



CARERS QUEENSLAND INC.

QUALITY OF LIFE AUDIT 2016

September 2016

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FOREWORD

In Queensland today 484,400 people will provide unpaid care and support to a family member or friend with a disability, mental health problem, terminal illness, chronic medical condition or frailty.

All of us will have our lives touched by caring - 1 in 11 of us will be carers at some point in our life and many of us will need care and support in our lifetime. Caring is a part of life.

Although thousands of people, including young carers, care for someone close to them, many do not see this as 'caring' but as just a part of being a husband or wife, partner, parent, child, sibling, extended family member or friend. Looking after someone is 'just something we do'. But caring can have a huge and long term impact on a person's life.

Whilst caring can be rewarding and bring about life affirming experiences, without the right support it can have significant negative effect on a carer's health, wellbeing, relationships, employment and social and financial inclusion. What all carers have in common is the need for support and understanding from their community and their governments.

For those carers who have very significant or stressful caring responsibilities, to have to battle with a community that does not understand disability or illness or caring can push them to exhaustion and potentially breaking point.

This is Carers Queensland's annual Quality of Life Audit, which gauges the health, wellbeing and social and financial inclusion of carers in Queensland. Because the nature of caring has remained the same, unfortunately over the last six years, many of the issues for carers have remained the same. Lack of suitable respite options, financial hardship, limited access to flexible education & training, access to timely information targeted to their specific circumstances, inflexible working conditions, fear of what happens to the person they care for in the future when they can no longer continue to provide care, loss of identity when their caring role finishes, and just plain exhaustion trying to manage the day to day needs of the person they love.

Carers Queensland remains committed to providing services to carers and advocacy to all levels of government for policy changes, system improvements, and funded programs that will improve the quality of life for all carers throughout Queensland.



Jim Toohey,
President,
Carers Queensland Board of Governance.



Debra Cottrell,
Chief Executive Officer,
Carers Queensland Inc.

INTRODUCTION

About Carers and Wellbeing

Measuring quality of life directs attention to the positive aspects of people's lives and extends traditional objective measures of health, wealth and social functioning to include subjective perceptions of wellbeing.

Studying wellbeing in a systematic and scientific way enables social scientists to identify the wellbeing of different population groups and the extent to which different factors influence how people feel about their quality of life. It also enables social scientists to identify those groups in the population, such as carers, who have lower quality of life and in turn how best to assist people with lower wellbeing.

The Australian Centre on Quality of Life distinguishes two broad categories of wellbeing – subjective and objective wellbeing.

Subjective wellbeing considers an individual's satisfaction with their own life and can be broken down into emotional wellbeing – that is the emotional quality of a person's everyday experience, and life evaluation – the thoughts people have about their life. Subjective wellbeing is normally a positive state of mind. It is a long-lasting deep sense of contentment, as opposed to the momentary burst of joy we experience when we laugh at a joke. Happiness is more often used to refer to subjective wellbeing.

Objective wellbeing is concerned with the material conditions that affect a person's life such as access to education and employment opportunities.

Subjective wellbeing homeostasis

Research conducted by the Australian Centre on Quality of Life suggests that we are born with a baseline level of happiness or grumpiness and whilst life events cause our baseline level to fluctuate, it is generally only a little. In a very similar manner to the maintenance of our body temperature we are generally able to self-regulate our wellbeing. Our in-built brain mechanisms allow our feelings of wellbeing to fluctuate a little, but the homeostasis does its best to maintain such feelings relatively steady over time.

We maintain this baseline level of happiness or subjective wellbeing homeostasis by drawing on a range of external and internal resources. External resources include personal relationships and money. Internal resources includes our ability to find meaning in a bad event and both enable us to cope with tough situations better. Failure of our homeostasis function on a chronic basis can result in a loss of positive wellbeing which can, for some, lead to depression.

Those at risk of lower wellbeing

Research conducted by the Australian Centre on Quality of Life in 2007 indicates that carers have the lowest wellbeing of any population group yet surveyed by the Centre. The average wellbeing score of the Australian population is between 73 and 76. The average score for carers was 58.4.

Those carers most at risk of lower wellbeing

-  sole parent carers
-  female carers
-  carers experiencing chronic pain
-  carers carrying a chronic injury or injuries
-  carers with intensive and/or prolonged caring responsibilities

Factors affecting wellbeing

Many factors influence wellbeing including stress, chronic pain, not receiving treatment for a significant medical or psychological condition, where you live, housing tenure, housing security, income, employment, and the presence or absence of a life partner.

The provision of personal resources such as money or relationships can strengthen defences against negative experiences. Moreover, for someone who is experiencing homeostatic defeat, the provision of additional resources may allow them to regain control and restore their wellbeing.

The things we can do to look after our wellbeing

1. Connect with family and friends – spending time with people we care about makes us happier and healthier, they have the strongest influence on our happiness.
2. Save for a rainy day – having money you can access counts when things go wrong.
3. Get involved in community – being involved with the local community is a great way to feel connected; it enhances our sense of belonging and security.
4. Engage in activities that give you a sense of achievement – we get a sense of achievement and drive when we do something good or useful.
5. Find a balance - between work, care responsibilities and leisure – this balance is different for each person.
6. Keep healthy – staying healthy is all about balance.

METHODOLOGY

Carers Queensland Liveability Audit

The Carers Queensland Quality of Life Audit was introduced in 2011 as a means to promote the importance of liveability in the development of effective national, state and organisational policies and planning processes relevant to carers and the people they care for and support. Now in its sixth year, the survey acts as a barometer, measuring and reflecting the changing mood of Queensland's carers as they adapt to significant changes in the disability, mental health and aged care sectors and in social welfare policy.

Methodology

The 2011 Liveability Audit formed the benchmark estimate of the quality of life of carers in Queensland. The 2011 audit was issued as both a paper survey through the regional offices and electronically through the Carers Queensland website and generated 575 responses; representing 0.1% of the 494,200 known carers in Queensland.

The 2012 Audit replicated the 2011 audit with only some very minor changes or additions to the 'personal demographic' questions and was launched on 1 September 2012, resulting in 480 responses.

The 2013 Audit was launched on 1 August via email to 3814 carers known to Carers Queensland and promoted through Carers Queensland's social media sites resulting in 485 responses. In 2013 we introduced a new component to the survey; six questions relating to a specific issue impacting carers. The 2013 questions related to carers experiences of being 'prepared to care'.

Launched on 1 August 2014 the survey was emailed to the 3105 carers known to Carers Queensland and posted on our social media platforms. In 2014 we introduced a new quality of life question; *in the next year do you expect your Quality of Life to: get better... worsen... stay the same.* 436 respondents completed the quality of life questions.

In 2015 the survey was distributed to 3105 carers known to Carers Queensland, promoted via our social media platforms and paper copies of the survey were provided to the regional offices for carers not internet connected. 571 respondents completed the quality of life questions. This year the six thematic questions broached the very challenging subject of abuse and violence in the caring relationship.

This year the survey was emailed to 5000 carers and posted on our social media platforms. This year the thematic questions captured the extraordinary number of hours carers provide in supporting family and friends. 702 people opened the survey and 481 respondents completed the quality of life questions.

PART 1 PERSONAL DEMOGRAPHICS

1.1 Respondent demographics

The 2016 responses closely reflected the 2015 survey responses across the personal demographic domains.

Of the respondents:

- ✚ 46% live in the Brisbane, Ipswich and Gold areas; 46% regional Queensland; 6% rural and 2% in remote Queensland
- ✚ 97% speak English as their first language
- ✚ 1.5% identify as Aboriginal and Torres Strait Islander
- ✚ 91% are the primary carer
- ✚ 89% are a current carer
- ✚ 86% are female
- ✚ 70% are married or in a committed relationship and 12% are single
- ✚ 2% are young or young adult carers

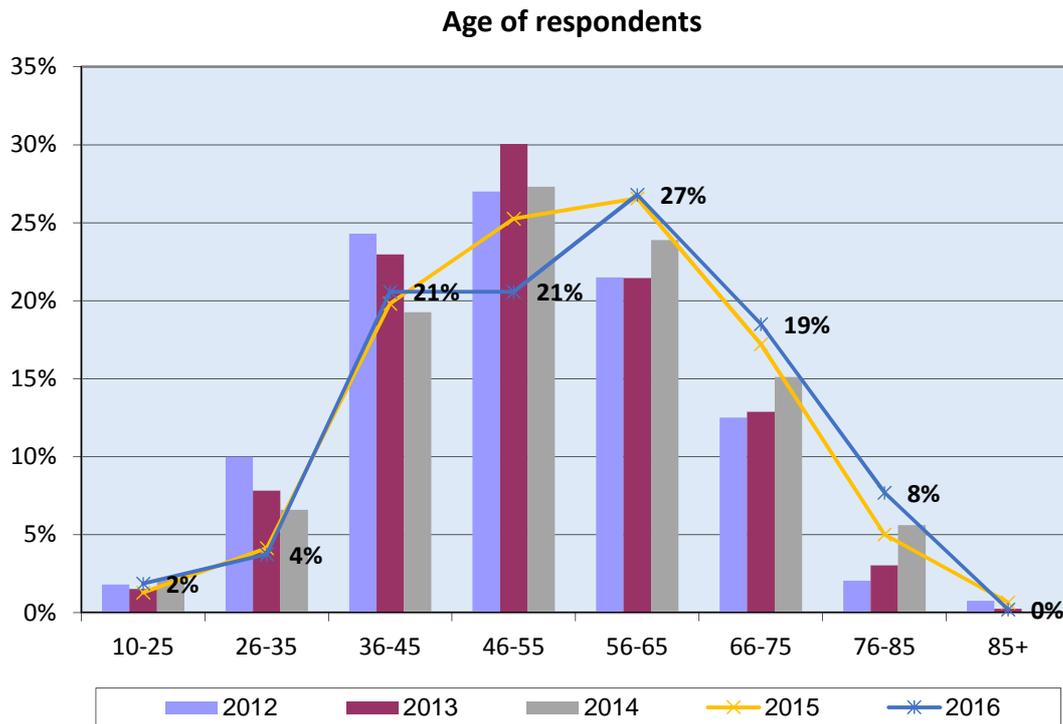
The age and gender profile of the audit respondents closely reflects the national profile; that is more men than women assume the caring role in the older age ranges. The 2011 ABS Census data suggests that the higher number of older male carers may be because life expectancy is shorter for men and because men are often older than their wives. Hence, older men who survive in older ages are more likely to be living with a spouse and will have assumed a caring role.

Data indicates that in the 'carer population' people who are married or in a committed relationship are overrepresented against the general population. This reflects the most common carer situation; that is where one spouse provides care and support to the other spouse.

Australia has an ageing population. Modelling suggests that by 2050 approximately 22.6% of the population will be 65 years and older. By 2050 the number of people 65 to 84 years is expected to more than double; and the very old (85 years and over) is expected to quadruple to 1.8 million. The increase in the older population will be accompanied by a rise in chronic diseases including dementia. In real terms this means that a higher percentage of the population will require more assistance and care.

The number of survey respondents aged 66 years and over rose by 5% in 2016

GRAPH 1



In the next ten years the demand for informal care will outstrip supply as the rate of people with severe and profound disability grows at a faster rate than the supply of family and friend carers. Although the carer ratio is falling there will be a rise in sandwich carers – that is people who care for more than one person across two or more generations.

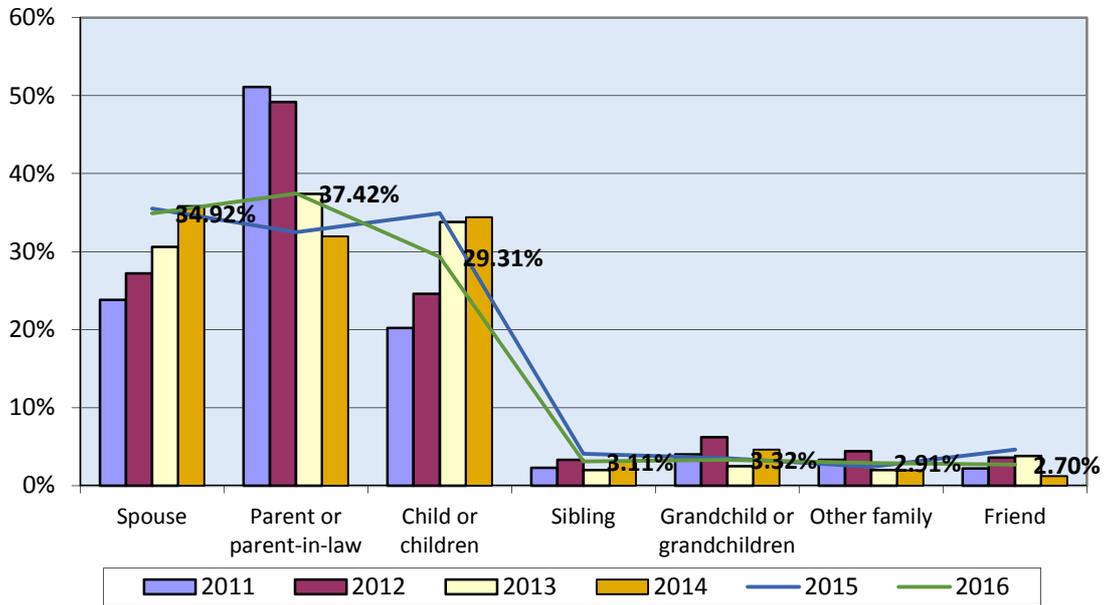
The 481 quality of life survey respondents care for and support 547 individuals and 3.3% are grandparent carers

Data from the Survey of Disability, Ageing and Carers 2012 suggests that:

- the need for assistance with cognitive and emotional tasks is four times greater for people aged 85 and over (28%) than those aged 65–84 (7%)
- over half (59%) of people aged 85 years and over reported a need for assistance with health-care compared with one-fifth (20%) of people aged 65–84
- a higher proportion of women aged 85 and over (69%) reported the need for assistance with personal activities than men in the same age group (56%).

GRAPH 2

Relationship to the person you care for



59% provide 12 or more hours per day

22% of survey respondents provide 6 to 12 hours of care per day

PART 2 QUALITY OF LIFE INDICATORS

2.1 Quality of Life

Australian Centre on Quality of Life research suggests that whilst most people don't live to work being employed is pivotal to how many people live; and that those people who want to work and who are unemployed incur lower self-esteem and happiness.

Carers generally experience lower than average rates for employment. In 2012, 38.4% of primary carers in Australia were employed compared to the population average of 64%. Primary carers experience higher rates of part-time employment than their average counterparts and a lower income level.

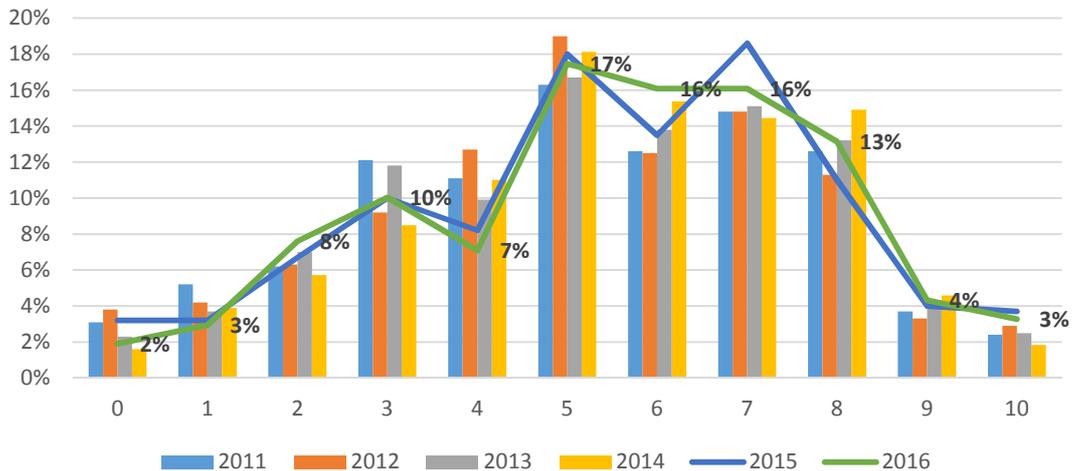
This year's data mirrors the 2015 data:

- 58% of survey respondents indicated that they were satisfied and 18% were neither satisfied or dissatisfied with their quality of life
- 58% of survey respondents expected their quality of life to stay the same

24% of carers said they were dissatisfied with their quality of life and expect their quality of life to deteriorate over the next year

GRAPH 3

How do you rate your quality of life?





Total change to my life in last 18 months; inadequate support to make these adjustments and gross lack of respite facilities in my area. I am totally exhausted, have no quality of life and almost no time to myself. Impossible to get a rest.

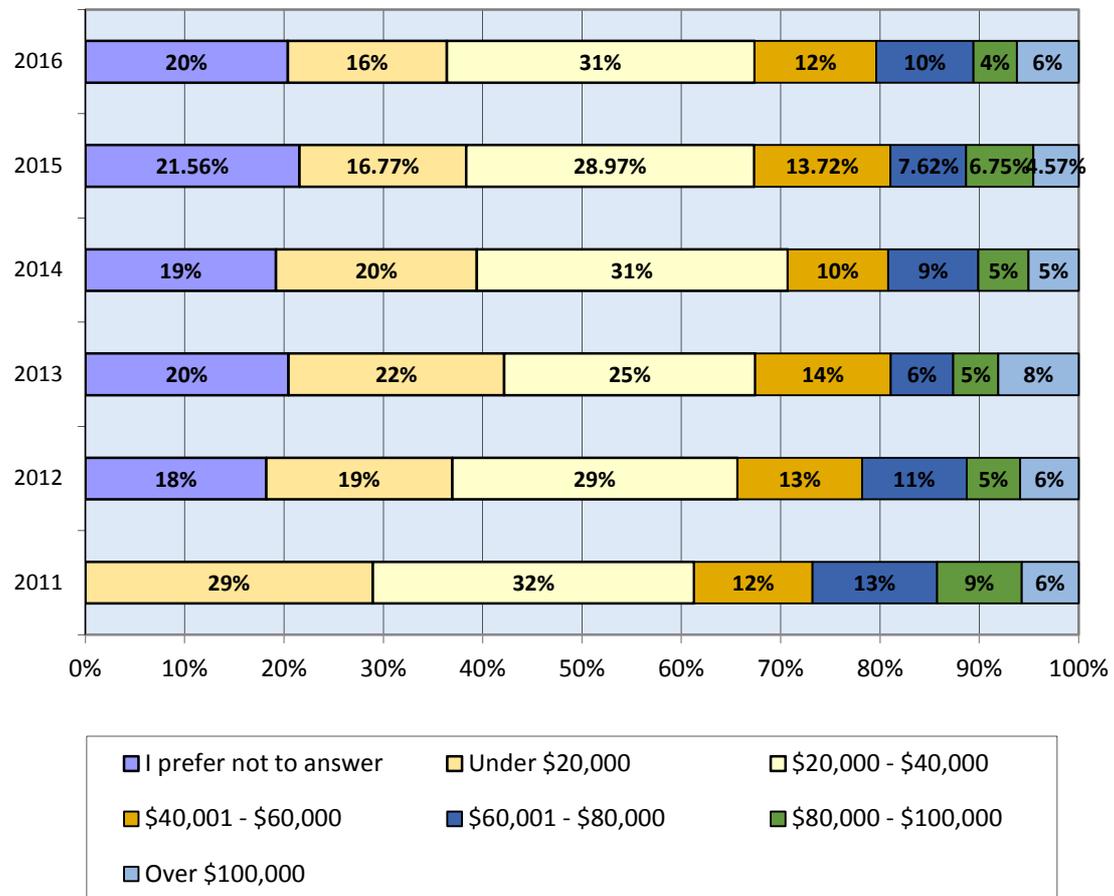
I wake up each morning sick in the stomach with fear about my ability to maintain my current standard of living. That means - financially because I am a self-funded superannuant; my ability to meet my partner's needs; my lack of community and family support; and the disregard with which seniors in Australian society are held.

2.2 Income, housing and cost of living affordability

An analysis of the Australian Unity Wellbeing Index over seven years reveals that whilst the wellbeing of men is highly linked to earning money, the wellbeing of women is highly linked to the capacity to manage it. Further, the research indicates that carers are almost twice as likely as normal to worry that their income will not be sufficient to meet their expenses, the result of which is a lower wellbeing.

GRAPH 4

Household income



47% of respondents manage on less than \$40,000 income per year

Australian research shows that at the aggregate level, carers have a higher rate of poverty on all measures. Carers who have been caring for two years or more have higher poverty rates than non-carers and are more likely to be living in persistent poverty. This is particularly so for co-resident and primary carers. Many carers pool household resources in order to cope.

Analysis by the Queensland Council of Social Services shows that low income households are the most affected by the rising cost of essential goods and services and are most at risk of falling into a cycle of poverty and disadvantages as a result of cost of living pressures.

Focussing on aged pensioners the analysis demonstrated that housing and utility costs continue to have a significant impact on the capacity of an individual in receipt of the aged pension to afford a basic standard of living:

- a. Rising housing costs is the single biggest financial burden; especially for those who rent in the private market
- b. Single and couple household renting privately are most likely to experience housing stress (with almost 50% of the gross income being spent on housing costs)

Whilst the Queensland Council of Social Service analysis focusses on aged pensioners the scenario is similar if not worse for carers in receipt of other types of income support. As many survey respondents attest, living on income support or a substantially reduced income, involves living week to week with little or no room to accommodate an increase in utility costs or an emergency after the essentials are paid for.

The constant stress associated with a lack of money to pay for necessary goods and services is known to contribute to health problems and stress on family relationships.

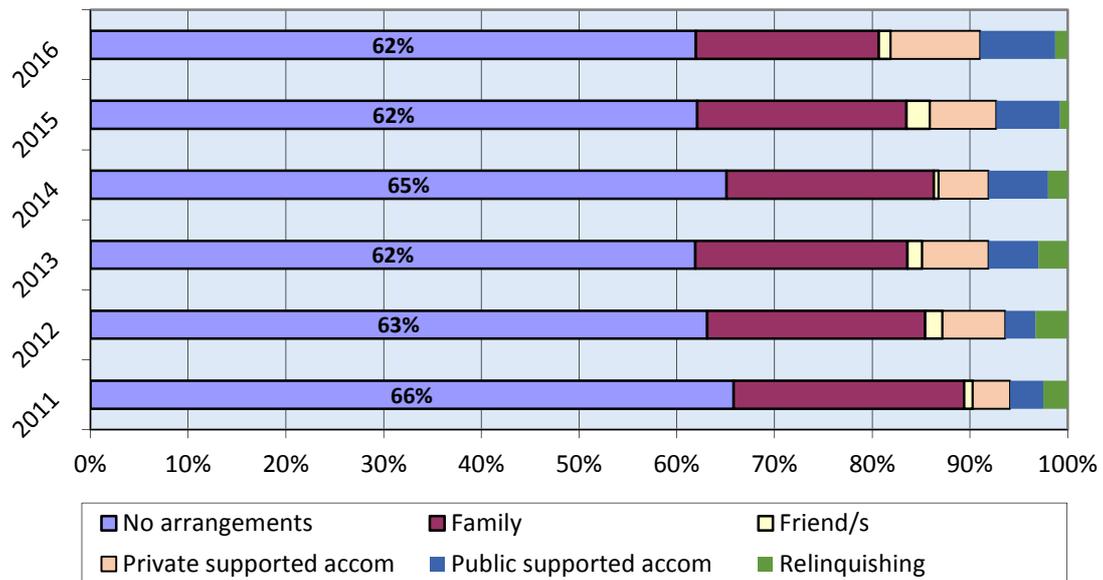
15% of respondents are dissatisfied with their standard of living.

39% of respondents, an increase of 4% from 2015, are dissatisfied with their ability to pay for housing and utilities.

Carers' satisfaction with their life and future security is very closely related to the security of their income and their home, their current sense of safety, satisfaction with their personal relationships and friendships and their ability to direct and/or control the long term care options for the person they care for and support.

GRAPH 5

Long term care arrangements



In the words of one carer:

The NDIS brings with it more questions than answers. The focus is on the disabled client not the parent/carer. Even in the workshops and information sessions there is little, if no, reference to those supporting and caring for those with disabilities. Very few of us know where we may stand into the future. The NDIS brings with it much apprehension and some sense of fear.

And another carer:

The NDIS, lack of services for person being cared for and high demand on those services that are available including limited respite mean that my future is unclear and a source of worry.



I accept my life, but I'm not satisfied, in comparison with other people I know. I find it difficult to contemplate a proper job, I tend to only have online friends because they are easier to fit in, I can't really take holidays or breaks, I am on call all the time, constantly vigilant.

Currently it's more stressful than usual, as my husband is without employment. He was made redundant 3 months ago, so life, appointments and activities, and general day to day responsibilities, are made just that little bit harder to handle, with the pressure of limited income.

My husband works very long hours to support us, but he earns too much for public housing despite having a special needs grandson for whom we are the full time carers. My husband cannot maintain these hours for ever and when he can't we will not be able to afford to privately rent... and the wait list for public housing is so long we will be in the streets before we get a house...

Renting is very unstable and unsettling especially with a child on the spectrum. I'll barely scrape by with bills and food, living in a one bedroom home. Other than food there is nothing left to clothe or care for myself (for example - no haircut for over a year, threadbare clothing).

2.3 Quality of air, land and water

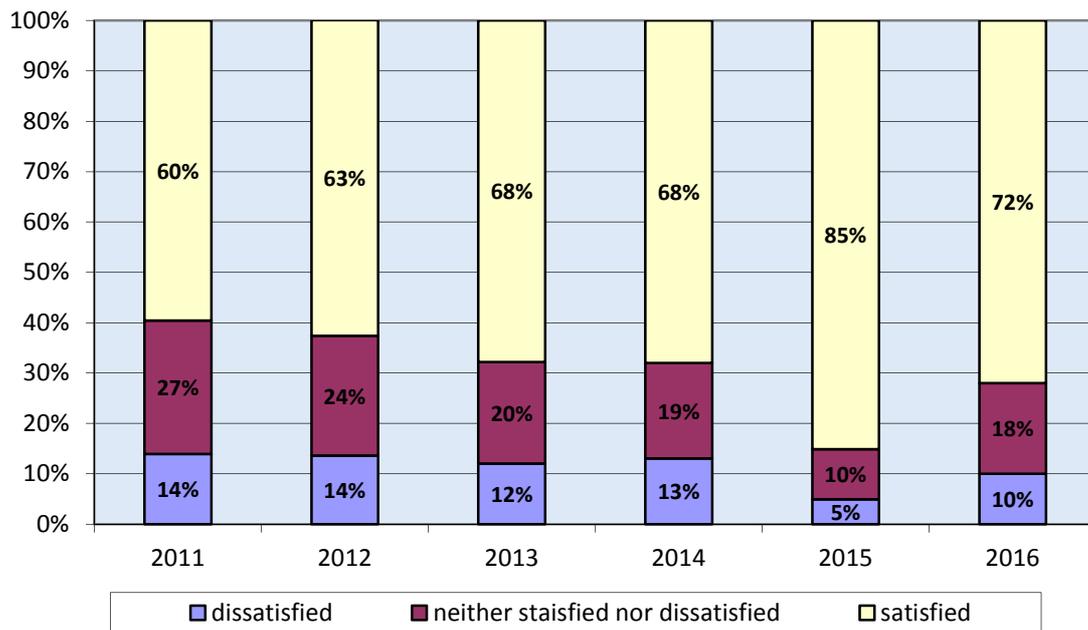
Whilst 86% of respondents were satisfied with the quality of air, land and water in their locality 14% spoke of their dissatisfaction with significant environmental issues affecting their health and wellbeing.

In the words of one carer:

Coal trains pass every 7 minutes and we know we're breathing black coal dust because of the dust on our furniture. There's colony of 3000 bats across the road - and we're drinking water out of our tanks. We're flooded every 3 years & we lose a lot of belongs each time.

GRAPH 6

Amenity, sense of place and social characteristics of your locality



2.4 Fairness, equity and equal opportunity

Although 63% of respondents are satisfied with the culture of equity, fairness and equal opportunity in their community or our society there is still many carers who feel dissatisfied at not being able to access services, take advantage of opportunities or be heard by those with the legislative capacity to make positive changes for carers.

35% of respondents in 2016 were dissatisfied with their ability to access educational and learning opportunities. A rise of 2% over 2015.

As with juggling work with care, juggling work with education can be just as problematic and stressful. Respondents of working age continue to express frustration at not being able to pursue educational and learning opportunities, either because of time restrictions, training costs, or lack of formal support services such as respite care and many feel trapped in poverty.

Carers in Queensland, particularly those in rural and remote Queensland, face the added burden of geographical distance, making any opportunity to access education more difficult.



People with a disability appear to be less valued in the community. There is still a stigma and lack of understanding of the wider community about ASD.

There is a lot of discrimination towards single carers who are trying to obtain part time work.

I want to improve our circumstances but continue to be judged and excluded from the private work force because of the unpredictable nature of the caring role for my children.

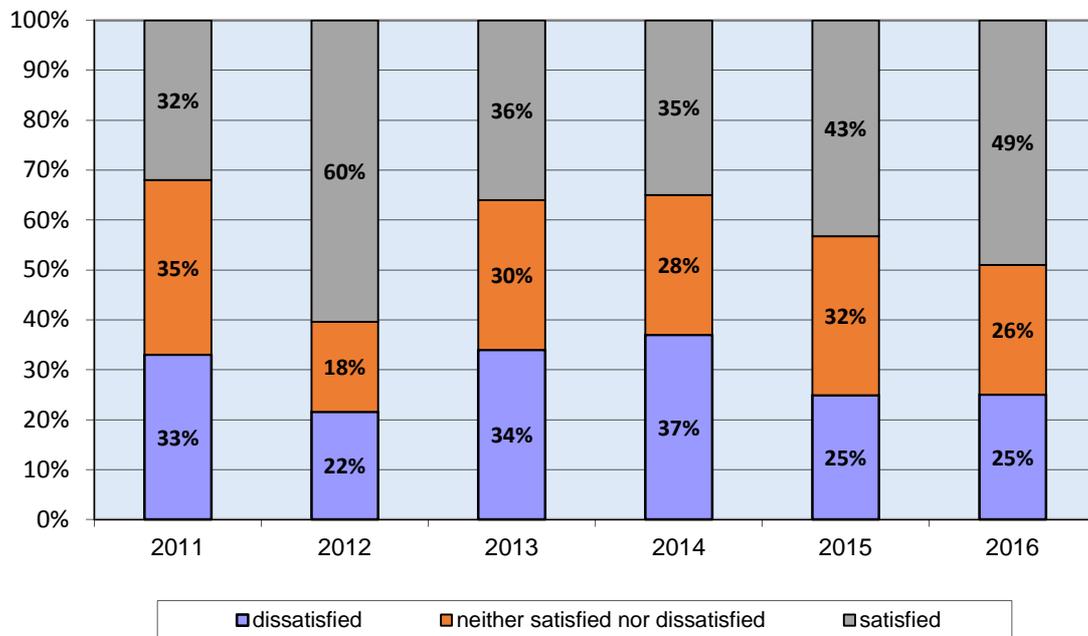
I struggle to find time for education/learning - becomes very stressful to fit training and education into our timetable at home. The expense of training is too prohibitive most of the time.

Australian Centre on Quality of Life research reveals that our satisfaction with elected leaders fluctuates in response to external situations. Our satisfaction rises during times of national threat and diminishes when there is political instability.

Many respondents consider that their elected and non-elected leaders fail to act on their concerns and issues from one election to the next. Understandably, some respondents feel threatened by the proposed changes to Australia’s social welfare policies or overwhelmed by the speed and complexity of change in the disability, aged care and mental health sectors driven by government reform.

GRAPH 7

Quality of elected and non-elected leaders



Politicians are good people however [they] have no idea what life is like for a carer or person with disabilities.

Better since the Labour Government came into Queensland.

2.5 Health and wellbeing

It can be extremely difficult for carers to find the money, time or the energy to look after their own health, such as preparing healthy meals, exercising, getting enough quality sleep or seeking medical attention. In the short term, the consequences of such actions is limited but over the longer term carers who fail to address their own health needs will have poorer health and wellbeing.

Although 60% of respondents indicated they were satisfied with their health, 40% were either dissatisfied or ambivalent about their health status.

Generally speaking, our satisfaction with our health decreases as we get older until we are about 55 years of age when subjective wellbeing increases for most people, with the exception of those who live with chronic and severe pain. Those living with chronic and severe pain, such as some carers, are at risk of homeostatic defeat and their wellbeing will be negatively affected.

The 2016 Quality of Life data, like data from previous years, indicates that many survey respondents place the health care needs of the person they care for and support before their own; often at the expense of their own health and wellbeing.

In the words of two carers:

I usually put myself last and am completely run down before I get myself medical help

Being a carer I have higher priorities than taking care of my own issues...

Carers who live in rural and remote Queensland continued to identify a 'double whammy' – long delays for an appointment to see a health professional and expensive travel costs. Many respondents spoke of 'treatment burden' – that is trying to coordinate appointments with multiple health and allied health practitioners and/or complying with multiple treatment regimes, often at different places and requiring extra travel and parking costs.

In the words of two carers:

Too hard to get in to see a doctor and I live a minimum of a 45 minute drive to the nearest hospital and most specialists are an hour and a half drive away.

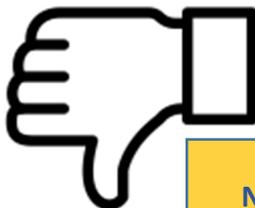
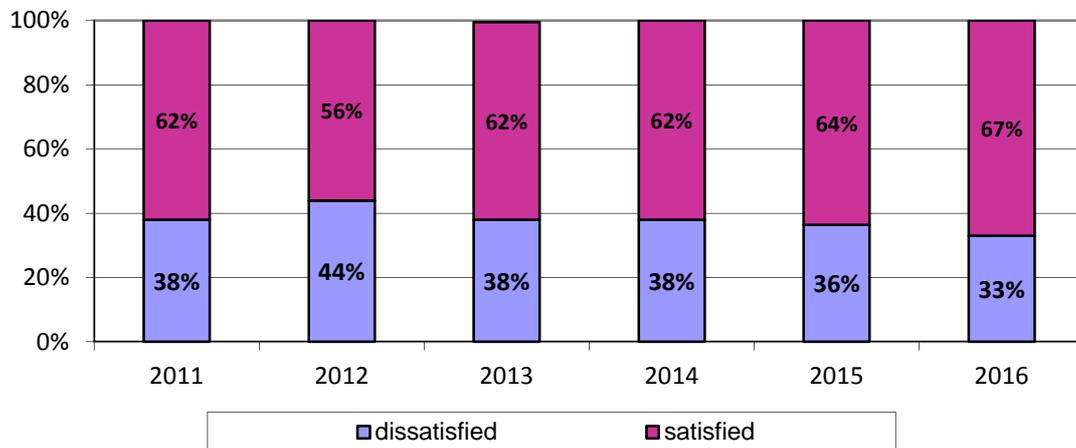
Living in a remote community you have little to choose from.

The recent changes to Medicare concessions, the introduction of new charges for some prescriptions and diagnostic services has negatively impacted carers to access and afford health care.

Australian Bureau of Statistics data shows that 10% of Queensland’s delay or do not buy prescribed medications because of the cost and those who are most likely to delay or not fill a prescription are those who need it most. This behaviour is linked to an increase in available hospital admissions.

GRAPH 8

Capacity to prevent health and wellness problems and access to health services



Never enough money to pay for all the services my son needs, find myself not eating just to pay the bills

Good nutrition is costly. Medications sometimes costly. Medical insurance out of our league. Podiatrists and dieticians costly and it seems access to test strips etc. for diabetes may become restricted. It isn't always possible to get doctor's appointment when needed. Hospital doesn't welcome you if not emergency.

Living in regional Queensland our access to healthcare is abysmal. Often those services that do exist do not take into account my caring role.

2.6 Personal relationships and community

Those carers who feel that their community understands and values them are much more likely to be able to maintain or balance the other aspects of their life. Those carers who are not supported by their communities are more likely to never or rarely be able to balance the non-caring aspects of their lives.

Research from the Australian Centre on Quality of Life indicates that more than 30% of people in Australia are lonely. Many of the comments of survey respondents highlight the isolating impact of societal attitudes towards disability and dependency, resulting in loneliness for the carer. Research from the United Kingdom has shown that how a carer is judged is based on an individual's perception or interpretation of the disability or illness of the care recipient.

21% of respondents feel dissatisfied with their sense of belonging in their local community

27% of respondents are dissatisfied with their personal relationships and 24% are dissatisfied with their ability to connect with carers, family and friends.

A carer's satisfaction with feeling a part of the local community is very closely related to their satisfaction with their personal relationships, the culture of equity, fairness and equal opportunity and the amenity, sense of place and social characteristics of their environment.

An individual's perception of their safety, and conversely their vulnerability, is a subjective assessment of their circumstances and is relative to a specific point in time. It relates to a number of variables, some of which are beyond the control of an individual. As noted in the anecdotal comments of respondents, many feel vulnerable in relation to long term care options, housing, physical and emotional safety and financial security.

20% of respondents are dissatisfied with their sense of safety



Not valued by my community in the role of carer.

I feel like I'm so isolated and bound to the care of my mother's disease (now it its late stage). I feel like I too have a death sentence on my life and am dying with her.

I care for two people, one of whom does not live here full time. There is no money for anything extra. Carers are underfunded. I feel lonely, depressed and anxious, however I keep smiling for the people I care for, because I never want them to feel they are a burden.

I have felt isolated as a carer which has contributed to us not coping as a family.

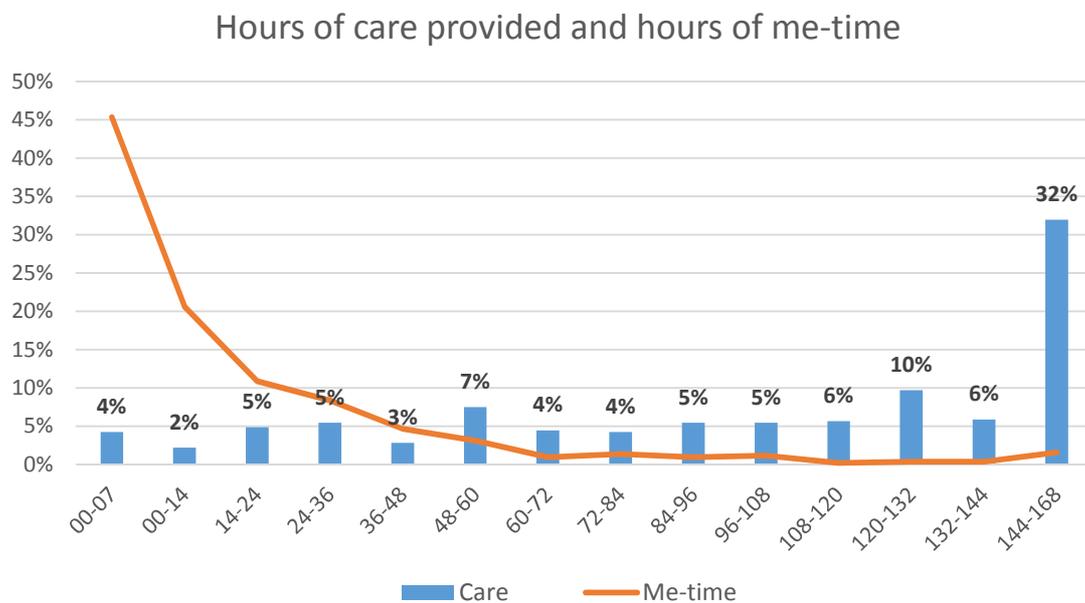
PART 3 THE CONTRIBUTION OF CARERS TO THE CARE ECONOMY

3.1 Carers contribution to the health and community care economy

There is no doubting it – carers are unsung heroes in our community and the pillars of our health and community care sectors. Allen Consulting Group estimate that carers provide 74% of all the care and support provided in Australia, supplementing the stretched resources of our funded services.

The contribution of carers to the humanity of our communities is invaluable. In this year’s survey we asked carers to identify how many hours of care and support they provided and hours of me-time available to them in the last 7 days.

GRAPH 9



The survey respondents provided 54,013 hours of care and support in the 7 days prior to completing the survey.

83% of respondents provide more than 36 hours of care and support per week or the equivalent to or more than a full time job.

45% of respondents have less than 7 hours of 'me-time' per week.

3.2 Working carers

The responses to the survey clearly replicate the national data; that is many carers who work experience difficulty balancing their employment obligations with their caring responsibilities.

Without support in the workplace or from the formal sector (for example respite care), many carers find it difficult to juggle both roles.

Research from Carers UK identifies three primary barriers to balancing work and care:

1. Some carers are reluctant or uncomfortable to disclose or talk about their caring role at work
2. Employer doesn't understand the demand and unpredictable nature or complexity of the caring role and relationship.
3. Employer doesn't have policies in place to adequately and appropriately support staff with caring responsibilities.

The results of our survey closely replicate the finding of research undertaken by Carers UK. Of those respondents who work, 83% had told their employer of the caring responsibilities and in the vast majority of cases the employer had made some provision to support the carers including:

-  41% flexible working hours and broken working patterns
-  7% paid time off work
-  6% reduced hours
-  6% unpaid time off work
-  7% working from home

Those who did not disclose their caring responsibilities in the workplace withheld the information because of fear of being discriminated against or losing the job. Those who do not disclose in the workplace or believe that the workplace does not understand their circumstances experience, more stress about being able to care than the person supported well.

Many of the respondents in work had encountered discrimination in the workplace including:

-  given less demanding projects to work on
-  kept on casual hours when permanent hours are available
-  passed over for promotion
-  team meetings and team development being held on days when the carer is not at work

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