him. It’s more about the day-to-day stuff. He actually even answered the telephone a couple of times, appropriately. That’s when we were working on that goal. It’s not something that has continued and it’s not something that we can tick off, because he won’t really do it now, but there was a period there when I could call to him, ‘Tommy, can you answer the phone?’”

The comments from carers during interviews are supported by findings from the quantitative survey. Respondents in the study did not, broadly speaking, express high levels of dissatisfaction with their current quality of life, despite the stresses and strains associated with caring for someone with disability.





Circle of care

Like all dads, Scott has many memories of his children. Some are great, some he'd rather forget.

One clear memory for Scott is of a poolside barbeque he went to with his two sons, Heath and Logan, who is autistic. They had only just arrived and Scott was setting down the esky when he heard the sound of smashing glass. Logan had found a beer glass and smashed it on the edge of the pool, sending shards of glass into the water. The pool had to be cleared and emptied, ending the pool party. Scott was so embarrassed, he gathered up his sons and went home.

Scott is a widower and busy sales representative. He loves spending time with friends and needs the social support, but says many people are wary of Logan, now 10, and don't know how to react to him. Having to leave parties and outings early because of Logan's behaviour is also hard on Heath, who is 13. The reality, Scott feels, is that their social circle is limited.

"We just don't get invited to stuff. I've only got two good friends who understand Logan."

When Scott's wife died a few years ago, he took on all the challenges of being a single parent. It was a very hard time for Scott, grieving his wife and adjusting to his role. Things were made more difficult because Scott and Heath did not have a good understanding of autism.

"Logan is a funny kid and makes you laugh," says Scott. "But when he gets annoyed, that's when the trouble starts."

Once a week Logan stays in Wesley Mission's respite accommodation and once a week he stays in another respite service.

This time gives Scott the opportunity to develop friendships and attend to other things.

"Shopping with Logan is a nightmare. Respite helps me do it more freely.

"It means I don't have to worry about where he is and what he is doing. I can visit friends and relax."

While in respite care, Logan can develop life skills and learn different ways to moderate his behaviour. The professional assistance Logan receives really pays off and Scott notices definite improvements in Logan's behaviour.

Like many parents, Scott finds it difficult to give his children equal attention. Logan's behaviour can be all-consuming, meaning there is little time left for Heath.

With the respite provided by Wesley Mission, Scott has been able to continue to coach Heath's cricket team. It means so much to Scott and shows just how crucial respite care can be in reducing family tensions and facilitating better parenting.

Respite also means Scott does not have to rush to leave work and can complete everything he needs to. It effectively means he can keep his full-time job. Scott believes that this support is a lifeline for him.

"You can never have too much respite. If I was to do it all myself, I would be pulling my hair out."

The big grin on Logan's face when he arrives at respite and when he comes home confirms for Scott that respite benefits Logan just as much as it benefits Heath and himself.

"Logan gets to respite, hugs all the staff and asks their names 20 times. And he comes home happier to see me. If I didn't have respite, I'd be tired and grumpy at Logan all the time."

At the moment, Scott is also fortunate enough to have loving parents and parents-in-law who play a significant role in helping to care for and manage Logan.

"As my parents and in-laws age, it means that support will disappear eventually," Scott acknowledges, as he considers how the future will look for him and his boys.

Despite all the challenges, Scott, Heath and Logan are still close and respite is a big part of that.

"Heath and I miss Logan when he is not around," Scott confesses, with a smile. "When we are planning a holiday, Heath always asks if Logan is coming.

"Of course, mate," Scott responds.



The impact of receiving disability services

One of the core aims of this study was to provide insight into the impacts that receiving disability services has on carers and the broader family unit. Literature clearly shows that disability services deliver more than simply practical benefits and that service provision has an impact on a range of social, emotional and interpersonal elements. This section explores how using disability services affects the mental and physical health of carers of people with disability, as well as how these services impact their social engagement, quality time and finances. It also provides insight into how carers feel their life would be if they didn't have these services.

Giving disability carers a break

The data used to understand these impacts comes from a range of sources, including published literature, the online survey with carers, and interviews with carers conducted as part of this study. The impacts of seeking help have been discussed in a range of literature and while many models for assessing these impacts exist, the Quality of Life Application Model (Schalock et al, 2002) provides an indication of benefit across a range of factors including:

- health
- education
- employment
- social engagement
- family life.

There is less certainty in the literature relating to the benefits of engaging in disability care services from a financial perspective for the individual or family. A review of Australian and international literature shows a dearth of insight in relation to financial impacts beyond macro-level impacts associated with the ability for carers (or the individual in receipt of services) to engage with education or employment opportunities, and the reduced cost burden associated with better health outcomes as a result of service engagement.

Key summary

- across all aspects measured (social, emotional and financial), carers indicated that they would be considerably less satisfied without the provision of care services
- a reduction in access to disability care services was seen to be most detrimental for carers' mental health, with 82 per cent of respondents in the survey indicating that their level of satisfaction with their mental health would decline without the provision of care services
- a similar proportion indicated that the level of stress in their lives would worsen if the provision of services was reduced (71 per cent)
- while impacts on financial aspects of life were less dramatic, more than one-third of respondents indicated that they would be less satisfied with their financial situation if access to services was restricted
- reviewing the data, we estimate that where a service assists a carer to return to work on a part-time basis, an annual value of approximately \$12.8 million would be created for those using Wesley Disability Services
- based on a review of ABS and AIHW data, we estimate that Wesley Disability Services provide an annual direct benefit of approximately \$64,000 in avoided treatment costs annually through a reduction in the incidences of anxiety and depression.





What if disability care services were not there?

In going some way to understanding just how crucial disability services are, all carers were asked to indicate their current level of satisfaction with their life across the key elements of quality of life as outlined by Schalock et al (2002), in addition to being asked to indicate how their levels of satisfaction may change should access to services be limited. The differences in satisfaction scores with and without service access provide some indication of the impact of services on carers, families and the individuals they care for.

When asked to consider how their life may be if they didn't receive the disability support services provided by Wesley Disability Services, levels of satisfaction decreased across all social and emotional measures, with particular declines seen in relation to:

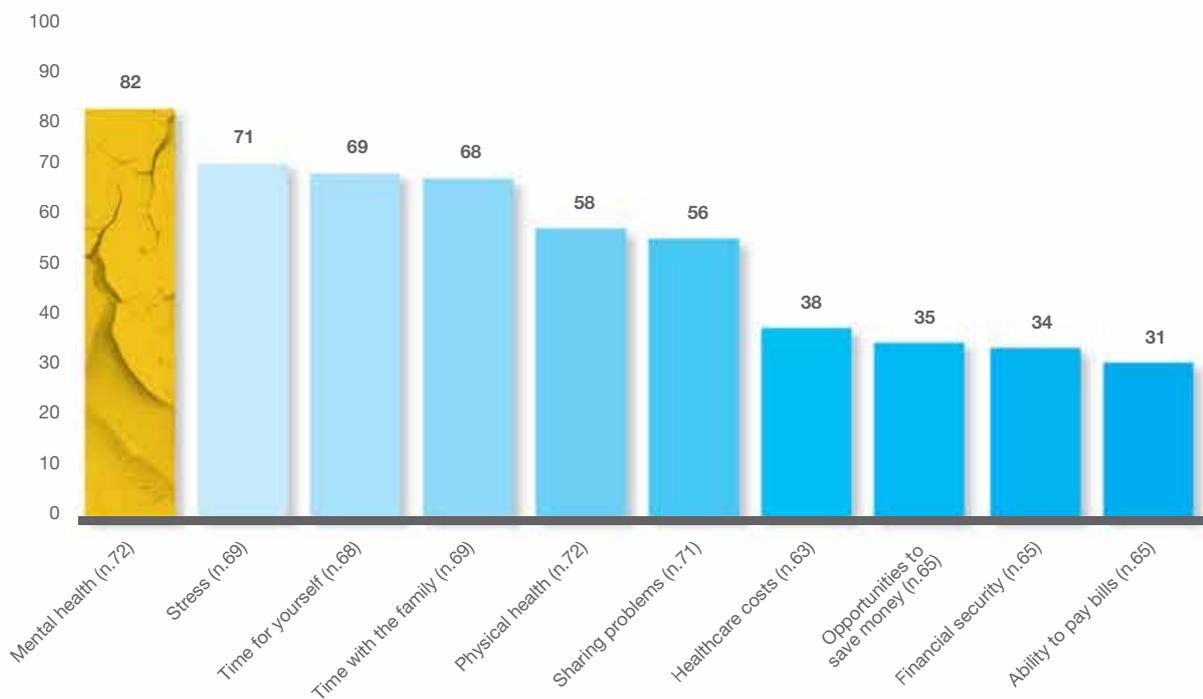
- mental health
- levels of stress
- having time for yourself
- having time for the family.

While impacts on aspects of financial services were less obvious, around one in three respondents did feel that a reduction in service provision would diminish satisfaction with their:

- healthcare costs
- opportunities to save money
- financial security overall
- ability to pay bills on time.

The change, and potential impact of any change, is discussed in more detail in the following section.

Figure 1: Those reporting a decline in satisfaction should service provision be restricted (per cent)



B1a: How satisfied or dissatisfied are you currently with ...?

B1b: Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ...?

Stressed about decline in services

82% of carers would be less satisfied with their mental health without care services



More stress if services reduced

Stress would worsen for 71% of carers if care services were reduced



Healthier with respite

Without disability services 58% of carers would be less satisfied with their physical health

Wesley Disability Services contribute



\$12.8 million by enabling carers to return to work on a part-time basis

\$64,000 in avoided treatment costs annually through a reduction in the incidences of anxiety and depression

Less personal time if services decreased

67% of carers would be 'dissatisfied' or 'very dissatisfied' with personal time if services decreased



“Support, respite, friendship, and I suppose a listening ear.

A listening ear is just what we want as carers.” A carer’s thoughts on the main benefits of receiving disability care services

Impacts of service provision on the mental health of carers

Provision of care services by Wesley Disability Services is seen by carers to have positive impacts on their mental health. Mental health was the area that carers recognised would be most affected should access to disability services be reduced, with eight in 10 respondents (81 per cent) indicating that they would be less satisfied with their mental health if they were no longer able to receive disability services.

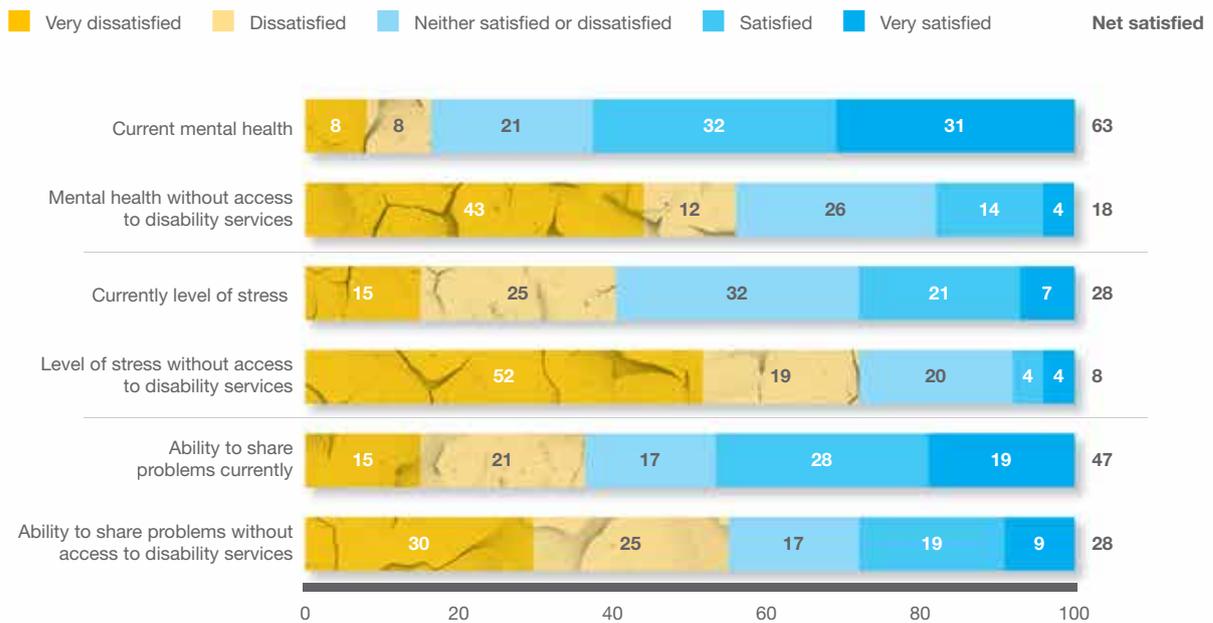
Exploring this in more detail, two-thirds (63 per cent) of all respondents in the survey were satisfied (either ‘very satisfied’ or ‘satisfied’) with their mental health under the current disability service provision arrangements and 16 per cent were dissatisfied (either ‘very dissatisfied’ or ‘dissatisfied’). Should they not be able to receive these services, predicted overall satisfaction declines significantly to 18 per cent (a reduction of 45 per cent) while predicted overall dissatisfaction increases significantly by 39 per cent, to 55 per cent in total.

The shift in satisfaction with mental health appears to occur at the extreme ends of the scale, reinforcing the potential impact a lack of service provision would have on carers and their families. Significantly, the proportion of carers ‘very dissatisfied’ with their mental health increases from less than one in ten (8 per cent) in the context of current service provision to almost half (43 per cent) should services not be available (see Figure 2). A corresponding decline in those who are ‘very satisfied’ with mental health is also seen, with only 4 per cent indicating that they would still be ‘very satisfied’ should services no longer be available (down from 31 per cent currently ‘very satisfied’).

Closely linked to mental health, it is apparent that limited access to disability services has an impact on both the stress levels of carers and the ability for carers to have time for themselves. Seven in 10 respondents in the survey (71 per cent) indicated that their satisfaction with the level of stress they have in their lives would decline if they were no longer receiving disability services and a similar proportion (68 per cent) indicated that their satisfaction with their ability to get time for themselves would decline. Again, changes in satisfaction are observed at extreme ends of the scale, with an increased proportion of those feeling ‘very dissatisfied’ with:

- their stress levels—increasing from 15 per cent currently to a predicted 52 per cent if services were not available (an increase of 37 per cent)
- their ability to share problems—increasing from 15 per cent currently to a predicted 30 per cent if services were not available (an increase of 15 per cent).

Figure 2: Impacts on mental health, stress and burden sharing (per cent)



B1a1, B1a3, B1a6: How satisfied or dissatisfied are you currently with your mental health/the level of stress in your life/the opportunities you have to share problems or concerns with family or friends?
 B1b1, B1b3, B1b7: Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ... ?
 Base: All questions on current satisfaction levels n=72, all questions on satisfaction levels without access to disability services n=69.

These findings align with comments from carers during the in-depth interviews, with mental health concerns and the degree of stress families and individuals experience frequently attributed to the level of stress experienced as a direct result of their caring role.

“For the first time ever in my life, I’ve had to take anti-depressants. For the last two years and I’m currently still on them. I’m on blood pressure medication and I’ve never been on these things before. Maybe it’s the age that all of these things start to happen but I guess it’s the impact of the [caring] lifestyle.”

“You know, it’s very stressful every day. Having to deal with the problems that you’ve had, or that your life has to revolve around someone else all of the time ... that stress that you have to be home from work on time or somebody has to be there all of the time. For the week or weekend that he’s not there, that stress is not there.”

Participants in the interviews often indicated that access to respite services was particularly valuable for their mental health, as it provided them with a period of time to think about things outside the day-to-day caring responsibilities. Respite offered the opportunity to address some of the underlying stressors discussed earlier, particularly the ability to gain a better sense of self, to reduce the complexity in their lives and to better juggle a wide range of family and carer responsibilities.

Critically, some participants in the interviews also indicated that interaction with Wesley Disability Services staff who had an appreciation of their situation and were able to provide a sympathetic ear also had a positive impact on their mental health.

Sharing their stories and talking to someone outside their family who could understand the issues was a key stress-release for carers, assisting them to manage their caring responsibilities

Impacts of service provision on the physical health of carers

Receiving disability care services was also seen to have considerable benefits on the physical health of carers. More than half (58 per cent) of all respondents indicated that not being able to use disability care services would result in them being less satisfied with their physical health. At a total level, satisfaction with physical health declines significantly from 50 per cent (either 'very satisfied' or 'satisfied' under the current service provision arrangements) to a predicted 23 per cent should service provision be restricted.

As with impacts on mental health, the largest variants are at the extreme ends of the scale, with the proportion of respondents 'very dissatisfied' with their physical health increasing significantly from 6 per cent to 38 per cent if service provision was limited (Figure 3).

Again, these findings are supported by discussions with carers who noted that caring for someone with disability affected their physical as well as mental health. Carers often indicated that they had experienced negative physical health consequences as a result of their caring role. Physical health issues were diverse and ranged from chronic health conditions, such as high blood pressure and blood clots, to physical issues due to the physical demands care could require.

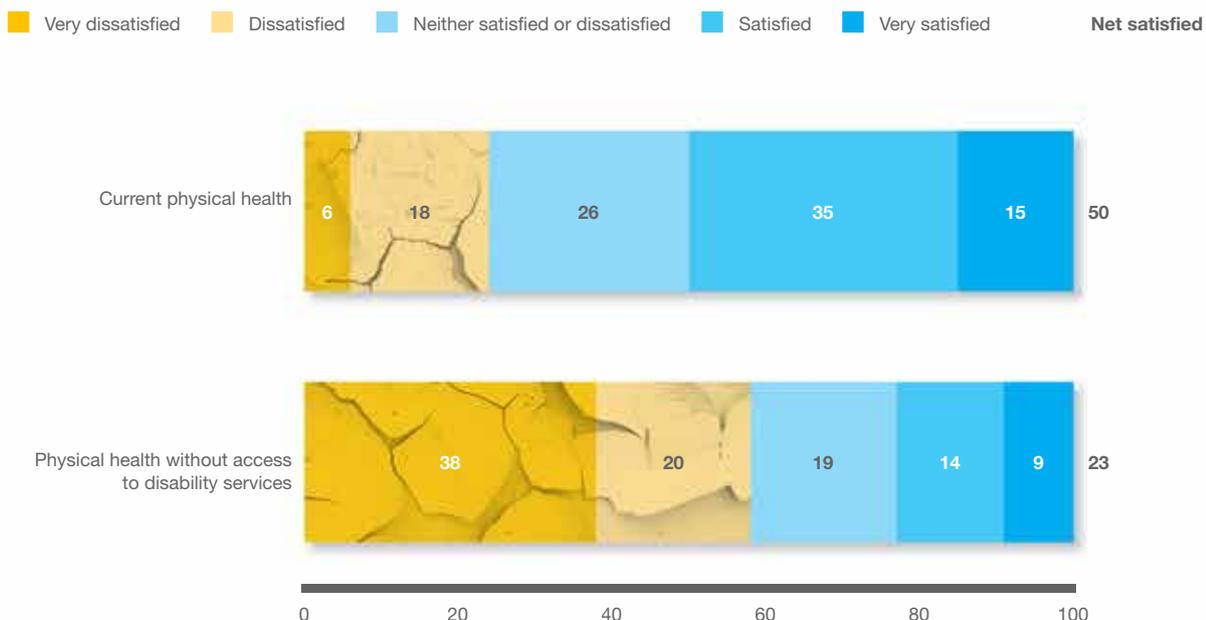
"Well she's a big girl, and she's very hard on us. Getting her in and out of beds and on and off toilets and things like that, it's difficult. Actually, we had her here a few weeks ago for four days and it absolutely nearly killed us."

Carers' comments are in line with broader literature on health, with a considerable body of research demonstrating the link between poor health and caring responsibilities (ABS, 2012a; Edwards et al, 2008; Mental Health Council of Australia, 2012). In addition, research has shown that carers are generally more likely to have a chronic health condition than non-carers, and to more often report high blood pressure, high cholesterol and to be classified as overweight or obese (Gill et al, 2008).

Impacts of service provision on social engagement and quality time for carers

Not surprisingly, given the extent of their caring responsibilities, respondents in the survey indicated that they would be less satisfied with their ability to have quality time for themselves or share time with the family if they were not able to receive disability care services (Figure 4). Having time for yourself was seen as particularly difficult, even with access to services.

Figure 3: Impacts on physical health (per cent)



B1a2: How satisfied or dissatisfied are you currently with your physical health?
 B1b: Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ... ?
 Base: n=69.

With the current care services they are receiving, only 35 per cent of carers felt satisfied (21 per cent ‘satisfied’ and 14 per cent ‘very satisfied’) with the opportunities they have for quality time for themselves.

When asked to consider the impact if access to services was no longer available, satisfaction with the opportunity to have time for yourself declines by half to 17 per cent (with 10 per cent ‘satisfied’ and 7 per cent ‘very satisfied’). In this scenario, almost half (49 per cent) of all respondents indicated they would be ‘very dissatisfied’ and two thirds of respondents indicated they would experience a level of dissatisfaction with their ability to take time for themselves (67 per cent ‘dissatisfied’ or ‘very dissatisfied’).

Currently, almost half of all respondents are satisfied with the amount of time they spend with family and friends (43 per cent either ‘satisfied’ or ‘very satisfied’). Should they no longer be provided with the care service, overall satisfaction would decline to 20 per cent. Again, impacts of restriction of services seem to be felt at the extreme ends of the scale, with the proportion of those being ‘very dissatisfied’ with the time that they spend with family and friends increasing from 13 per cent currently to a predicted 42 per cent should disability services not be available.

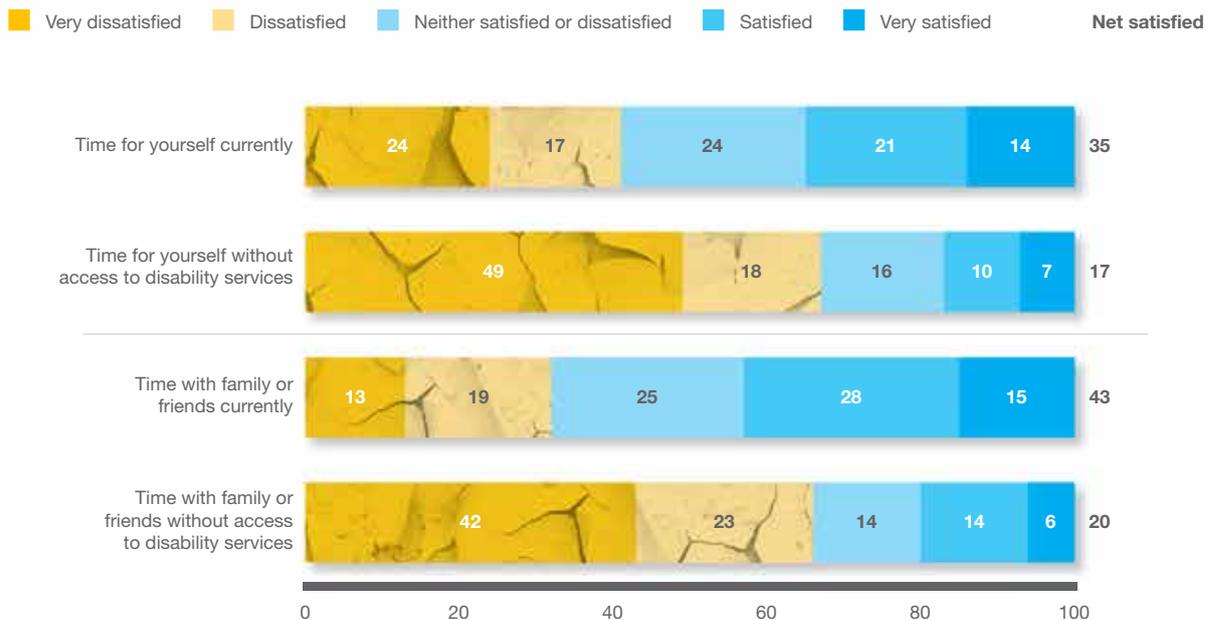
These findings are supported by the comments from carers during interviews. Participants often described how their social life and family life were affected by their role as a primary carer. Many felt that the only opportunity they had for time for themselves was when the person they care for was in respite (or using other disability services). Time for social activities (when not caring) or time to connect as a family was sparse.

“When your son is in respite you suddenly think, ‘I am actually free!’”

“I have another daughter who has two young children and I don’t have enough time to be just with them, without Penny, so I don’t. I haven’t been on a holiday with my husband alone for three years now.”

Participants in discussions also often indicated how caring for someone with disability could make it difficult for the individual with the disability and the carer to connect with society as a result of being misunderstood or, in some cases, discriminated against. For some, this led to feelings of loneliness and social isolation.

Figure 4: Impacts on social engagement and quality time (per cent)



B1a7, B1a5: How satisfied or dissatisfied are you currently with the opportunities you have for quality time for yourself/ time you are able to spend with family or friends?
 B1b5, B1b7: Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ... ?
 Base varies by question: Time for yourself currently n=68, time for yourself without access to disability services n=71, time with family or friends currently n=69, time with family or friends without access to disability services n=72.

Giving disability carers a break

“Sometimes I just feel, I don’t know, you feel alone. You know that you’re not, but you feel alone, and you have to make all the decisions. You don’t know where to go, what to do ... I just feel they class the disabled as second-class citizens, I suppose. They’re not. I’ve never treated them that way but some people do. Sometimes when you’re trying to speak to a person, they’re not listening. They’re listening on the surface but they’re not listening to what you are saying.”

Recent research conducted by the Mental Health Council of Australia (2012) supports these comments, with a majority of carers either always or often feeling alone as a direct result of being a carer. A majority also indicated that they had experienced some form of discrimination within the local community as a result of their carer role.

The propensity for isolation, and the negative impacts such isolation can have on carers and their families, highlights the importance of being able to receive appropriate, tailored disability care services.

The financial impacts of service provision on carers

One of the key aims of this study is to provide insight into the financial impact that the provision of disability care services has on carers, their families and the broader Australian society. In the quantitative study, respondents were asked to indicate whether accessing Wesley Disability Services had an impact on their personal/family financial situation. They were also asked to provide an indication of the financial value of the service provision, which could include:

- savings as a result of the provision of free or discounted services (for example, subsidised access to respite, zero-cost homecare)
- savings as a result of a reduction in expenditure as a direct result of using a service (for example, reduced GP visits as a result of a reduction in stress levels, reduced medication costs as a result of improved health management)
- increased household income (or reduced financial pressure) as a result of an increased ability to engage in paid employment.

In addition to impacts at an individual/family unit level, the provision of disability care services can also have an influence on the wider Australian economy. For example, greater opportunities to engage in paid employment can contribute to a stronger economy and a reduction in the need to seek primary healthcare services can lead to a reduction in health costs for the Australian health system as a whole.

The following section provides a summary of the findings from the quantitative survey and discussions with carers in relation to the financial impact of receiving disability services on carers specifically and the household more generally. This section also includes a preliminary review of the potential impacts of accessing services on the macro-economy as a result of key benefits identified and discussed by participants in this research.

Impacts on the individual and the household

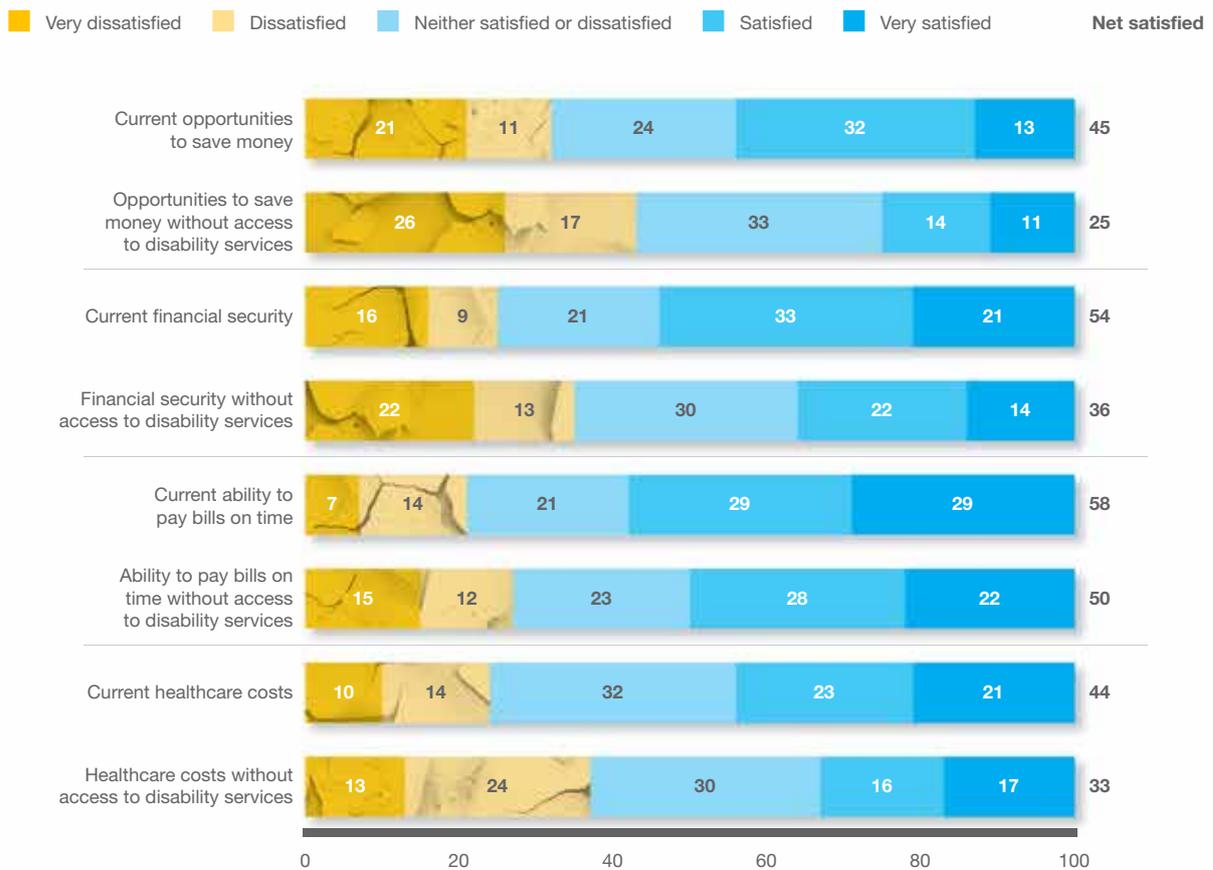
While some respondents were able to provide an indication of savings associated with using services, it was clear from the quantitative findings and discussions with carers that estimating the specific financial impact of care was extremely difficult. Figure 5 provides an outline of the perceived impact of a reduction in disability service access on key financial aspects.

At a macro-level, savings associated with service provision were identified, with a reduction in disability service access being seen to result in negative financial impacts for the family. Across all aspects measured, carers felt that a reduction in receiving services would have a negative impact on their financial situation. Significant differences between current and predicted satisfaction include:

- opportunities to save money—45 per cent of carers were satisfied (either ‘very satisfied’ or ‘satisfied’) under current care service provision arrangements, declining to a predicted 25 per cent should access to service be restricted; a significant decline of 20 per cent
- financial security—54 per cent of carers were satisfied (either ‘very satisfied’ or ‘satisfied’), declining to a predicted 36 per cent: a significant decline of 18 per cent.

Despite the fact that differences in other aspects of financial impact are not significant, the consistent downward trend across all four elements assessed lends weight to the conclusion that there is a relationship between financial stability and capacity and the ability to access disability care services.

Figure 5: Impacts on financial capacity and stability (per cent)



B1a8, B1a9, B1a10, B1a4: How satisfied or dissatisfied are you currently with your opportunities to save money/ financial security/ability to pay bills on time/healthcare costs?
 B1a8, B1a9, B1a10, B1a4: Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ... ?
 Base varies per question: Current opportunities to save money n=72, opportunities to save money without access to disability services n=66, current financial security n=70, financial security without access to disability services n=64, current ability to pay bills on time n=72, ability to pay bills on time without access to disability services n=65, current healthcare costs n=71, healthcare costs without access to disability services n=63.

While the relationship between satisfaction with financial capacity/stability and service provision is apparent, when respondents were asked to identify specific savings or costs associated with receiving services, very few were able to provide a concrete figure across a range of aspects including health, welfare, education, employment and household expenditure.

In part, an inability for carers to estimate specific financial benefits associated with care provision is a direct result of the impact of caring for someone with disability. As already noted, caring for someone with disability is all-encompassing: it consumes time, energy and effort, and as a result, carers often

indicated during interviews that they simply did not have the time to truly understand their finances. This being the case, they could not estimate savings as a result of accessing services.

An inability to identify specific savings or the financial impacts of receiving care also appears to be related to the extended length of time that many respondents had been accessing care. Respondents did not know how much alternative care arrangements or services may cost, as they had used the same service providers for quite some time. As a result, predicting cost savings or implications as a result of not receiving current services was difficult.

Estimating the financial value of returning to work

What was clear from discussions, however, was that caring for someone with disability, and the benefits of accessing disability care services, had a significant impact on the ability for carers to engage in the labour market.

Some carers described how the demands of their caring role had resulted in a cessation of full-time employment, while others indicated that they had been required to adjust their career ambitions by choosing jobs that were more accommodating to their caring responsibilities and more easily able to adapt to sporadic service provision.

“It ties into career progression. If I see something come up that I think I would like to progress to, if it requires extra travel or something I think, ‘Oh, I can’t do that because of Sarah.’ I need to be around because of her, so in that way it has impacted.”

“He [husband] is sort of trapped in the work that he’s doing because of the hours and that it works out with our son. He’s not that happy with his work but he’s never going to leave because he knows that he’s never going to get that sort of work with that flexibility.”

“I’ve been in my job for 27 years because they let me leave at three o’clock, but I absolutely dream about getting a better corporate job and getting a sitter to mind my son, you know, five afternoons a week so I can stay at work and earn the big bucks.”

A review of the literature reinforces this link between caring for someone with disability, the ability to access care services and engagement in the workforce. Labour force participation of people with disability and their carers is significantly lower than that of the general population (ABS, 2012 in: NDS, 2013), and carer responsibilities are often linked with a temporary break in a career, a requirement to change jobs or the need to look for job opportunities that offer flexible work arrangements (Edwards et al, 2008).

Critically, the difficulties of accessing flexible support services (particularly long-day and out-of-hours respite care) has been shown to have a detrimental impact on the ability of carers to engage in the workforce. Findings from the Commonwealth Government (2009) report on the parliamentary inquiry into better support for carers draws out evidence from the SDAC which indicates that 38 per cent of primary carers who had left employment to care indicated that they had done so because alternative care was not available, was too expensive or because they had been unable to change their working arrangement. The report also highlights the Australian

Institute of Family Studies analysis of labour force participation data which identified key barriers to carer engagement in the workforce, including:

- having no alternative disability care arrangements available
- difficulty arranging working hours around care needs
- high costs of paying for disability care while at work
- a high degree of disruption for the person with disability.

Regardless of the struggle, carers clearly desire to continue employment and to maintain careers. Beyond the financial benefits of employment, carers interviewed for this study indicated that work gives satisfaction in life—many were not looking forward to becoming a full-time carer, even though this could make their lives easier.

“There are days when it all goes pear-shaped and these are the days when I think I should give up work and become a full-time carer at home. But then the other way of looking at it is—as much as it’s not a pleasant thought—if something happens to her tomorrow, where does that leave me? A woman in her fifties with no job and no skills and, you know, on the dole, so to speak.”

Given the clear desire to maintain engagement in the workforce and evidence that services can have an impact on the ability for a carer to remain in or gain employment, it is possible to estimate the overall financial impact that access to disability care services has for the individual and family.

Reviewing the data, we estimate that where a service assists a carer to return to work on a part-time basis, an annual value of approximately \$12.8 million is created for those accessing Wesley Mission Disability Services. This estimate is based on the following assumptions:

- average weekly earnings for full-time work are \$1,407.80 (ABS average weekly earnings, ordinary time, for New South Wales, May 2013, seasonally adjusted figure, ABS, 2013)
- carers are assumed to return to work for an average of 2.5 days per week
- a total of 350 carers are included across the entire Wesley Disability Services cohort
- there is adequate capacity in the economy to absorb this extra labour supply, and that additional supply is small enough not to have an effect on wages.

While these figures are obviously estimates, they provide a clear indication of the value of care services not only to the Australian economy as a whole, but to individual families who use disability care services.

Estimating the value of better mental health

Beyond financial benefits associated with improved ability to engage in employment, there is the potential for access to disability services to have a financial impact as a result of improved mental health for carers.

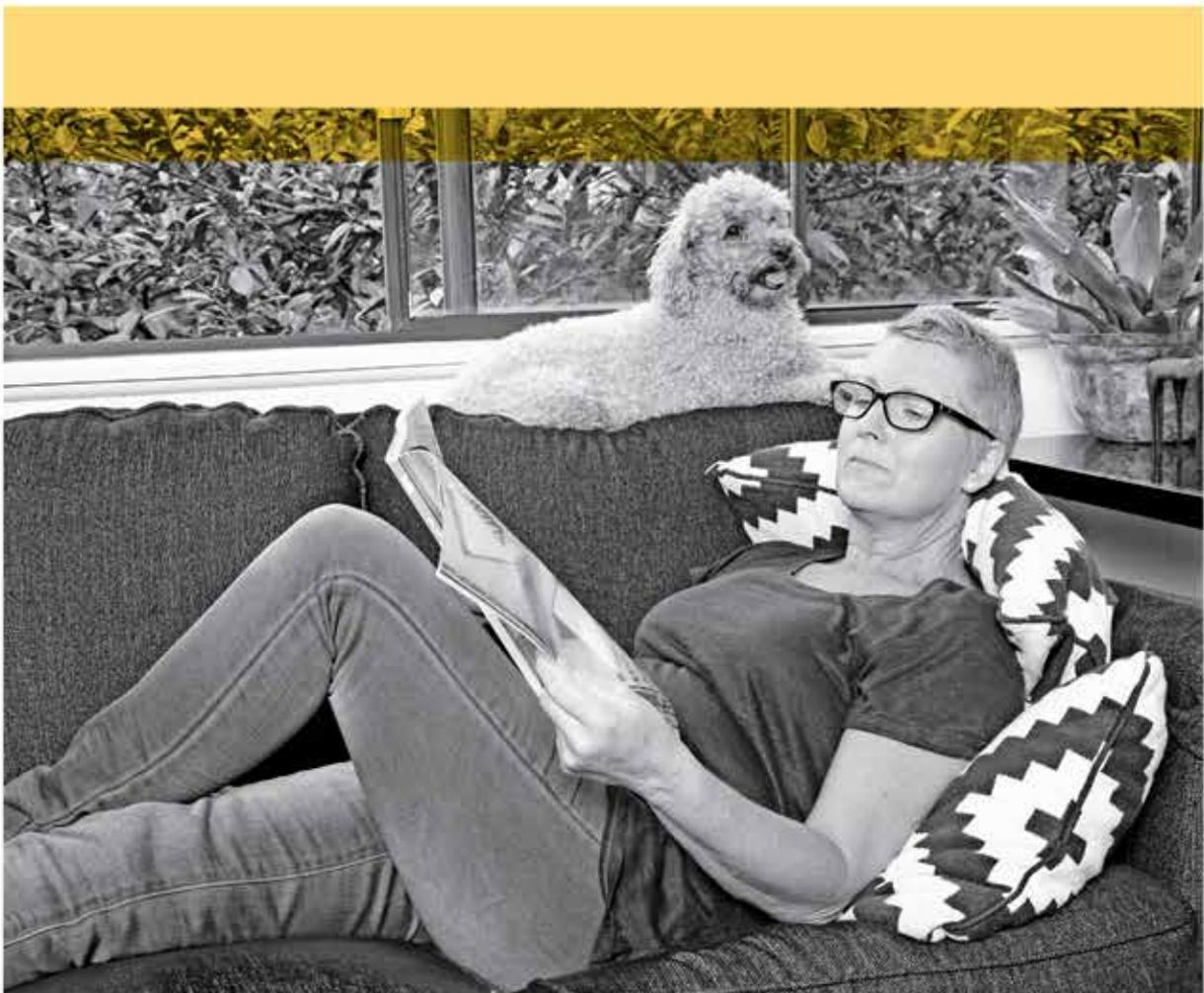
As noted, a number of carers report that without the support of Wesley Disability Services their levels of stress would increase and their mental health would deteriorate.

Based on a review of ABS and AIHW data, we estimate that Wesley Disability Services provide an annual direct benefit of approximately \$64,000 in avoided treatment costs through a reduction in the incidences of anxiety and depression. This estimate is based on the following assumptions:

- Australia spends approximately \$2.073 billion per year on the treatment of depression and anxiety disorders—AIHW estimates \$1.407 billion in 2004/05 disease expenditure database, inflated to 2014 dollars by health expenditure index (AIHW, 2010; ABS, 2014)
- the ABS estimated that 3.299 million people experienced an anxiety or affective disorder during the past 12 months in 2007 (ABS, 2010)

- annual expenditure on anxiety or depression is approximately \$629 per experience (based on the above assumptions)
- a negative impact of a caring role on the physical and emotional wellbeing of primary carers has been demonstrated in Wesley Mission's previous study (The Wesley Report, 11, 2012). Following on from this, ABS estimates that the physical or emotional wellbeing of 29 per cent of primary carers has changed due specifically to their caring role (ABS, 2011). This is used as a benchmark to estimate the proportion of carers who may suffer from anxiety or depression in the absence of Wesley Mission support
- a total of 350 carers are included across the entire Wesley Disability Services cohort.

Again, while these figures are obviously estimates, the deferred costs of the provision of disability care services are clear and complement the identified social and emotional benefits reviewed and discussed by carers of people with disability.





Always on my mind

Candice is autistic, non-verbal and has a fascination with plastic items. When at the park for a family picnic, if she sees a plastic bottle she will immediately run off to grab it, whether near or far away, whether safe or not. At home—or, for that matter, at friends' houses—Candice, in her mid-20s, has the compulsion to sort through cupboards and rubbish bins.

Candice's mother Vicki, 61, has to be constantly looking out for what Candice is doing. And Candice's behaviour can make socialising a bit awkward. The family don't visit friends very often.

Vicki needs to lock the fridge, the bedrooms, the bathroom, hallway and the back yard to prevent the family home from descending into chaos.

"Sometimes I feel like I'm a prisoner in my own home," Vicki spells out when reflecting on the hyper-vigilance required to curtail her daughter's compulsions.

"If we go to someone's house she will immediately start to go through their cupboards. She's a very strong person and doesn't take kindly to being stopped.

"Candice is getting too physically strong for me. If she sees something she wants in the supermarket she will pull me over to it."

Vicki also needs to shower Candice twice a day and feed her. Caring for her daughter is a full-time job and there is very little time out, but respite does allow Vicki to take a much-needed break and do a thorough clean of the house.

Candice stays in Wesley Mission's respite accommodation two weekends each quarter and spends the same amount of time in another respite service.

Respite enables Vicki to take two trips a year with a group of other mothers who also have children with disability. This group of friends provide a lot of support—and a lot of laughs.

Candice feels the frustration of their family life just as much as Vicki and will sometimes butt her head against walls and windows. She has recently put a hole in a wall.

Respite allows Candice to be part of a different environment, which can relieve some of her tension. Vicki recognises how important it is for Candice to have this alternate care.

"I don't want her stuck inside our house all the time. Part of the benefit of respite is that she can get away from all the 'No' and 'Don't do that'. I don't have to be the baddie all the time," Vicki remarks.

"She enjoys respite. When she arrives, she goes straight in."

Life with an autistic daughter is a struggle but respite helps Vicki cope. It means there are some times when she can switch off from the continuous routine of keeping an eye on Candice.

"Some days I can't get started. I need to have a cry and then get on with it," Vicki reveals.

"Without respite I would break down."



Policy and practice implications

The following recommendations have been developed based on the findings of this study and in consultation with frontline disability service staff and specialists, calling on their experience and understanding of the clients and carers they assist through Wesley Disability Services.

1.

Create clearer pathways to access disability services

While services for people living with disability exist across a wide range of support needs, it is clear from this study that carers find it difficult to understand the pathways to access services for the person they are caring for. In some instances this can be due to:

- a general lack of knowledge about what services are available
- confusion on how to access financial support for disability services
- lack of clear understanding about what will happen at key life-stage transition points, such as when their child leaves the education system.

For parents and carers of those living with disability there is a level of uncertainty and anxiety about key life-stage transitions—particularly for school-aged children nearing the end of their schooling. It is understood that the family of a child living with disability leaving the New South Wales education system receives some transitional assistance; however, concerns raised in this study indicate that some families are uncertain about support services and programs after schooling. It also appears that the information on transitional support available to families varies significantly.

We acknowledge that support and funding for carers and people with disability is provided from a wide range of government departments and non-government organisations, based on assessments from different specialists from both clinical and educational backgrounds. We also recognise that each person living with disability has different abilities and is assessed individually, resulting in a very complex system for accessing services.

Wesley Mission advocates for clear resources that enable carers and individuals with disability to easily navigate service provision options. This could be underpinned by a centralised online tool that they can access, outlining the support available to them based on their individual situation, assessment, geographical location and life-stage.

2.

Recognise that carers are incidental clients

The literature review leading into this study revealed that 60 per cent of people living with disability require assistance with at least one daily activity (ABS 2012a). This fact highlights the crucial role that carers play in the daily lives of people living with disability. In addition, this current study draws attention to the situation of carers and the significant positive impact that disability services have on them.

We recognise that it is primarily the person living with the disability who is viewed as the client, not the carer. The level of service provision available is based on the client's needs and abilities. This is reflective of the model of person-centred care and has resulted in shaping the current and developing service delivery models.

It is important to ensure that, while moving to a model of client-directed services, there is a clear understanding that 'the client' is more than simply the person with disability. Services should be tailored to include the role of the primary carer (and in many cases their family), and their needs should be considered together in supporting the person with disability.

There is increasing acknowledgment of the important role that carers play in both Australian and overseas service models, such as seen in some Scandinavian countries. In Australia, the new NDIS has acknowledged the essential role of families and carers in supporting people with disability.

Despite this, as highlighted in the first recommendation, carers in this study reported having a poor understanding of the pathways into, and between, available services. This confusion and lack of comprehension adds further complexity to their caring situations.

Wesley Mission recommends increasing the flexibility of service provision to take into account the needs of both carers and clients. This flexibility would be welcomed in ensuring that the right services are provided, while also decreasing the burden on already time-poor carers in order to enable them to carry on their caring responsibilities. Support for carers should also ensure that eligible carer payments keep pace with inflation and reflect the value of unpaid informal care in Australia.

3.

Create networks to prevent carers becoming socially isolated

It is clear from this study that, despite all the pressures of their role, carers of a person with disability show high levels of resilience and carry out their caring role with a clear love for those they care for. The care they provide is usually full time, 24/7, and it is this resilience and love that often provides the drive to continue.

As outlined in the previous recommendation, we understand that the services that are engaged provide primarily for the person with disability and not the carers themselves.

In many instances these services (aside from out-and-out respite services) do provide an incidental or unintentional level of support for carers. Services such as day-programs, employment and activities temporarily remove the immediate demands of intensive care.

From discussions with disability service staff, it is clear that carers interact with service staff for a level of support perhaps best defined as 'informal counselling'. Carers feel that disability staff are some of the few people they can talk to who genuinely understand their situation.

It would be of comfort and benefit to facilitate support groups for carers, enabling peer-support and providing a network of understanding and information-sharing, in much the same way that young mothers use mothers' groups. Such a group would help to provide vital support to otherwise isolated and potentially vulnerable carers.

We acknowledge the presence of existing groups supporting carers and recommend increased awareness and promotion through disability services to carers who may not be aware of the support groups available to them. Governments can also help by facilitating the development of carer support groups, and providing training, skills and opportunities for community capacity building and shared vision.

4.

Enhance community understanding

The crucial role that carers play in the community does not appear to be widely acknowledged. Disability—both intellectual and physical—has tended to be misunderstood or have an attached stigma. Much work has been done by the sector in recent years to shift this perception and show how people living with disability contribute meaningfully to the community, particularly through supported employment.

Despite this, carers can still experience a level of discomfort or even embarrassment when explaining their role in supporting the person they care for.

Wesley Mission sees the value in continuing to advocate for both carers and people with disability, knowing that carers themselves are the strongest advocates of those that they care for, highlighting their important place in society. Without informal carers, and the work they do, there would be a significant additional burden of care placed on the community at large.

We recommend enhancing community understanding and generating appreciation by emphasising these specific benefits carers bring to the broader community:

- **the family unit, the person with the disability, the carer and other family members, are, in most circumstances, better off when they receive appropriate support, avoiding relationship and family breakdown. This follows the model that family services follow, with an emphasis on keeping the family unit together as best practice**
- **by carers remaining in their role they are removing the responsibility and additional funding that would be required for that caring role to be provided by the community through full-time services.**

Carers provide a role that significantly reduces the burden on the community. Ultimately, providing them with appropriate support enables them to continue to effectively support their family directly and society indirectly.

Appendices

Appendix A

Disability services available

Type of service support	Main area
Accommodation support	Services that provide a person with disability accommodation, support to remain in existing accommodation or support to move to more suitable or appropriate accommodation.
Community support	Community services supporting persons with disability, carers and families in different areas, including therapy for individuals, early childhood intervention, behaviour intervention, counselling, regional support, support teams, case management and coordination.
Community access	Services focused on learning and life skills development for people with disability and services offering recreation/holiday programs.
Respite	Services supporting people with disability, carers and families in different types of arrangements, including own home arrangements, centre-based arrangements and host family respite.
Employment	Services supporting people with disability in open employment, supported employment or a combination of both.
Advocacy, information/referral services, as well as mutual support or self-help groups, and alternative formats of communication	Services and self-help groups supporting individuals in relation to advocacy and information delivery.
Other support services	Other support services include research and evaluation, training and development, peak bodies and other support services (such as one-off funding for promotional activities or buying aids and equipment).

(Source: AIHW, 2013)

Appendix B

Methodology

Literature review

The literature review was summative in nature and aimed at understanding current Australian and international literature in relation to the impacts of engaging with disability services and the impacts of caring for a person with disability. The search for relevant literature was focused on material produced within the last decade in Australia and overseas, and focused on gaining an understanding of:

- the impacts on the individual and family as a result of caring for someone with disability
- the impacts of accessing assistance for the carer and the family, including economic, emotional, social and physical impacts
- the economic benefits of reduction in key stressors (social, emotional and physical).

What was clear was that much of the literature on disability care services focuses on the need for care, the characteristics of those who use care and the preferences of those who have accessed services. There is very little literature that focuses specifically on the impact and outcomes of the provision of disability services for the individual and the family.

There is a dearth of literature related to the financial impacts of seeking assistance for someone with disability. All research identified as part of the literature review focused on the financial impacts of accessing disability services on a macro-level (impacts for broader society) rather than micro-level (impacts for the individual).

Survey with carers using Wesley Disability Services

The second stage of the study comprised quantitative research with carers of people with disability who were using Wesley Disability Services. A paper questionnaire was designed to be filled in by carers. The questionnaire focused on:

- understanding the context of the caring role, including the profile of the carer
- comparing satisfaction with quality of life (including health, social life, emotional wellbeing, financial security and employment) when access to disability services is provided compared to when access to disability services is not provided
- exploring the financial impacts (including the costs of care services, health expenses and accommodation services) of using disability care services on the household.

A total of 324 carers were sent a paper copy of the questionnaire and a reply-paid envelope to provide completed questionnaires. A total of 74 completed questionnaires were returned by the deadline of 24 January 2014, representing a response rate of 23 per cent.

All data was analysed using SPSS for this report. Significance testing was undertaken at the 95 per cent confidence level.

Interviews with clients

The final stage of the research involved a series of qualitative telephone interviews with carers of people with disability. A total of 10 carers were interviewed. All interviews took place between 12 and 28 January 2014, and each interview lasted up to one hour in length.

From a profile perspective:

- eight carers were female, and two were male
- at the time of the interview, seven carers were in paid employment while the remainder were unemployed
- most carers were parents of a child with disability, a few were looking after their partner or sibling(s)
- all participants had been in a caring role for more than 10 years.

The final question in the questionnaire asked respondents to indicate whether they would be willing to participate in further interviews and all participants included in this stage of the study agreed to further participation.

Appendix C

Section A: Caring for someone with a disability

This questionnaire is designed to be completed by the primary carer of someone with a disability. Firstly, please read the following description of a primary carer:

A primary carer is a person who provides any informal assistance or help to an individual with a disability or a long-term condition or an older person (aged 60+ years). The primary carer assists the individual with 'everyday types of activities', such as assistance in health care, housework, meal preparation, paperwork, transport or in communication. The assistance has to be ongoing for at least 6 months.

The first few questions are about your caring role.

A1. Are you currently the primary carer for someone with disability?

Please tick one box

- 1 Yes
- 2 No

A2. Are you currently the primary carer for more than one person with a disability?

Please tick one box

- 1 No—just one person
- 2 Yes—more than one person

If you answered 'no' to this question, the remaining questions in this questionnaire won't apply to you

Please note: If you care for more than one person with a disability, please answer all following questions thinking about the person who uses Wesley Mission Disability Services most often.

A3. Is this person your ...?

Please tick one box

- | | |
|--|---|
| <input type="checkbox"/> 1 Mother | <input type="checkbox"/> 12 Former wife |
| <input type="checkbox"/> 2 Father | <input type="checkbox"/> 13 Husband |
| <input type="checkbox"/> 3 Sister | <input type="checkbox"/> 14 Former husband |
| <input type="checkbox"/> 4 Brother | <input type="checkbox"/> 15 Partner |
| <input type="checkbox"/> 5 Daughter | <input type="checkbox"/> 16 Former partner |
| <input type="checkbox"/> 6 Son | <input type="checkbox"/> 17 Step-sister/sister in law |
| <input type="checkbox"/> 7 Grandmother | <input type="checkbox"/> 18 Step-brother/brother in law |
| <input type="checkbox"/> 8 Grandfather | <input type="checkbox"/> 19 Step-daughter/daughter in law |
| <input type="checkbox"/> 9 Granddaughter | <input type="checkbox"/> 20 Step-son/son in law |
| <input type="checkbox"/> 10 Grandson | <input type="checkbox"/> 21 Another relative |
| <input type="checkbox"/> 11 Wife | <input type="checkbox"/> 22 Someone else non-family related |

A4. For how long have you been the primary carer of this person?

Please tick one box

- 1 Less than 1 year 3 3–5 years 5 10 years or longer
- 2 1–2 years 4 5–10 years

Giving disability carers a break

... NOW ANSWER Part 2

Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ... ?

Very dissatisfied ← → Very satisfied

1. Your mental health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
2. Your physical health	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
3. The level of stress in your life	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
4. Healthcare costs (e.g. costs for seeing a GP, costs for medication)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
5. The time you are able to spend with family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
6. The opportunities you have to share your problems or concerns with family or friends	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
7. The opportunities you have for 'quality time' for yourself	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
8. Your ability to pay bills on time (like gas or electricity)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
9. Your financial security	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
10. Your opportunities to save money	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10

B2. Please answer the following questions if you are currently employed and working for a salary.

If you are not employed, please skip to Section C

FIRST ANSWER Part 1 ...

How satisfied or dissatisfied are you **currently** with ... ?

Very dissatisfied ← → Very satisfied

1. The type of work you are doing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
2. Your performance at work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
3. Your opportunities for career progression or promotion	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
4. Your salary	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
5. Your job security	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10

... NOW ANSWER Part 2

Without the support provided to you by Wesley Disability Services, how satisfied or dissatisfied would you be with ... ?

Very dissatisfied ← → Very satisfied

1. The type of work you are doing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
2. Your performance at work	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
3. Your opportunities for career progression or promotion	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
4. Your salary	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
5. Your job security	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10

Please answer the following questions if you are currently employed and working for a salary.

If you are not employed, please skip to Section C

B3. Without the support provided to you by Wesley Disability Services ...

Please tick either 'yes' or 'no' for each statement

	Yes	No	Why? Why not? Please provide as much detail as possible.
Without the support provided to you by Wesley Disability Services, would there be any negative impacts on your employment situation? (e.g. not being able to continue working, doing less interesting work)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
Without the support provided to you by Wesley Disability Services, would you need to reduce the number of hours you work?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
How many fewer hours per week would you need to work?			_____ fewer hours per week
Without the support provided to you by Wesley Disability Services, would you need to increase the number of hours you work?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
How many more hours per week would you need to work?			_____ more hours per week
Without the support provided to you by Wesley Disability Services, would your household income decrease ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
How much would your household income decrease per month?			\$ _____ per month

Please answer the following questions if the person you care for is currently employed and working for a salary.

If the person you care for is not employed, please skip to Section C

B4. Without the support provided to the person you care for by Wesley Disability Services ...

Please tick either 'yes' or 'no' for each statement

	Yes	No	Why? Why not? Please provide as much detail as possible.
Without the support provided to the person you care for by Wesley Disability Services, would there be any negative impacts on his/her employment situation? (e.g. not being able to continue working, doing less interesting work)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
Without the support provided to the person you care for by Wesley Disability Services, would he/she need to reduce the number of hours they work?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
How many fewer hours per week would he/she need to work?			_____ fewer hours per week
Without the support provided to the person you care for by Wesley Disability Services, would his/her household income decrease ?	<input type="checkbox"/> 1	<input type="checkbox"/> 2	
How much would his/her household income decrease per month?			\$ _____ per month

Giving disability carers a break

Section C: Impact on financial situation

C1. Has accessing Wesley Disability Services ...

Please read all the questions and tick all boxes that apply

	1. Helped you save money on any of the following expenses?			2. If so, how much are you able to save for each type of expense?	3. Is the amount of money you are able to save, per week, per month or per year?			4. Please describe for each element why and how you are able to save money. What makes it possible for you to do this?
	Yes	No	Don't know		Per week	Per month	Per year	
Care services (e.g. training, personal support, specialist care services, respite care, home assistance etc)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	\$ _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
Health expenses for the person you care for (e.g. costs for medication, costs for visiting a GP or other health specialists)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	\$ _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
Health expenses for you and your household (e.g. costs for medication, costs for visiting a GP or other health specialists)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	\$ _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
Accommodation costs and expenses for the person you care for (e.g. costs for rent or mortgage, property maintenance)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	\$ _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
Accommodation costs and expenses for you and your household (e.g. costs for rent or mortgage, property maintenance)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	\$ _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	
Education expenses for the person you care for (e.g. costs for study material, school fees)	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	\$ _____	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	

Section D: Your living situation

Before we finish, just a few more questions about you and your living situation.

Your answers cannot be used to identify you in any way.

D1. What is the highest level of education you have completed?

<input type="checkbox"/> 1	No formal schooling
<input type="checkbox"/> 2	Primary school
<input type="checkbox"/> 3	Some secondary school
<input type="checkbox"/> 4	Completed secondary school (HSC, Leaving Certificate, etc)
<input type="checkbox"/> 5	Trade or technical qualification (eg TAFE)
<input type="checkbox"/> 6	University qualification (e.g. undergraduate or graduate degree)

D2. Is English the only language spoken at home?

<input type="checkbox"/> 1	Yes
<input type="checkbox"/> 2	No, please specify which other language(s) are spoken at home: _____

D3. Which of the following best describes your household situation?

<input type="checkbox"/> 1	Live alone
<input type="checkbox"/> 2	Live without a spouse or partner, with children
<input type="checkbox"/> 3	Live with a spouse or partner, with children
<input type="checkbox"/> 4	Live with a spouse or partner, no children
<input type="checkbox"/> 5	Live with other family members
<input type="checkbox"/> 6	Live in a group or share household

D4. Are there any children aged under 18 living with you?

<input type="checkbox"/> 1	Yes, please indicate how many children: _____
<input type="checkbox"/> 2	No

D5. What is your approximate total annual household income before tax?

<input type="checkbox"/> 1	Less than \$20,000	<input type="checkbox"/> 6	Between \$100,000 and \$150,000
<input type="checkbox"/> 2	Between \$20,000 and \$35,000	<input type="checkbox"/> 7	Between \$150,000 and \$200,000
<input type="checkbox"/> 3	Between \$35,000 and \$50,000	<input type="checkbox"/> 8	More than \$200,000
<input type="checkbox"/> 4	Between \$50,000 and \$70,000	<input type="checkbox"/> 9	Prefer not to say
<input type="checkbox"/> 5	Between \$70,000 and \$100,000	<input type="checkbox"/> 10	Don't know

Section E: Invitation for interview

**Thank you very much for completing this questionnaire.
We really appreciate your feedback.**

Wesley Mission will be preparing wider advocacy work following the report, and will be talking with their clients who are willing to share their story. This conversation will take place separately from the feedback you provided in this questionnaire. Your response to the questionnaire will still remain anonymous. If you are interested in taking part in an interview, please fill in your contact details below, and we may contact you in early 2014 to speak with you about your experiences.

E1. Are you interested in taking part in an interview?

Please tick one box

<input type="checkbox"/> 1	Yes
<input type="checkbox"/> 2	No

E2. If you are interested, please enter your details below:

Name:

Daytime phone number:

Email:

Appendix D

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How we assist

Wesley Disability Services

Wesley Disability Services offers those living with disability access to a wide range of support, ensuring that they and their families have the best opportunity possible to live full and productive lives. Our services include programs to develop life skills, social and integration support, employment services, community and in-home support as well as respite for families and carers.

Wesley Disability Accommodation

Wesley Mission offers supported accommodation for those living with disability. This affords our clients the chance to experience the self-esteem that goes with independent living and decision making, while still enjoying any extra support they might need.

Wesley Disability Respite

Wesley Disability Respite aims to assist in the maintenance of the relationship between the family and the person with disability through the provision of regular away-from-home care. Our respite centres provide pre-planned and emergency respite care for people with disability.

Wesley Community Living

Wesley Community Living supports people to live independently in their own homes, and to have an active role in the community. The service also assists people to gain the skills to transition to independent living. People with a mild to moderate intellectual disability who are living in their home or wish to transition to their own home are able to apply to join the program.

Wesley LifeSkills

Wesley LifeSkills is a well-established program offering a range of activities designed to assist young people with varying support needs. The program offers them opportunities to learn, grow and socialise.

Wesley Supported Employment

Wesley Supported Employment provides employment and training opportunities for people with disability. We are committed to providing opportunities for people so they can enjoy the satisfaction, independence and sense of purpose that comes from being employed.

We provide employment in the area of gardening, cleaning, packaging and product modifications.

Get involved

Donate

Wesley Mission operates 365 days a year and, in order to continue our work, we rely heavily on donations from people like you. For more information, or to make a donation, call 1800 021 821 or go online wesleymission.org.au/donate.

Volunteer

As an organisation that reaches out into almost every section of the community, Wesley Mission always has opportunities for people to volunteer. To talk to us about volunteering, call (02) 9857 2521 today.

Leave a gift in your Will

A bequest to Wesley Mission in your Will provides a lasting legacy that makes a real difference. For more information about leaving a bequest, please contact us on 1800 021 821.

Corporate partnerships

Wesley Mission is always keen to partner with corporations who share our desire to do good in the community. Call 1800 021 821 today to talk about how you can get involved with Wesley Mission.

Share

Engage with us online to keep up to date with our news, campaigns and media. You can also share our online updates with your friends and family.



facebook.com/wesleymission



youtube.com/wesleymissionsydney



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linkedin.com/company/wesley-mission

Wesley Mission services

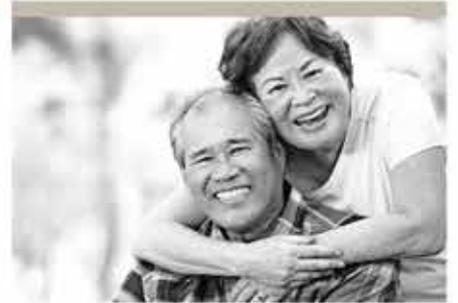
For over 200 years our commitment to our Christian faith has guided us to create long-term holistic solutions that address the needs of the whole person, not just their current challenges.



Wesley Child & Family



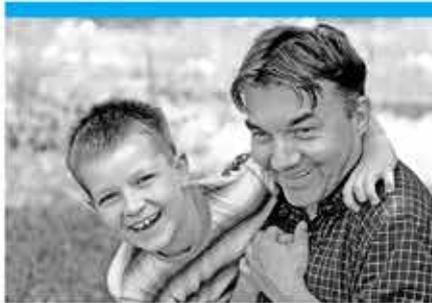
Wesley Youth



Wesley Seniors



Wesley Congregational Life



Wesley Foster Care Services



Wesley Disability Services



Wesley Homeless Services



Wesley Counselling Services



Wesley Mental Health Services



Wesley Carer Services



Wesley Help at Home Services



Wesley Employment, Training & Conferences



Get involved

To volunteer, donate, leave a bequest or for a downloadable PDF copy of this report visit wesleymission.org.au

Wesley Mission
220 Pitt Street, Sydney NSW 2000
PO Box A5555, Sydney South NSW 1235
(02) 9263 5555
wesleymission@wesleymission.org.au
wesleymission.org.au

Superintendent/CEO: Rev Dr Keith V Garner

Wesley Mission is a part of the Uniting Church in Australia.

Do all the good you can because every life matters