

Warwick & District Disability Needs Analysis

Final Report



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Executive summary

Introduction

The University of Queensland was commissioned by the Warwick and District Disability Support Group Incorporated to conduct a needs analysis for people with a disability and their Carers in the Warwick District. The output is this report and the Warwick and District Disability Resources Directory.

Methods and Sample

A survey of Carers and people with a disability was conducted, with 56 Carers and 26 people with a disability providing data. Eight Carers, two people with a disability and four Key informants were interviewed.

Results

Carers

The profile of 56 Carers who completed the survey questionnaire shows that approximately three-quarters are parents, a similar proportion care for one person with a disability, more than two-thirds of those they care for require assistance from a Care giver and approximately the same proportion have more than one disability. On average these Carers are 55 years of age, but almost a third are 60 years or over. More than three-quarters of these Carers are female. On average these people have been Carers for 22 years, with just more than half being sole Carers. Three-quarters of this sample report receiving financial assistance from government for caring for a person with a disability, and for almost one-half, CentreLink is their primary source of income.

The eight Carers who were interviewed were selected to represent diversity in terms of location, age, age of the person they cared for, and the type of and number of disabilities this person had.

The interviews revealed that the main everyday challenge for Carers is that caring is 24/7 – it is continuous, whether it be because the person being cared for has high needs or because constant supervision is required. In addition there are difficult behaviours to contend with, and these in addition to the relentless nature of being a Carer require patience. The physical demands through lifting and providing personal care are taxing. The role of Carer is unpredictable because it is dependent on how the person with the disability is managing on a day-by-day basis, but also because service delivery can be erratic. The outcome of these everyday challenges for Carers are fatigue and mental stress, and the lack of a social life.

What these Carers said keeps them going when life is very difficult, is simply that there is no one else – they have no choice, but to continue. That most interviewees kept on caring for the person with the disability because there was no one else to provide the care is telling. While support from family and friends and their interests help Carers, their key driver is that they feel responsible for the person, and despite the everyday challenges, keep on with this demanding caring role.

The 'costs' of caring are significant. While the emotional costs are deep, it is the social limits that serve as constant reminders of simple pleasures these Carers may never have. The financial costs range from struggling to purchase basic requirements such as food, to the provision of accommodation for long term care.

Remarkably Carers did not report using any services directly for themselves. Instead the few who commented here indicated that either they were not aware of any or they 'muddled' through with help from friends or on their own. Carers who completed the questionnaire reported higher levels of psychological stress than in the general population.

Person with a disability

A profile

The people with a disability who completed the survey questionnaire provide a valuable contrast to the group reported on by Carers. The 26 people with a disability who responded to the survey are on average 53 years, while the 70 reported on by Carers are on average 31 years, so the people with a disability who completed the questionnaire themselves, on average are older. They are all adults with the youngest being 23 years, with the majority between 40 and 60 years. By contrast in the group reported on by Carers, the youngest is 1 year old with almost a quarter being children. The differences in age suggest that the disability self-report sample represents a more independent group of people than the group reported on by Carers (even though there is a degree of overlap) who are at a different stage in life.

There is a difference in the sex breakdown between these groups, with almost two-thirds of those reported on by Carers being male while two-thirds of the disability self-report sample is female. The final demographic that distinguishes between the two groups is the relationship with the Carer. While in the Carer sample it is predominantly a parent who is the Carer, by contrast in the disability self-report sample, there is diversity in the type of Carer – spouse, unspecified relative, Endeavour and paid Carer. In particular, almost one-quarter of Carers of those in the disability self-report sample are spouses, while in the Carer sample, only 12% are spousal carers.

Number of and types of disability

When the types of and numbers of disabilities are compared between these two groups, there are more similarities than differences. For both of the disability samples, the most frequently reported Primary disability is intellectual. For the sample reported on by Carers almost half have this as their Primary disability, and for the disability self-report sample it was more than one-third. While the 2nd and 3rd most common Primary disability reported by the Carers is Autism and ABI, by contrast, in the disability self-report sample, the 2nd and 3rd are Physical and Neurological respectively. However when the five most frequently reported Primary disabilities are compared for the two samples, four are common to each: Intellectual; Physical; Neurological; and ABI.

The self-report disability sample has a smaller number of non-primary disabilities (8) when compared to the Carer response sample (11). Consistent with the Primary disability results, while the rank order of the most frequently reported non-primary disabilities varies between the two disability samples, four of the five most frequently reported disabilities are the same for both samples: Speech; Physical; Intellectual; and Vision.

How time spent

Detail about how time is spent provides further insight into the disability samples. In both samples approximately half occupy most of their time at home. In the Carer sample, almost one-fifth attend school, while none in the disability self-report sample do (because of their age). In the Carer sample only 10% percent are employed however in the disability self-report sample, more than a quarter are employed.

Financial circumstances

The financial circumstances of the two disability groups are similar for both groups – the primary source of income support for the majority is from CentreLink, and one-half to two-thirds receive assistance from paid services. However the funds spent on accommodation show a disparity – while approximately one-quarter of those reported on by Carers pay more than a quarter of their income on accommodation, almost half of the disability self-report group do so. This difference may be accounted for in part by many of the younger sample living at home. It implies though that the older and more independent group have limited disposable income.

The similarities and differences between the two disability samples in the level of support they require highlight key service requirements – in general the older, more independent group require a lower level of support than those reported on by Carers, which in some respects is to be expected. As the children being cared for grow older some of this group would be expected to become more independent, however those reported on by Carers who currently require a high level of care will continue to need this. Support needs are:

- More than half in both groups require support for domestic life and learning, applying knowledge and general tasks. These are fundamental requirements, so a lack of provision of support in these areas would have a significant impact.
- One-half or more in both groups require support with working and interpersonal interactions and relationships. While those employed comprise a small proportion, paid employment not only provides cash which would be important for the more independent group, but self-esteem and the opportunity to develop social networks. So support in these two areas is important for the longer term benefits that can result.
- The areas where the least amount of support required is the same for both groups: mobility, communication and self-care. A key difference in the groups is the level of self-care required by the group reported on by Carers who require more support. However because of the fundamental nature of such care, without it, the challenges would no doubt be insurmountable. Similarly with mobility – without this the person with the disability would be just unable to conduct their everyday life. Similar percentages in both groups require support with communication. While Carers become adept at communicating with the person they care for, without the ability to communicate effectively on their own, people with a disability may not have their needs met.
- Apart from education, the greatest difference in the needs of the two groups is with community and economic life. Approximately three-quarters of those reported on by Carers require support here, and by comparison, only one-third of the self-report disability sample does so.

These support needs demonstrate the comprehensive and intense level of care that is provided to many people with a disability, predominantly by informal Carers.

Services and service gaps

Accommodation

- In the survey, overwhelmingly, respondents indicate that a house/unit (with appropriate support) is the accommodation 'best suited' to the people with a disability in this study. Just less than half in each sample indicate this type of accommodation is 'best suited'. Why this is considered suitable by Carers is because they think it would suit the personality of the person with the disability and because that person would be safe. However for the self-report disability sample, their reasons are different: family, having pets and company – so mainly familial and social reasons. The Carers who indicate a preference for Village style accommodation chose this largely because of the social aspects of this style of accommodation, but also because of the support that would be provided.
- The majority of people with a disability in this study live privately. This suggests that many are living in the accommodation 'best suited', since this is most likely to be in a home.
- While more than three-quarters of the people with a disability reported on by Carers live with family, by contrast just 40% of the disability self-report group do so. Almost one-third of the latter group report living alone and more than one-quarter live with others.
- The average length of time the people with a disability have lived in their current accommodation is similar - for those reported on by Carers it is 18 years; for the disability self-report sample, 16 years. However while half of the group reported on by Carers have lived in the current accommodation for 20 years or longer; in the disability self-report group,

half have lived there for 10 years, and 13% for just one year. So the self-report disability sample appears to be a more mobile group.

- Almost 90% of Carers indicate that they think the current accommodation for the person with the disability is suitable and almost three-quarters of the disability self-report sample do so. The most frequently mentioned elements regarding accommodation are proximity to desired services/activities and the physical structure/layout of the house. Accommodation in close proximity to shops and health services is considered an asset as is a house that promotes ease of movement within it, with the opposites contributing to making the current accommodation less suitable. An element mentioned by both groups in relation to accommodation is the importance of learning/teaching independent living skills.
- Similar percentages of Carers and people with a disability who self-report indicate they are happy with their current accommodation – Carers 85%, and people with a disability who self-report almost 81%. These are similar percentages to those who report that the accommodation is suitable. Carers and people with a disability gave different reasons for the person with the disability being happy/unhappy with the current accommodation. Common to both groups is the importance of family and the desire for close proximity to desired locations/services. Importantly for those with a disability who self-report is mention of being contented and well supported.
- While more than three-quarters of the Carers indicate that they would like the person they care for to continue to have the opportunity to become progressively independent in their accommodation and living arrangements, just over half of the people with a disability indicated that they would like this opportunity. The Carers stressed the importance of independence even though a number indicated that this was not possible in their case. For some of the people with a disability, increased independence was a goal while others appear to have reached that goal.
- More than half of the people with a disability who self-report and more than 40% of Carers indicate that they do not foresee a need for a change in accommodation in the future. Carers think this because the person they care for seems happy and they feel they can continue providing care. However almost one-third of Carers and one-quarter of the people with a disability giving a self-report expect the accommodation needs to change within the next 5 to 10 years. Carers report this because they believe by then they will be unable to provide care, and stressed the importance of independent living. The people with a disability who self-report feel by then their health will have degenerated and this would create the need for a change.

Accommodation service gaps

- Less than 20% of Carers report that long term, high needs, 24 hour care is available to them and almost one-quarter of the self-report disability sample indicate this. The contrast is greater with long term, low level support – only 6% of Carers indicate it is available, yet almost 40% of the disability self-report group do so. This disparity may be apparent because a proportion of the self-report group may currently be residing in low support accommodation which is currently available in Warwick, but is limited. The contrasting results for the availability to the individual of independent community housing is similar, with more than one-quarter of the disability self-report group indicating it is available, yet less than 10% of the Carers reporting this.
- The results show that the greater majority of people with a disability in this study live in private accommodation, largely find it suitable and generally are happy there. The results reporting the availability of different types of accommodation suggest that the alternatives are few, and so the accommodation landscape for people with a disability in the Warwick district has significant gaps:
 - Long term, high needs, 24 hour care

- Long term, low level support
- Independent community housing

- Key informants identify service gaps in: supported accommodation for people with high care needs; and younger people with a disability with high care needs.
- In Carer interviews they report that supported high care needs accommodation is needed in the Warwick district. Independent living accommodation is also required and the ability for people to transition into different accommodation to what they have currently.

Respite – a service gap

- In the survey Carers report greater availability of both planned and emergency respite care, than the people with a disability who self-reported. This may reflect a greater knowledge due to their need to use it. However just over one-third of Carers report having access to planned respite, and less than one-quarter can access emergency respite care.
- The lack of access to respite is identified by Key informants: respite for people with high care needs; and that there is a limit to the existing availability of respite for those with low care needs.
- The Carers when interviewed report that a range of respite services are required: overnight respite for a person with high care needs; short term respite for a person with high care needs; day respite for a person with high care needs; holiday respite.
- Clearly planned and emergency respite are important service gaps; as is respite for people with high care needs.

Day activities – a service gap

- The survey results demonstrate that for these samples, there are significant unmet needs for day activities for people with a disability in the Warwick district. While the largest gaps in services for day activities reported in the survey are in the provision of recreational opportunities (trips and activities)(half to two-thirds can access these), as reported by Carers and the self-report disability sample, of more fundamental importance are the unmet needs for day care (long hours and School holiday)(between 20%-40% can access these) in the Carer sample, and opportunities to learn skills for independence reported by Carers and the disability sample (between 23%-38% can access these).
- Key informants report service gaps with post school options and learning skills for independent living. They report that one facility provides this type of activity but is believed to be at capacity or close to capacity. These interviewees report the need for structured activities for older people with disabilities, particularly those beyond retirement age.
- Carers, when interviewed identify a need for day activities in Warwick. Several mentioned the need for a day activities centres; also named are day activities for a person with high care needs; and age appropriate day activities.
- When Carers were asked if there was just one service they could have that is not currently available, several reported that it would be a Day activity centre/Learning and Lifestyle centre. This is seen to be a productive/meaningful outlet not currently available.

Transport – service gaps

- In the survey both Carers and the people with a disability report that transport needs are largely met.
- Key informants identify a service gap with transport. This is because of the heavy reliance on taxis by people with a disability in the Warwick district and the cost of this to people on a limited income.
- In Carer interviews several transport requirements are identified: non-emergency medical transport; wheel-chair accessible transport; reimbursement for petrol costs; and just having a car/vehicle.

Other service gaps

- Central point for information about disability services
- Support, practical help and recognition for Carers
- Financial support such as a loan/advance is identified as a need.
- Key informants identified the need for more supported employment places in the Warwick district, as there is currently a waiting list for places at the existing facility.
- Poor wheelchair access in the town of Warwick is identified.
- Services for older people with disabilities

The impact of service gaps

- Key informants perceive that an impact on Carers is lack of time out and related to this, social isolation. In addition they identify several connected burdens – the emotional burden of being a Carer when there is inadequate support, the financial burden (current and possibly future), and the burden of transporting the person with the disability.
- Key informants identify the impacts of service gaps on people with a disability as: anxiety; social isolation and lack of community integration; and the impact of poor wheelchair access.

Service delivery

Who should provide/fund services? Generally Carers believe that government should fund the services and they should be delivered by accredited organisations, however some believed that local community groups, banks/large organisations could well undertake the funding/provision of services, and the individual was seen as having some responsibility.

How services should be provided in a small rural community? The common answer here is – collaboratively, though one person mentioned the need for a central point for information and another that incentives were required to attract professionals.

Barriers to service delivery: Key informants indicate that funding is a key barrier, how much money, how the money is prioritised and distributed and that organisations compete for it. A second barrier reported is a lack of awareness of disability in the Warwick district with the third being the challenges of interacting with government. The other barriers are the stoicism and pride of people and also the stigma associated with disability.

Future

When Carers were asked what their main concerns were about the future, as they aged, for ALL Carers their constant concern was the unresolved future care of the person with a disability who they care for. In addition some worried about their continued physical capacity to provide care and whether they would have any life for themselves at a future point.

Recommendations

Priority One - Establish or increase the following services

These recommendations are in rank order.

1. Create a central point for information about disability services.

While this point is not the strongest point made, it is the top priority because without access to information about what services exist, people with a disability and the Carers, will not be able to access services that do exist. A key argument here is that not even the Key informants could provide a comprehensive list of the services available in the Warwick district, for people with a disability. While the responsibility for this service does not inherently lie with any one organisation, this is a service that needs to be sustainable. Because people with a disability and their Carers access

specialist and generalist services, but in a specified geographical location, a logical choice to host this service is local government.

2. Develop a plan for the current and future provision of disability services

This is a key recommendation. Not once was planning for the provision of disability services mentioned by respondents. However the *lack* of a plan is apparent in so many of the comments made by people with a disability, their Carers and the Key informants. While it is clear that there is a high level of commitment and interest in providing for the needs of people with a disability and their Carers in the Warwick district, equally, service delivery appears to be fragmented and sporadic.

3. Collaborate for service delivery: Revisit existing collaborations and develop further collaborations to enable scarce services to be provided.

4. Address respite care service gaps

Some respite is available for people with a disability; it is well used and appreciated by Carers, but access is quite limited. In addition there are significant gaps where limited or no respite is available. These gaps are:

- a. Emergency respite
- b. Planned respite
- c. Respite for people with a disability with high care needs

5. Address accommodation gaps

There is some long term supported accommodation in Warwick, but it is limited. There appears to be no long term supported care for people with high care needs, and little or limited independent accommodation. A primary concern for many Carers in this study is what will happen to their child when they are no longer able to provide care, anticipated to happen in the next 5 to 10 years. While they want the security of knowing there is future care, they may not be ready to relinquish their role of primary carer yet. Therefore, transitional accommodation – places specified as such in supported accommodation – would provide the opportunity for the Carer and the person with the disability to make this move over a long period of time, as is required. Key accommodation gaps are:

- a. Long term supported, high care
- b. Independent living accommodation

6. Create a day activities centre

The value of a day activities centre is that it provides two services in one – respite for Carers and a potentially a productive use of time for the people with a disability. The people in this study want more opportunities for people with a disability to learn independent living skills – this is associated with the need for some of these people to learn to become more independent when their current Carer is unable to continue providing care. It is also because the current options are limited. The recommendation is for a day activities centre:

- a. To provide respite for Carers
- b. To provide people with a disability with constructive activities
- c. To teach independent living skills

7. Employment: Provide more supported employment places in the Warwick district.

8. Transport:

While most (but not all) transport needs appear to be met, specific problems with possible solutions have been mentioned. These are:

- a. Investigate the possibility of public transport being available to transport employees of the Endeavour Workshop
- b. Investigate how collaborations between service providers could improve transport options within and outside the town of Warwick

- c. Investigate how increased transport options could be created to meet the needs of people with mobility issues

9. Mobility: Investigate improving wheelchair access to commercial premises in Warwick

Priority Two – further investigate the following:

10. Respite

- a. Long hours
- b. School holiday
- c. Age appropriate

11. Day activities

- a. For elderly people with a disability
- b. Age appropriate activities

12. Investigate how Carers can be supported directly.

1. Introduction

Background

In the Warwick district unmet needs for people with a disability have been identified for almost 20 years. They were first documented in 1994 when the Southern Queensland TAFE identified a need for housing for people with a disability (in Department of Anthropology and Sociology, 1995). Then in 1995 a health and social needs assessment identified a need for respite for intellectually disabled people (Department of Anthropology and Sociology, 1995). In addition, while almost two-thirds of Carers (of elderly and disabled people) reported receiving no assistance with caring, two-thirds expressed a need for some form of assistance, specifically short term respite, personal counselling and financial assistance. In 2007 the Warwick and District Accommodation Support Group in association with a community forum, conducted a survey, which identified a need for day activities and long term accommodation (Warwick & District Accommodation Support Group, 2007). More recently in the Southern Downs Regional Council commissioned Warwick and District Futures Plan a number of service gaps and issues surrounding people with a disability were reported (Cavaye, 2009). The following points are made:

- Limited respite (no emergency care; in-home respite unavailable after 5pm or on weekends)
- More quality, affordable housing for people with a disability required (supported and independent)
- Limited options for care of people with a disability when their Carers become too elderly to provide the care
- Limited support for people with a disability in schools
- Difficulty for people with a disability accessing services on turning 18 years of age
- Improved building access required for people with mobility problems
- More disabled parking required
- Need for a single point of contact for information on disability
- Limited financial support packages available for people with a disability
- Lack of coordination between groups providing disability services
- Low level of interaction between community members and people with a disability

In this report, of a needs analysis of people with a disability and their Carers in the Warwick district, many of the previously identified issues are re-iterated.

Prevalence

While the Australian Bureau of Statistics (ABS) data shows a lower prevalence of disability in Queensland (17.9%), than in Australia (18.5%), prevalence rates are highest for Inner Regional areas (22%) of which Warwick is one (ABS, 2011c). The ABS defines disability as any 'limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities' (ABS, 2011a, p.27). By definition this description can include (but is not limited to) temporary conditions arising from accident or illness, as well as diseases such as Asthma, age related arthritis and dementia, and mental illness.

In 2008, the most frequently reported type of disability was Intellectual (28%), followed by Psychiatric (18%) then Physical (16%)(AIHW, 2011). The majority of persons with intellectual disability experience severe or profound limitations in core activities and have an additional disability, the most common being psychiatric (AIHW, 2008).

Of those people with a disability in Queensland, 31% experience severe or profound limitations compared to the national rate of 34% (ABS, 2011a). A severe or profound core activity limitation refers to a serious impairment of a person's mobility, communication or their ability to self-care.

ABS data shows a higher prevalence of severe and profound disability in rural than urban areas on the Darling Downs (ABS, 2011c). Of the Queensland population in the 2006 Census approximately 4% had severe or profound limitations due to disability and required assistance with core activities, yet approximately 5% (1070) of people in the Warwick Shire did so (COMSIS, 2011).

The prevalence of disability is higher in the community of Warwick than on the Darling Downs. While there are 4.7% (10,037) people with a severe and profound disability in the Darling Downs Statistical Region (Australian Bureau of Statistics collection area), when Toowoomba is excluded from this figure, the prevalence increases to 4.9% (4,851). In addition, a higher percentage of this group of people live in the community – 3% in the Darling Downs Statistical Region and 4% when Toowoomba is excluded from these figures. In the Warwick Shire, of the 1070 people with a severe or profound limitation due to disability, 879 lived in the community (COMSIS, 2011). These figures indicate that unmet need is likely to exist in the Warwick district.

While the scale of this study is small, it is the indepth focus that is the strength of the study. The voices of the Carers and the people with a disability are heard through the quote. These are provided to illustrate the points from the analysis. This complements the quantitative data that outlines what the needs are for disability and Carer services in the Warwick district.

2. Methodology

2.1 Commissioning

The University of Queensland was commissioned to conduct a needs analysis of the Warwick district (pre-amalgamation Warwick Shire) for the Warwick and District Disability Support Group Incorporated (WDDSG), and to produce a Resource Directory of disability services. The stated mission of the WDDSG is 'To ensure that the best possible services are provided for people with disabilities so that they are able to maintain a lifestyle which allows them to reach their potential'. This report is the outcome of the research undertaken for the needs analysis.

The geographical boundaries of the study are consistent with those of the pre-amalgamation Warwick Shire, and this area is referred to in the current report as the Warwick district (see Appendix 1 for maps).

2.2 Governance arrangements

A reference group was formed at the outset of the project to provide insight and expertise in the area of disability and disability services. This consisted of representatives from: the Endeavour Foundation; Department of Communities, Disability and Community Care Services, Local Area Coordination; Southern Downs Regional Council; and Warwick and District Disability Support Group Inc. The reference group provided support through: consultation during the development of the questionnaires and interview guides; regular progress meetings; consultation on the development of the Resource Directory; and consultation on the preliminary results and draft report.

The project was led by Dr Jennifer Moffatt, Research Fellow, Rural Clinical School (RCS), School of Medicine, The University of Queensland (UQ) and Ms Donna Rouse, RCS, UQ, was the Project Officer. A laptop and software, wireless card, mobile phone and USB stick were provided to the research team by the WDDSG for the project.

2.3 Methods

In order to determine the current services available to people with a disability and their Carers within the Warwick district, both qualitative and quantitative data were collected:

- Survey of people with a disability and Carers of people with a disability. The purpose of the survey was to quantify the need, and input from both groups was sought to capture a more comprehensive perspective.
- Semi-structured interviews with people with a disability, Carers and Key informants. The aim of the semi-structured interviews was to comprehend why these are needs, and to elicit this understanding from those who are best informed.

The methods used in the current study to identify and recruit participants is typical of previous research. In this study the identification and recruitment of paid and voluntary service providers and seeking their assistance in identifying potential participants from membership/registration lists occurred. This approach has been employed in the past by researchers who have looked at aspects such as carer quality of life (Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009; Minnes, Woodford, & Passey, 2007), carers' needs and coping strategies (Jorgensen, Pasrsons, Jacobs, & Arksey, 2010; Mac Donald, Fitzsimons, & Walsh, 2007), uptake of respite (Doig, McLennan, & Urichuk, 2009), housing needs (Eley, Hegney, & Boyes, 2006; Ellison, White, & Chapman, 2011), health and aging (Shaw, Cartwright, & Craig, 2011) and other issues applicable to both carers and persons with a disability. The distribution of questionnaires by service providers has also been

utilised, predominantly to maintain client confidentiality (Burton-Smith, et al., 2009; Eley, et al., 2006; Mac Donald, et al., 2007).

Interviews and questionnaires have been utilised both separately and in combination in previous research to gather quantitative and qualitative data across a range of topics pertinent to persons with a disability and their carers. Dillenberger (2009) employed both a structured questionnaire, administered within the interview session, and an open-ended interview schedule to obtain data from carers about a range of health, family, and planning issues. Minnes, et al. (2007) employed a range of standardised questionnaires administered in an interview setting to obtain quantitative data on a range of issues associated with health and ageing in carers and persons with a disability. Burton-Smith, et al. (2009) distributed postal questionnaires comprising a range of standardised instruments yielding quantitative data. By contrast, Eley et al. (2006) used an self-administered questionnaire for qualitative and quantitative data then semi-structured interviews of selected participants.

Publicity in the form of newspaper articles, radio interviews and a flyer were used to raise awareness of the study. The WDDSG was responsible for all publicity about the project (see Appendix 2), and this consisted of:

- Five articles in two local newspapers (the Warwick Daily News and the Southern Free Times)
- Three radio interviews aired on ABC Southern Queensland's breakfast show
- A flyer was produced and placed in numerous locations around the Warwick township

The impact of the publicity is apparent in return rate peaks approximately four days after publicity events (see Appendix 3).

2.4 Procedure

2.4.1 Survey

Questionnaire distribution commenced on 11th July 2011 and closed on 26th August.

Targeted distribution

The research team packaged the questionnaires with an Information sheet and Consent form, Reply Paid envelope and Introductory letter (see Appendices 4 and 6) in a sealed, envelope then this was provided to:

- Warwick and District Disability Support Group Inc
- Organisations identified as significant service providers to people with a disability or Carers, and who agreed to provide this support – Endeavour Foundation (Warwick), Blue Care (Warwick), Department of Communities (Warwick), and Carers Queensland.

Members of these organisations then either addressed and added a stamp to the envelope or gave it directly to a person known to be a Carer for a person with a disability, or a person with a disability. This approach included providing individuals with a questionnaire package, who contacted WDDSG as a result of publicity about the study.

All of these distributors received further questionnaire packages to send out as reminders, at one week then two weeks following the initial distribution. Reminders included a note stating it was a reminder, and the questionnaire should only be completed once. The exception to this is where questionnaires were hand-delivered to people with a mild intellectual disability only once, as it was considered inappropriate to confront them with multiple requests for participation.

As many disability service users are known to more than one organisation, it is acknowledged that some people (notably Carers) would have received multiple questionnaires.

Drop-off distribution

With this strategy quantities of both Carer and Person with a disability packaged questionnaires were distributed to points around the Warwick district. Members of the WDDSG recruited these organisations, and maintained the supply of questionnaires at these locations. These sites were publicised in radio and newspaper articles, and on the flyer. Distribution sites within the Warwick township are:

- Warwick Library
- Office Member for Southern Downs, Lawrence Springborg
- Condamine Medical Centre
- Warwick Caltex Service Station

Questionnaire packages were placed at the following locations in the Warwick district, outside the town of Warwick:

- Killarney - St Vincent de Paul
- Allora Pharmacy
- Southern Downs Regional Council Mobile Library questionnaire packages available while servicing Karara, Killarney, Leyburn, Maryvale, Pratten, Wheatvale and Yangan.

Signed Consent forms and completed questionnaires were returned in the Reply paid envelopes directly to the research team.

2.4.2 Interviews

Seventy-three percent of Carer respondents (n=41) indicated on their questionnaire they were willing to be interviewed. Interviewees were selected to represent a range of Carer characteristics: location (in town/out of town); relationship to person with a disability; Carer age; person with a disability age; main disability type for person with a disability; and sex of Carer (see Appendix 5 for the variable matrix). Carer interviews occurred between the 1st and 15th of August, 2011.

Sixty-five percent (n=17) of respondents to the person with a disability questionnaire indicated on their questionnaire they were willing to be interviewed. People with an intellectual disability were excluded due to ethical considerations. Two interviews with people with a disability occurred on the 11th of August, 2011.

Key informants were chosen to represent major service providers of their type in the Warwick area or because of their profile in the disability community and were invited to participate. Interviews were held between the 15th and 21st of August, 2011.

Signed consents were obtained from interview participants prior to the interview; all interviews were digitally recorded and transcribed for analysis.

2.5 Instruments

2.5.1 Questionnaires

The two questionnaires constructed, one for Carers and one for people with a disability, were designed to collect quantitative and qualitative data (See Appendix 6). Some items were developed by the research team and others were drawn from previous work, some with modifications. The questionnaires were developed in consultation with the WDDSG.

Details of items drawn from previous work are:

- Primary and other significant disabilities; level of support required - Commonwealth-State/Territory Disability Agreement National Minimum Data Set Collection Service User form, 2006-7 (CSTDA, 2006).
- Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983).
- Current living arrangements, future accommodation needs, accommodation availability - Eley et al (2006).

2.5.2 Interview guides

The interview guides were developed by the research team in consultation with WDDSG (see Appendix 7).

2.6 Data analysis

Quantitative data were analysed using the Predicative Analytic Software (PASW) Statistics 18. Descriptive statistics were used to summarise data. Qualitative data were analysed using QSR NVivo 9 software. Concepts were developed using inductive and deductive processes. These were then developed into themes. Quotes are used to illustrate these themes in the Results sections. To protect the anonymity of interviewees, each person was allocated a number within their group. For example C03 represents the third Carer interview. This code is provided in brackets at the end of each quote.

2.7 Ethics approval

Ethical clearance was given by the University of Queensland Behavioural and Social Sciences Ethical Review Committee (#2010000667).

2.8 Limitations

A limitation of the report is that the results cannot be generalised because purposive samples were used. Therefore these results apply to this study alone, so any comparison with other research is indicative only, but provided to assist the reader.

3. Results - Carers

3.1. Carer surveys

A total of 71 questionnaires were returned from Carers. Of these 56 qualified for inclusion in the study. Of those carer questionnaires excluded from the study, 8 were from outside the geographical area specified for the study, 4 had incomplete or missing Consent forms, 2 were from people who were not Carers and 1 was from a person caring for someone other than a person with a disability.

3.1.1 Carer's responses and locations

Respondents were asked to provide their postcode by entering the relevant numbers into boxes. Of the 56 who completed Carer questionnaires, 83.9% (n=47) lived in a 4370 postcode (covers Warwick and Maryvale), 7.1% lived in a 4362 postcode area (Allora, Deuchar, Goomburra and Mount Morgan) and the remainder in 4361 (Clifton, Ellangowan, Elphinstone, Headington Hill, Kings Creek, Manapouri, Missen Flat, Mount Molar, Nevilton, Ryeford, Sandy Camp, Spring Creek, and Victoria Hill), and 4373 (Killarney). These areas are in the geographical area of interest – the pre-amalgamation Warwick Shire.

3.1.2 The person with a disability cared for

The Carers were asked to provide information about the person they cared for, by selecting relevant items from a list (their relationship was with the person/people with the disability - Parent; Sibling; Other relative; Friend; and Other; Sole carer – yes/no). The number of people cared for was calculated from responses, as was the number of disabilities the person had. Information about the person with a disability being cared for is reported here to illustrate this aspect of the Carer and some information is repeated in Section 4 for descriptive purposes. In total the 56 Carers reported on the 70 people with a disability whom they cared for. Details are:

- Most Carers (77.6%; n=45) are parents, 12.1% (n=7) are a spouse/partner, 5.2% (n=3) a sibling, two Carers are 'other relatives' and one is a friend.
- While 80.4% (n=45) of Carers cared for one person with the disability, most of the remainder (17.9%; n=10) cared for two people with a disability.
- Sixty-three percent (63.2%) of those reported on by Carers have more than one disability.

(See Section 4 for further detail)

3.1.3 Age and sex

The respondents were asked to give their year of birth, which was converted to an age, and their sex. The mean age of Carers is 55 years and ranges from 28 to 83 years. Almost one-third (32.7%; n=18) of Carers are under 50 years, and almost one-third (28.8%; n=18) are 60 years or over. Eighty-four percent (83.9%; n=47) of Carers are female and the remainder males.

3.1.4 Length of time as a Carer

Carers were asked to indicate the number of years they had been a Carer. Participants reported being Carers for an average of 22 years, which ranges from one to 50 years. Approximately one-third (32.7%; n=18) have been Carers for up to 16 years, and about one-third (34.5%; n=20), for 27 or more years. Almost half (45.5%; n=25) have been carers for up to 20 years; a quarter (25.5%; n=14) for up to 12 years. Just over half (54.5%; n=30) of the Carers are sole Carers.

3.1.5 Carers and financial assistance

By selecting 'yes' or 'no', participants indicated whether or not they received any financial assistance from the government for caring for the person/people with a disability. Three-quarters (75.0%; n=39) report receiving financial assistance from the government for this purpose.

Respondents were asked to select from a list their primary means of income support. For almost half (47.2%; n=25) CentreLink was the primary source of income; 18.9% were employed fulltime; 17.0% were supported by their spouse; and 9.4% were employed part-time.

3.2 Carer interviews

3.2.1 Being a Carer

The Carers who were interviewed comprised a selection of those who had volunteered via the questionnaire to be interviewed and those identified by the Reference group. Eight Carers and two people with a disability were interviewed. Carers were selected to give some diversity in terms of their location (in town/out of town; their age; age of the person/people they cared for; the type of and number of disabilities). Demographic details of this group were not collected. Consistent with the survey sample, the most common disability is intellectual, followed by physical; for two the person cared for had multiple disabilities.

3.2.2 Everyday challenges for Carers

When Carers were asked in an interview 'What are the everyday challenges for you as a Carer?' all spoke of caring being '24/7'. The two people with a disability who were interviewed were also asked what their everyday challenges were. Five of the eight Carers also mentioned the difficult behaviours of those they cared for as an everyday challenge, and most of these Carers also mentioned the need for patience associated with these behaviours, and generally being a Carer. Nearly half of the Carers mentioned that the physical requirements of being a Carer could be challenging and that the unpredictability of care was an everyday challenge. Quotes are provided to illustrate these themes.

What emerged when this question was asked are not just the everyday challenges, but the personal impacts that result. Themes here are: fatigue and mental stress; and lack of a social life.

The everyday challenges of being a Carer:

- Caring is 24/7
- Difficult behaviours
- Having patience
- The physical requirements
- Unpredictability of caring

24/7: This label is self-explanatory. Many of the people with a disability being cared for require constant care or constant supervision. The comments below illustrate the range of circumstances that Carers are faced with on a daily basis.

So I guess that the hugest challenge is to get her up and get her moving ... She's low in iron, very low in iron. She doesn't walk, or she can't help you at all ... trying to get her up and get her going and get her on the day can sometimes take until lunch time ... I got her to school

today midday and that was quite difficult to get her there by that time. Three o'clock, school is over. .. it's difficult to do anything then after school except for, again care for X. See what she wants to do. If she wants to sit in front of the TV for an hour or so that's good. That gives me a chance to do some things ... and give her dinner. Take her to the toilet, shower her, get her ready for bed. ... trying to get a good night's sleep is well; some nights it's better than others. But she usually wakes at least once through the night, grinding her teeth ... not requiring a lot of attention unless - X's incontinent, so that means sometimes a bed full of poo and I really mean that. Everywhere, up her back, through her hair, everywhere. She's that doesn't happen every day. ... if it happens through the night, you've got to change the whole bed. Wash her, clean her. ... Sometimes I don't have to get up to her, but it's enough to disturb my sleep. ... if she gets sick ... even with a cold- she's really, really sick. ... I can face the day a little bit easier than he can, if I've got to be up through the night. So ... it's challenges, 24 hours a day (C03).

It's because someone else has got to do it for them, OK? I've got to think about booking him in for a massage, or the physio or the chiropractor, or the doctor. I'm the one who would administer any medication to him, or any herbal remedies, or any exercise, or anything, to keep him feeling on top of things. ... Just maintaining his lifestyle, like his social life. I have to be on top of that all the time, organising things for him to do ... so everything that has to be done virtually by me, or my partner (C04).

... he ended up locked in the bathroom there, in the toilet at least one day and we had to get the ambulance because he was jammed with his back up against one wall and his feet up against the other ... we had to ring for the Ambos and they came and one managed to squeeze in through the door and couldn't get to the hinges ... so they had to ring for the Furies so next thing I know the Furies come screaming up the hill here and in they come with axe raised ... they had a little skinny fellow and he was able to get in and between he and the big ambulance fellow they were able to lift X up, get him on to the raised toilet seat ... then got him out onto one of these chairs ... and just checked him out ... so you really can't afford to run the risk of just leaving him on his own for any length of time (C05).

... my day starts at 8.30 she might not get out of bed till 9 o'clock and so ... I go and tidy up the kitchen, I feed the cat, if I've got some washing off the line and just chucked it on the bed in the spare bedroom I'll go and fold that put that away, change the bins. ... I cook her meals and get her lunch, get her breakfast, I shower her I dry her, I dress her. She can walk but very short distance not long at all so she's got a wheelie walker that she walks around the house with. I clean her house, if we've got to go shopping I drive my car to the shops get her shopping, put it back in my car drive home, unpack it put it all away. Do her ironing ... and for the trips ... I have to run her to the airport and that's more than my four hours ... then I've got to unload her, take her into the airport, get her all set up take her to the toilet, then get her all set up ready to go, book her in and do all that sort of stuff ... and then I make sure she's got lunch and something and then I come out get in my car and then come home another three hours or so driving (C06).

There's no time for cleaning, most of the time you're making sure what is he doing, no you can't go and play the computer I need you to sit here for five minutes and just watch this show so I can hang out some washing, or things like that ... (C08).

But X needs somebody all the time. One on one (C04).

... she wouldn't let me have the break because she'd keep ringing me, so there's really no break, do you know what I mean? (C06).

I was getting to the stage I don't know how much longer I could have gone on, because I'm changing her virtually three times a day. You're here, she's here, every day. I get somebody to come in once a week ... and they're here for five hours. Then Saturdays and Sundays I get an extra two hours because they've got to have a three-hour block before they have a break. So, they come at 7 o'clock for an hour. They get X up, shower her, change her, put her in the chair. They're here for two hours and then we've got to change her again before they go home. ... changed then and put to bed until 6 o'clock at night (C02).

... instead of leaving X at home on her own for half an hour, which I really don't like in case anything happens ... We came home one day and X's muscle spasms turn her legs really badly and of course she slipped out of the chair. ... because she did it in the shower chair about a month or so ago, and we now virtually have to strap her legs in so that she doesn't slip ... So, you never know what could happen (C02).

Difficult behaviours: This describes both inherently difficult behaviours such as tantrums and constant questioning or manipulation, and everyday behaviours that become difficult for a Carer at the everyday level because of the extra effort required to manage them.

... so he doesn't decide he's going to rip out the saw or the chisels or whatever, most things are under lock and key most of the time and he's got a very good skill where he can distract you by having a disaster somewhere that you've got to fix up so he can still go and do what he was going to do originally ... (C08).

Even shopping is a minefield, I want this and I want that and it's like a five year old tantrum in the shops, stamping our feet and crying sometimes because we don't get what we want. But just balancing him and his constant requests every five minutes, when's daddy coming home, what's X doing at school, all day with just doing things that need to be done, whether it's washing or ironing or cooking tea or whatever. ... Or he's crying in the aisle at Big W because he wants a new shaver. No, you're not getting one, oh woowoo, and you get the foot stamp and the arms flap, he's almost crying and X says just buy it for him will you, the kids from school can see us (C08).

She can dress herself, she just chooses not to most nights or most mornings ... as soon as she gets tired her cognitive functioning goes down, her ability to receive information, process it and act upon it is greatly impaired, so simple things like getting from her classroom to the car and through the car park on an afternoon after school, that can be really hard (C01).

So, you're up and down to her ... when she's ripping up they can go all the floor, so you're forever picking things up on her (C02).

... but just got to be at X all the time to tell him what needs to be done, he sort of can't see what needs to be done, that's a problem. That's a problem I'm up against, very, very dogmatic (C05).

Sometimes just the mood she's in, that can really have a very adverse affect on me, I can let a lot go over my back like water off a duck's back, but a few things she's said has being like stepping over the mark ... (C06).

We're going away on holidays at the end of October and we're going for three weeks and he's coming too, whereas, normally in the past he would have stayed here ... he's very, very anti-social he doesn't like mixing with people ... (C05).

Patience: Carers indicate that they require patience for the difficult behaviours and just the extra time it takes for the person with the disability to be cared for.

... I just sit there and calm myself down and think well yeah that's her, that's her personality I don't have to take that onboard and that, but sometimes it's hard not to, again, I'm only human too and you can only take so much. There's some times I've just had a cry, I've just come home and cried because it's just too much on me ... (C06).

A lot of her behaviours are just that of a five year old; she doesn't listen to her parents, she doesn't tidy up her room. We accommodate with simpler instructions, more take-up time. ... I do need to physically assist her in and out of the car, just because I don't have the time wait 20 minutes for her to climb in and out of the car by herself (C01).

You get a bit desperate at times you've got to nag, nag, nag, he sort of gets fed up with you nag, nag, nagging, it's just because of the brain damage that was done ... (C05).

Physical requirements: Some Carers indicate that one of the everyday challenges can be the physical component of caring. This refers to lifting and providing personal care.

I do think that there's a lot more physicality involved in parenting her in that I do need to physically assist her in and out of the car, just because I don't have the time wait 20 minutes for her to climb in and out of the car by herself. ... I'm ... pregnant and carrying a 20 kilo child to the car while making sure that this one [participant indicates her pre-school child] doesn't get run over so that can be difficult ... (C01).

If I bend over and lift her too much, my back goes. I've got arthritis in three places in my back. My hip's gone from where she used to lean on me ... My knee on the right side - my hip on the right side ... my knee on the right side ... with the arthritis mucks up. The knee on the left side mucks up with the arthritis and my foot on the left side, the doctor said I've got degeneration in it. So, it does make it harder from time to time to do things for her. ... With the arthritis in my hands, although there's not a lot of pain, there is times I don't feel things. Therefore trying to grip X when you try and pull her pants up, or you're trying to spread her legs and that, my hands just give way from time to time. So far, it's not very often, but I can probably expect that it will get worse ... it's whether or not my body can hold out. So far, it's only been by the grace of God that I am continuing (C02).

Because sometimes the work can be very physically draining otherwise it's all mental (C06).

Unpredictability of care: A component of what makes being a Carer 24/7 is that while some people with a disability do not require constant care, because of how services are delivered, the Carer must ALWAYS be available. Another aspect of 'unpredictability' is how the person with the disability is managing and when constant care is required, their care must be the priority.

Getting out doesn't worry me too much, although it's good to get out every so often. It's just a case of, there's not a lot you can always do. Because you're waiting for the physio to come, you're waiting for - because at lunchtime they come anywhere from 11 o'clock to 1 o'clock

to change her, ... There's no consistency. You can't plan anything to do anything, because you don't know who's going to turn up and when they're going to turn up or anything else. ... It's just hard for X. You try to do the best you can for her (C02).

Look, you just can't make appointments to go anywhere. It's no good saying, 'Yeah I can do that meeting. At nine o'clock I'll be in Brisbane, Toowoomba by 10'. You can't do that, because the day has to revolve around X. She has a bad night at night time, or if she sick, that's; it's off (C04).

Well I got told by DSQ four hours a day; it doesn't happen. I can be sometimes with her eight, ten hours (C06).

... costly and stressful, because then you've got to wait for the ambulance. You ask for a time for them to be there. They say, "No, we can't do that". It's usually two hours beforehand. Say I said quarter to one, they'd say, "Oh, no, we can't do it at quarter at one. It would have to be quarter past ten". Then you're waiting. Okay, fine. You ring up those - or where she's going and say, "She's going to be earlier". Which means they've got to get somebody there to take her at the other end. Then that time comes and they're not here. Like the other day, they were supposed to come at quarter to twelve. They rang up at quarter to twelve and says, "Oh, somebody's got to pick up the ambulance. They've have had a couple of runs this morning. They've got to pick up the ambulance. They'll be there by half past one". They turned up at quarter to three. That stresses me out. That stresses X out ... (C02).

The personal impacts of being a Carer:

- Fatigue and mental stress
- Lack of social life

Fatigue and mental stress: This results from a combination of the mental and physical demands of being a Carer. Half of the Carers interviewed spoke of this.

So, it was just getting to the stage, and I'd had my two young grandchildren here for several weeks and most of the school holidays and I was just exhausted this time (C02).

I can face the day a little bit easier than he can, if I've got to be up through the night. So it's challenges 24 hours a day (C02).

Yeah, and I can come home and I could be with her for four hours and I will be absolutely flat and I couldn't go and get the clothes off the line because I was just drained and that to walk out there would be too much (C06).

Yes, just the brain stress by the end of the day, it's just mentally exhausting and I think that's probably the hardest part. Just the brain going to mush and going round and round the same question all day, and by the time you get to the end of the day, when my husband gets home from work, here talk to X for five minutes, I need him to stop. Please can he go to sleep now? When is he going on sleepovers to Blue Care again? (C08).

I don't know if a lot of others my age were brought up this way or if it's just that my parents were quite proud, but when X was little ... everything was just chaotic, you don't put your

hand up for help or they'll think you're a bad mum and they'll take him away. So when he was little there was no respite because you didn't go and ask for help because that means you're not coping and you're not a good mum, so there's that whole stigma of asking for help, so it makes it a little bit difficult you don't want to admit that it's not going so well. I'm going just a little bit insane (C08).

Lack of social life: Having social needs met is an important component of living a rewarding life – some Carers and one person with a disability report the limits they experience.

I've always done everything for her, so I don't have a life. I never think of myself, but I've got to start, because I'm 60 in a couple of weeks ... (C02).

It's really hard to be a good granny, because my days are taken up with X and like, to babysit, X and a baby, it's very difficult, you know. So I don't mean to be sort of resentful towards X, but it gets a little bit like that. You just feel like saying 'can you just go away for a minute? I really would like to do some baby', you know, that sort of thing. It's hard to do that, you know, and I should be able to do that. But X is, well she's demanding and she needs that attention, so you know, it's hard to do those sorts of things (C03).

These quotes illustrating the everyday challenges show very clearly the relentless nature of caring for a person with a disability. While it could easily be assumed that only people with severe disabilities require high levels of care, these quotes show clearly that this is not so – supervision can be required constantly, in order to protect the person with the disability from harm or to ensure that support services are received.

3.2.3 What keeps Carers going

Carers were asked 'What is it that keeps you going at the times when life is very difficult?' While the responses were diverse, five of the eight Carers said they kept going because they had no choice. A number of Carers named people who provided support. Interests and inner strength are also mentioned. Quotes that illustrate these points follow.

What keeps Carers going?

- Having no choice
- Support
- Interests
- Inner strength

No choice: Most Carers continue caring for the person for the disability because they see no other choice.

Lack of choice, there's no choice in giving up. When you're a parent that's just it, that's where your life stops ... I'm going to cry here. Her needs are greater than mine, that's just it, so it doesn't matter ... it would be the same thing for X and for this one coming ... we just push through for them. ... Knowing that there's nobody else around at the moment to look after X. That's the only thing that keeps me going, is that she needs me and I need to sit down, grab myself together and keep going. ... So, at the moment, I've just got to keep going and knowing that she needs me just keeps me going (C01).

I guess my love for her to do it for her because I know no-one else would, honestly, and I wouldn't see her go without, I couldn't sit here and know that just because she annoyed me that then she'd have to do it by herself or get Blue Care to come in and do it. Because what I do for her ... they don't have the time or the staff or whatever to be able to do for her and she deserves a happy life, she deserves to live in her home if she wants to and it's not for me or anyone else to make that judgement ... So I know if I don't go then it'll be taken out of her hands ... I think everybody has a right to live what life, as long as they're not hurting other people and doing bad things, but to live the way they want to and experience whatever (C06).

There's nobody else, really at the end of it, if I dropped him off at the hospital doors and said no I'm not doing it anymore, there's no-one else who would look after him, so we kind of have to just, that's how it is. We were desperate to have somebody and we had him, so and I must admit that I yelled at my sister-in-laws, two of them a few years ago and that's why they don't talk to me anymore, that no it's not a blessing having a disabled child and I said no it's not, there's no blessing involved, and it's not that they're given to special parents, they're given to the guys who just are unlucky, we're just the one the cloud settled over that day and there's no choice you just have to keep going, and at the end of the day that's how it is (C08).

Support: Carers spoke of the support they received from family and friends; a pet was mentioned by one of the people with a disability.

I have a girlfriend down in Sydney that, if I need to, if I'm really bad ... I rang my girlfriend up and I talked to her for five hours and that got me through it. So, I've got that, is about the only back-up I've got (C02).

My grandchildren, my children and my husband, you know. The family. Best friends.(C03)
I guess family. I got a little granddaughter now (C03).

If I'm starting to get down or something, I usually have my children (C02).

We need each other. I pat him [interviewee indicates pet dog] every day quite a lot and he likes that and I like that, so I get as much out of it as he does (PWD01).

Interests: For some Carers their personal interests helped them to keep going.

I keep active, busy doing things. I like to do craft and art, and I sew, and paint, and I like to garden (C04).

I sing and play guitar, so I guess I sit down upstairs and play my guitar. It keeps me going I guess (C03).

Inner strength: One Carer spoke of inner strength. 'Inner strength I suppose, I've come from good English stock' (C05).

3.2.4 The 'costs' of Caring

Carers were asked 'What are the costs of caring?'. Mentioned most frequently were the emotional costs of caring (by five Carers), and the social limits imposed by being a Carer (by five Carers). Other costs mentioned are financial.

The 'costs' of Caring:

- Emotional
- Social limits
- Financial

Emotional costs: These are the personal costs that Carers report.

It took a lot of the joy out of buying toys for her because we'd have to find the educational toy or the toy that worked on the pincer grip or rolling over ... You can't buy a toy just for aesthetics or anything like that, you have to buy the toy that has the function (C01).

I am prepared as much as you can. I'm not going to bury my head in the sand, saying, "No, she's not going to die". As she's deteriorating, you can see it. I would prefer to keep her at home so I can see it. Instead of having her away, where I'm not seeing it all the time, and it will be harder for me to let go at the end (C02).

This is our life until we die ... there's no easier bit ... It's like having a baby, still, at 50 (C03).

Social limits: Carers report that caring creates social limits in their life. This is consistent with the 'lack of social life' mentioned as a personal impact of Caring. Because they give the person they care for priority, this results in them missing out on social events and opportunities that they would enjoy. Some of these limits occur because of a lack of support services.

Social and emotional I suppose are the worst ... I shouldn't probably say that because if we had the finance to employ a carer or if there was some sort of scheme that enabled you to get a carer into the house, you'd be able to do the social thing that you want to do. ... I can just see in years to come when my little granddaughter has to go to a sports day. I'll have to not go because you try pushing a wheelchair over the grass, trying to have a nice day where you're looking at the sports. X won't want to be there, you know and I'd have to look after her anyway, so you just, you don't go. Lots of things you don't go to. Lot of friends sort of pass you by, because you really can't go. Like if X and I wanted to go out, unless we had a babysitter ... services don't provide anyone after five o'clock, so you just, you don't go. You can't go (C03).

... she's been having a hell of a lot of trouble with this other scooter that she's had and next minute she can be broken down and then I'm back in town again. So if I'm going to do anything with friends then I have to pull the pin on them to go and do her because I can't leave her in the middle of a street or out in the sun or the cold ... (C06).

... the circle of friends restrict very tightly from when they're tiny ... gees they're different to our kids and you lose a lot of friends along the way, we only have a handful left ... (C08).

... the costs of caring for X, you probably don't always get invited everywhere, you know?(C04).

Well, you're limited in what you can do and where you can go. I can't go out a lot because I have to be here with X. I go to church. They have functions on; I can't go to them, because I've got to be back here for X. ... My granddaughter and I went to the pictures ... at lunchtime when somebody was here, which is very rare. ... I can't even get to Toowoomba,

because in that four hours, it's an hour up to Toowoomba and an hour back. There's two hours (C02).

Sometimes I get caught doing different things and X is here and I've got try and rush back ... It would be good if you get a carer to come in for one night a week or one night a month or something, where X can stay at home ... and I just go out and do my thing for the night or for the weekend (C08).

... there's always three of us. The costs are, when I see friends and family, friends, and even family, who buy vans, and go tripping around Australia, that's not us, unless there's going to be three of us doing it. That's something that's a cost. You can't just say, let's go away for two weeks. There's always three of us (C04).

Financial: The financial costs of caring reported here vary. It includes: struggling to purchase food; being unable to purchase care because of the high cost; being unable to work; petrol and a vehicle; medication and nappies.

... we're struggling to feed everybody every week, but probably better off yes, we do spend more time at home together (C08).

... at Blue Care, and I said like 'I would be happy to meet half way' ... we'll pay half and they'll pay half. But I was told that it's ... 36 to 40 dollars an hour to pay a carer to go to Blue Care to look after X ... we're trying to help ourselves and it's just, it's out of the question (C03).

I don't even want to think about dollars, what's missing in the dollars for not being able to work (C08).

You've got to get web packs. Now, most of the chemists in Warwick now do not do web packs ... They do it for people who want them all the time, but they do not do it for those that just want it occasionally. ... last time I got it done, charged me \$20 for a web pack for a week. I found the discount place, they only charged me \$5 this time (C02).

There's a lot of running around, in the car, picking him up, and taking him places, and in that regard, there's a fair bit of cost, and the fact that we built a little unit for him on the side of the house. That was a huge cost (C04).

... just something to help me out with the cost of running my car ... makes it really hard when you're on this little amount of money, rent takes that much so I'm left with this much and I've still got to buy food, I've still got to pay my car ... it's either have insurance on the car or don't eat (C06).

... they subsidise nappies ... they only subsidise, they don't give you a whole lot, there's a six week break until you get the next lot. So you got to buy the pull-ups for six weeks So I bought two cartons. I think they were about 90 dollars each (C03).

The medications, the vehicle. We're planning to get another vehicle. For X to be transported around we still rely on a taxi. ... but holidays is a big concern too, trying to find a unit which has disability handrails, showers, toilets (C07).

3.2.5 Services and Carers

3.2.5.1 Services used by Carers for themselves

The data for this question is drawn from the interviews with Carers and with Key informants. Carers were asked 'What services do you currently access for yourself?'. The results indicate that they access very few for themselves; the only service mentioned is Blue Care, for respite. Responses to this question are reflected in the following comments:

Occasionally X goes to Blue Care overnight, probably once every couple of months ... there's nothing else. ... I don't get any service (C03).

No because I didn't know they existed (C06).

No, we sort of muddle through the best we can ... and talk to some other parents from time to time and I still keep in contact with my friends down in Brisbane that have other kids, a group of us started at the same school as teacher aides at the same time and we all had kids with ASD (C08).

Don't really feel I need it, I mean I've sort of coped all these years, of course I'm pretty easy going so things don't tend to put me in a flap or worry me too much, I suppose I've just got used to coping (C05).

Key informants were asked 'What services are currently available to specifically support Carers in their role?'. Services mentioned are listed alphabetically:

- Blue Care for skills for independent living
- Community Options, Blue Care and Disability Services for respite; perhaps specialised transport from Community Options
- Carer Respite Service which is reported to be ceasing mid 2012 – which currently provides transport and cash contribution towards the cost of overnight respite
- Carers Queensland operate a Local Carers group that meets monthly with guest speaker provided and lunches; respite program for older parent carers; Friend's Care mentoring program for Carers; free counselling
- Parent to Parent, a support service for parents of people with a disability (Toowoomba)
- Public Trust for financial situations; Guardianship Tribunal

3.2.5.2 Service gaps for Carers

When Key informants were asked 'What do you think are the gaps in services for Carers in the Warwick district?', most comments were made about the need for: more respite and supported accommodation to give Carers a break; Post school services/Skills for independent living to both give Carers respite and to provide young adults with constructive activities; and a central point for information about services. Transport is also mentioned.

Service gaps for Carers:

- Respite
- Supported accommodation
- Post school services/Skills for independent living
- Central point for information about services
- Transport

Respite and supported accommodation

More respite I guess, and some reassurance of what's going to happen to their son or daughter, if they die, pass away, who is going to look after their son or daughter (KI01).

Well the big gaps are respite and post school. ... I mean it's hard enough looking after normal children, let alone looking after children with disabilities, and then older parents who've had a child with a disability all their lives, there's nowhere for those children unless they can get into supported accommodation ... So you're finding that there's a lot of elderly people who have looked after their children for 50, 60 years and they've never ever accessed services because they've just seen it as their duty, but they're very tired ... for them to be able to continue in their caring role, they need support ... it's very hard, particularly if you've got someone with challenging behaviours as well as intellectual and physical disabilities, it's very tiring on families. So if the government really wants to keep the family unit together, keep these people out of aged care residential because that's the only option for them, then they've got to start providing more respite. Families need a break, they're tired (KI03).

Post school services: Two Key informants mentioned post school options as a gap.

... so there needs to be some respite for the parents because the parents don't have a life, and while their children's at school they've held down a job, so their expected then to resign from their work, because there's nowhere for their children to go, that doesn't seem fair (KI03).

... there is no opportunity for these students to go into a situation where they can be supported to get employment ... The obvious answer is a day activity programme, a ... learning and life skills programme ... but we don't have enough places to pick up everyone who needs it. So the supply's not meeting the demand, and this is where it's going to have a major impact on families, because they're so used to having the break while their child's been at school, and suddenly what are they going to do, because we're suddenly faced with seven day a week, 24 hour a day and there's nowhere for this person to go, and they're on a waiting list ... (KI03).

Skills for independent living This service is associated with respite for parents, and post school services.

Probably most of the parents, particularly the ones with young teenage kids who are leaving school ... one of the things they say is they've never learnt any life skills at school, so there is an expectation from parents that they are taught those things at school. ... for example you get back to the old sex education that gets taught in school. Well that gets taught in schools ... human relationships education, well for the kids with disabilities that's a huge area of need because a lot of the kids don't have those social skills, or those communication skills anyway, so the parents do need to know how to talk about it, but it's broader than that, it's about sexuality and what it is about me being a girl, because when you have a disability you don't understand those things. So that's really a challenging area for parents to have to teach in, so they do need that sort of support from the schools to teach those sorts of things ... (KI04).

Central point for information about disability services The importance of having access to relevant information is raised.

... there's not always that information out there, especially revolving around payments ... CentreLink is not always forthcoming ... you almost have to know the system to be able to access it ... They will tell you if you ask, but you've got to know what questions to ask ... wasn't aware of mobility allowance ... the family just wasn't aware of it at all, even though their son was on the disability support pension, it's something they'd never been told that was available. ... or the taxi subsidy scheme ... entitles them to a half fare ... So the information isn't out there all the time (KI01).

What's missing is a central point – a portal, a one-stop shop – that says “Oh, you're in the Warwick area and you have a child with special needs” – those special needs might be hearing impaired, visual impaired, in a wheelchair, whatever – “You need to know this phone number because that deals with this service, you need to know that phone number ... Oh, you have a child who has Asperger's system? Right, the phone number for the local Asperger's person is this and there we are. Oh, you're dealing with dementia? Right. Alzheimer's? Right, the Alzheimer's Awareness Association's phone number is – here it is there”. ... One of the things that need to be done is to draw together ... a central repository of contact details for service providers and related organisations within this area. ... that the communities page, the Southern Downs Council, should be where people begin to look (KI02).

A lady rang me ... she is the secretary of the Alzheimer's Society of Warwick and they get no help through anybody. ... They get no support – formal or informal, they get nothing from disability services, they probably don't even know that they can apply, they didn't know of the existence of Carers Queensland ... How would they know? No-one tells them so they're just assuming – like a lot of country folk – that you just tighten the belt a notch or two and knuckle down and get on with it (KI02).

... a resource centre where they can go and get access to the information that they need, when they need it. That's one of the biggest issues ... but they don't know what they don't know, so if you're a Carer and you had one of these community centres in your town that might be some place that you go to find out. ... carers don't have access to internet to be able to do the research ... so the community centres often offer, like a computer there so that you can come in and do the research, or show them ... So there's a lot of just basic stuff that carers need access to, so that's access to information and support when they need it, in a timely manner, is probably one of things I think is most lacking in the Warwick area (KI04).

Transport This comment on transport indicates that this is an issue that has the potential to be resolved, because suitable transport currently exists.

Transport. Most people as they age, aren't able to carry or move people and when you've got a charge who has some mobility issue, this becomes very difficult for you. How do you organise to get these sorts of things done? All of the service organisations provide mobility issues for aged people – you'll see the buses everywhere. Some of those have got turn and lifters in them; the cab has a turn and lifter in it; they've got specialised bits and pieces that address all these issues (KI02).

Key informants reported gaps in services for Carers and people with a disability. They indicated there are gaps that would provide Carers with much needed respite – in the form of more respite services

and supported accommodation – and for people with a disability, ways to productively use their time and at the same time provide respite for their Carers – with post school options and teaching skills for independent living. Transport was also mentioned as a service gap.

3.2.5.3 The impact of service gaps on Carers

Key informants were asked 'What impact do you think these service gaps have on people with a disability and/or their Carers?' In this section of the report, material on Carers only is presented. The comments about service gap impacts on people with a disability are at Section 6. The impacts perceived by Key informants are: financial, emotional and transport burden; lack of time-out; and related to this, social isolation.

The impact of service gaps on Carers:

- Financial
- Emotional
- Transport
- Lack of time-out
- Social isolation

Financial, emotional and travel burden: These are the impacts grouped together, so could be considered the key impacts. Without adequate services/support these are the areas where Carers are called upon.

Financial burden ... if one of our supported employees is earning \$50.00 a week and their taxi fares are costing then \$60.00, then someone's got to make up the shortfall. ... if they've got school aged children and it's trying to get everyone where they want to be by 8.30am, because we start at 8.30am, ... then they've got ... pick them up in the afternoon. ... Some of our parents live out of town, so it's coming in and out of town to pick up their son or daughter ... if they don't have transport, what if the mum or dad doesn't drive, or they're too sick, or it costs too much to run a car ... the financial burden is always a bit of an emotional burden as well isn't it ... having to worry about finances ... if they're only earning \$50.00, forking out \$60.00 on transport, how are they saving for their future, who is going to take care of them financially in the future ... (KI01).

I think we have an increased depression ... when they can't get the services they need to look after their loved one. Increased depression, anxiety, stress and therefore, and financial stress as well ... having to travel to get the services that they need to sometimes, or even just getting them in their own community. So financial stress ... plus the emotional strain, the anxiety, the depression, most of the depression and anxiety, ten times higher in carers than in any other group in our society, did you know that? (KI04).

Lack of time-out and social isolation: Both of these items reinforce the constancy of being a Carer.

... it gives them time to have a breather, it gives them time to go and have their hair done, gives them time to catch up on a few things that they want to do – for themselves – without having to worry about where their charges are ... (KI02).

Isolation is the biggest thing I believe ... and the same applies to the parents. If the parents are bound to the house, or to their child, then they're not having a normal lifestyle either ... then you are socially isolated (KI03).

Well basically they don't retain the skills that they need, they don't really learn the skills that they need to ... life skills ... in the end too it isolates them from the community. It isolates the person with the disability and their family from the community. They're not really feeling included, they don't have access to jobs and that sort of stuff that normal people do and therefore it effects their self esteem, their self confidence ... The impact I think in the longer term will be that these people will become more isolated and less respected and less needed in the community and my great theory is that we'll go back to the old days of institutionalisation and those sorts of things, and parents are only given that choice. If I had a dollar for every parent that I know who was told just leave them in the hospital and walk away I think I'd be a wealthy lady these days (KI04).

3.3 Carer anxiety and depression scores

The Hospital Anxiety and Depression Scale (HADS) is a self-report survey initially developed to assess anxiety and depression in a clinical setting (Zigmond & Snaith, 1983). However it is now widely used in a variety of health settings as well as for normal populations in many countries. The two subscales have been shown to be reliable and valid measures of the presence and severity of anxiety (HADS-A) and depression (HADS-D) (Bjelland, Dahl, Haug, & Neckelmann, 2002) as well as providing an overall measure of psychological distress (HADS-T) (Pallant & Tennant, 2007). The instrument consists of 14 items, evenly divided between the two subscales. Each item has four response options corresponding to varying degrees of distress or anxiety. An example of the depression items is **I can laugh and see the funny side of things;** with the response options: **As much as I always could; Not quite so much now; Definitely not so much now; Not at all.** The instrument provides cut off scores for anxiety, depression (both 10) (Herrmann, 1997), and psychological distress (12) (Pallant & Tennant, 2007), although other cut-offs are used (Herrmann, 1997). The Hospital Anxiety and Depression Scale was used to measure psychological distress in both carers and persons with a disability.

Anxiety

The mean Anxiety score for the Carer sample is 8.14. A score of above 10 is considered to be an 'abnormal' level of anxiety (Herrmann, 1997). In the Carer sample 28.0% (n=14) scored an 'abnormal' level of anxiety.

Depression

The mean Depression score for the Carer sample is 6.44. As with the Anxiety scale a score above 10 is considered to be 'abnormal' depression. In the Carer sample 16.8% (n=8) scored an 'abnormal' level of depression.

Psychological distress

When the Anxiety and Depression scales are combined, this gives a Psychological distress score, with a cut-off of 12 (Pallant & Tennant, 2007); the mean for the Carer sample is 14.17. In the Carer sample 62.5% (n=30) scored 'abnormal' psychological distress.

4. Results – Person with a disability

A total of 26 questionnaires were returned by people with a disability and all qualified for inclusion in the study. Of these 69.6% received assistance in completing the questionnaire.

4.1 The two 'person with a disability' groups

There is data on two groups of people with a disability:

- 1) Those who are reported on by the Carers; and
- 2) Those with a disability who provide their own responses.

Sections labelled 'Carer responses' provide information reported by the Carers, on the person with a disability they care for. Correspondingly, the sections labelled 'Person with a disability self-report' provide information that comes directly from the person with the disability.

Based on the Consent forms it appears that there is a small overlap between the two person with a disability samples – a total of five respondents appear to be both reported on by a Carer and to have provided a self-report. As the provision of contact details was optional it is possible that there is greater overlap than this.

Despite this overlap the data depicts two samples that have clear differences. The results for both samples are reported together in order to highlight the differences and similarities, and to provide a comprehensive view of what the needs are of people with a disability in the Warwick District, from this study.

Carers' responses

Respondents were asked to provide some details about the person/people with a disability who they cared for. They were asked to give the postcode for the area where the person/people with a disability resided. Most (83.9%; n=47) of the persons with a disability resided in a 4370 postcode area (covers Warwick and Maryvale). Four percent (3.6%) lived in the 4373 area (Killarney) and 3.6% in the 4362 area (Allora, Deuchar, Goomburra and Mount Morgan) (both n = 2), with the remainder living in 4305 and 4350 areas (all n=1), and some unspecified. This indicates that some of the people with a disability lived in a different postcode area to their Carer. Interview data indicate that some children lived elsewhere because no suitable accommodation was available locally.

Person with a disability self-report

As with the Carer questionnaire people with a disability were asked to give their postcode. Of the 26 people who completed the questionnaire, 88.5% (n=23) live in the 4370 postcode area (covers Warwick and Maryvale); 7.7% (n=2) in the 4362 postcode area (Allora, Deuchar, Goomburra and Mount Morgan) and one person in the 4373 (Killarney) postcode area.

4.2 Relationship between Carer and person with a disability

Respondents were asked to select from a list, their relationship with the person they cared for/their relationship with their Primary care provider.

Carer's responses

Most Carers (78.6%; n=45) are parents, 12.0% (n=7) are a partner/spouse, 5.0% (n=3) a sibling, 3.6% (n=2) an unspecified 'Other' relative, and one Carer is a friend (Figure 1).

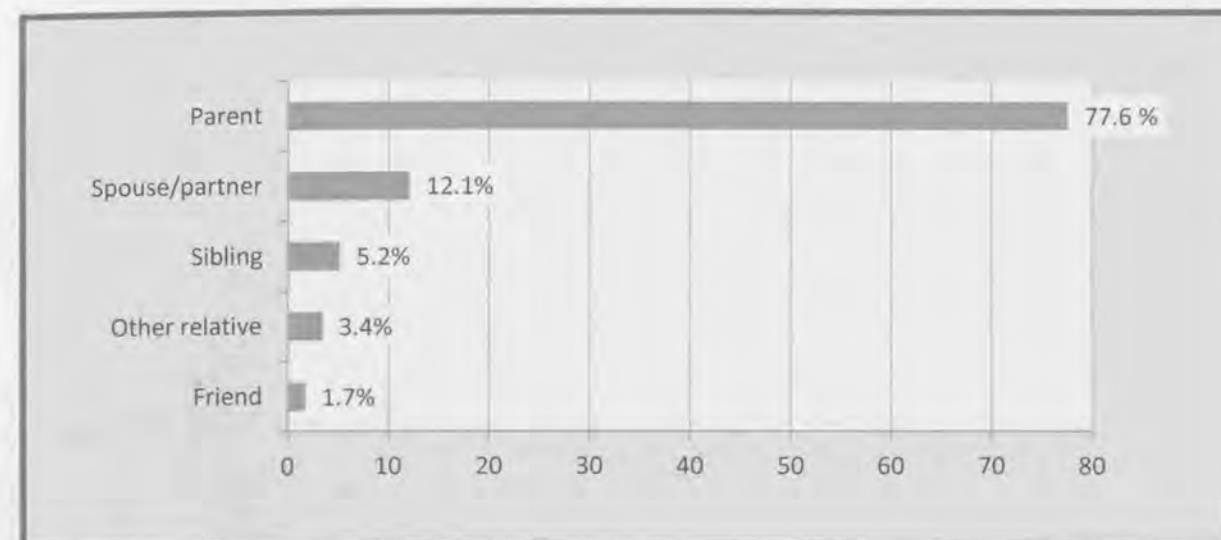


Figure 1: Carer responses – who they care for.

Note: Numbers do not add to 100% because some Carers reported multiple relationships due to caring for more than one person.

Person with a disability self-report

Respondents were asked to select from a list of items, their relationship with the Primary care provider (Child; Sibling; Other relative; Friend; Other). A spouse was the most frequently mentioned primary carer (23.8%; n=5) with Endeavour and unspecified 'Other' relative both at 19.0% (n=4). This was followed by 'Other paid' Carer at 14.3% (n=3), followed by a Friend as Carer (9.5%; n=2), with each of a Sibling, Child and unspecified 'Other' as carer (5.0%; n=1) (Figure 2).

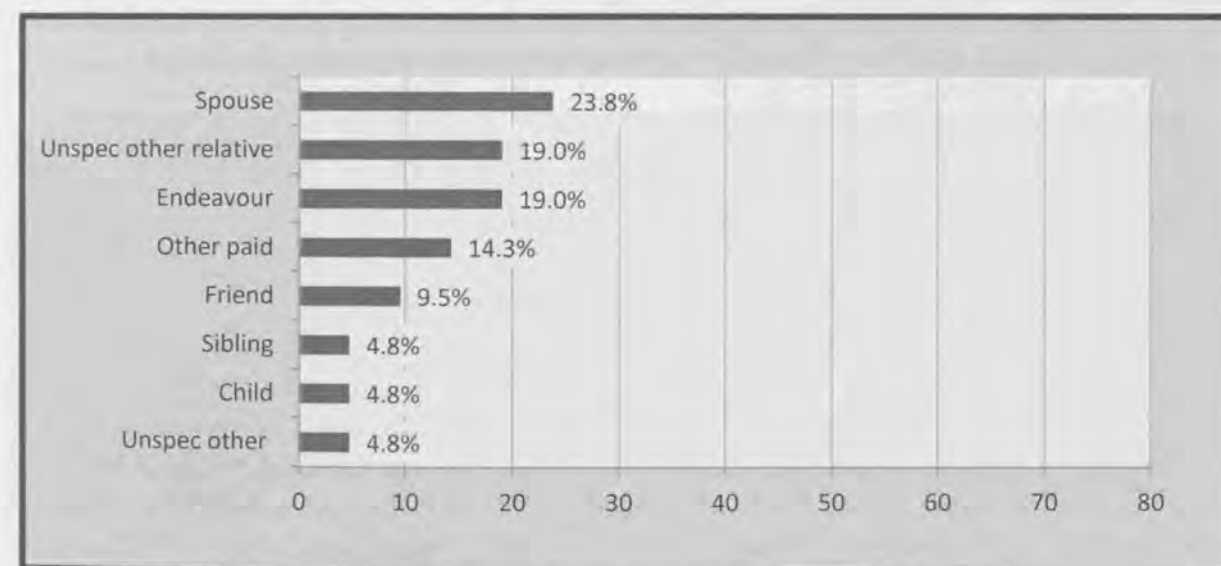


Figure 2: Person with a disability responses – who is their carer.

Note: Numbers do not add to 100% because some Carers reported multiple relationships due to caring for more than one person.

What the previous two figures indicate very clearly are differences in the two 'person with a disability' samples. While in the Carer sample it is predominantly a parent who is the Carer, the contrast in the person with a disability sample, is the diversity in the type of Carer. Another notable difference is the high percentage of spouses who are Carers (23.8%) in the disability sample, while in

the Carer sample, only 12.1% are spousal carers. Another difference lies with the self-report disability sample listing paid Carers, but also one 'child' Carer.

4.3 Age and sex of the person with a disability

Respondents were asked to give the year of birth of the person/people with a disability they cared for, and the sex. The year of birth was converted to an age.

Carer's responses

The average age of the person with a disability being cared for is 31 years, and ranges from 1 year to 79 years; with 22.9% (n=16) being children; and 57.1% males.

Person with a disability self-report

The average age of the person with a disability self-report is 53 years, ranging from 23 to 80 years. With only two respondents in their twenties, two in their thirties, and two over 60 years, the majority are between 40 and 60 years. Fifty-seven percent of respondents (57.7%) in this sample are females.

Therefore the Carer sample of people with a disability is on average younger (31 years) than the disability self-report sample (53 years). The sex breakdown also contrasts. Almost two-thirds of the Carer sample of people with a disability is male, while almost the same percentage are female in the person with a disability self-report sample.

4.4 Number of and types of disability

Sixty-three percent (63.2%; n=36) of those reported on by Carers have more than one disability and 50% of the self-report sample do. This count includes Primary and non-primary disabilities.

4.4.1 Primary disability

Respondents were asked to select one primary disability from an eleven item list of types of disability labelled 'Primary disability group'. The identical list was in the Carer and Person with a disability questionnaire. Items are: Intellectual; Specific learning/ADD (other than intellectual); Autism-including Aspergers' Syndrome; Physical; Acquired Brain Injury; Neurological – including Epilepsy and Alzheimer's Disease.

Carer's responses

The most common primary disability in the group of people Carers reported on, is intellectual (46.7%; n=28); next most frequent is Autism (18.3%; n=11). This is followed by: Acquired Brain Injury (ABI) (10.0%; n=6); Physical (8.3%; n=5); Neurological (5.0%; n=3), Psychiatric (3.3%; n=2) and one person each had as their primary disability: DeafBlind; Vision; Hearing; Speech; and Developmental delay (Figure 3).

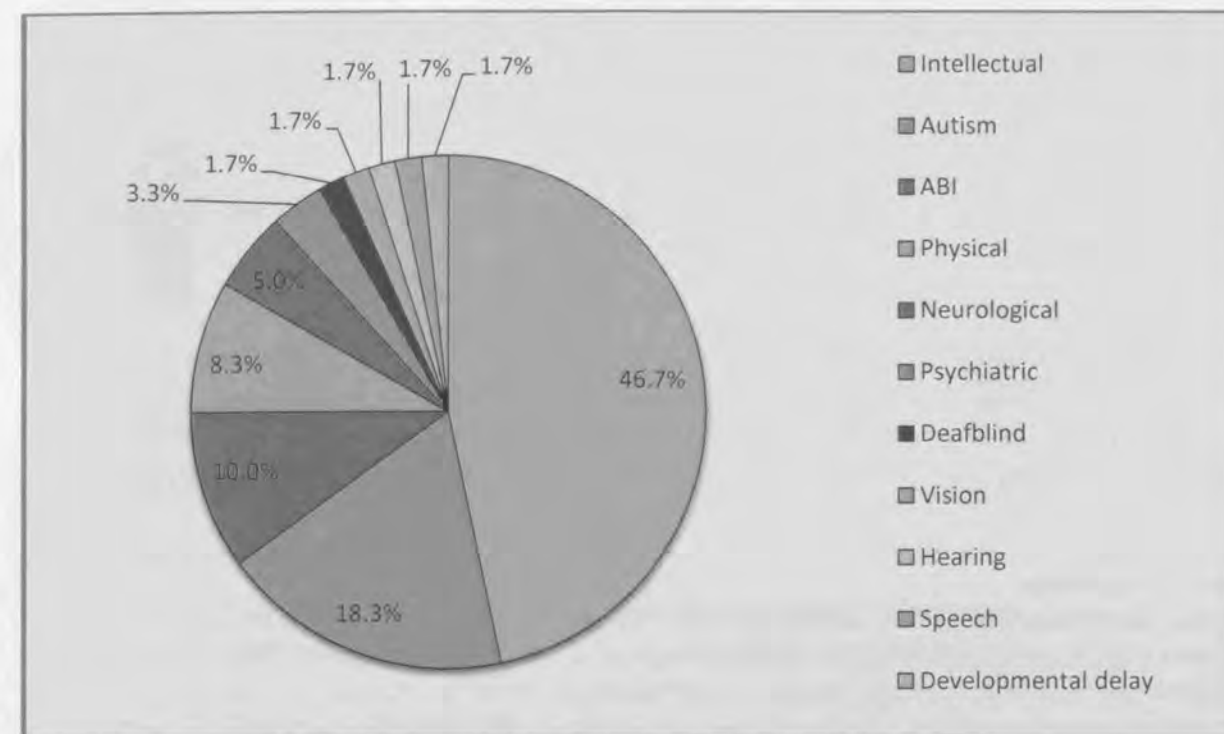


Figure 3: Primary disability – Carer's responses.

Person with a disability self-report

The most frequently mentioned primary disability reported was intellectual (38.5%; n=10), followed by physical (26.9%; n=7), then the same percentage reported neurological and psychiatric disabilities as their primary disability (7.7%; n=2); and one person each reported ABI, Specific learning/ADD, vision and Hearing as their primary disability (Figure 4).

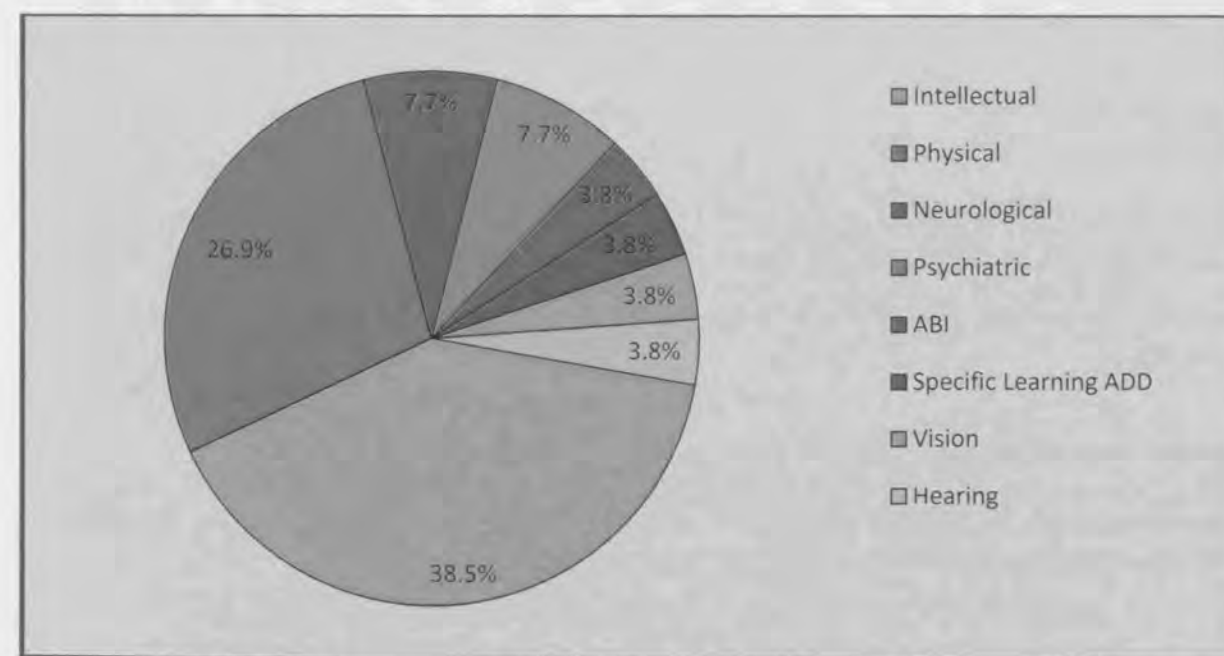


Figure 4: Primary disability – Person with a disability self-report

While for both samples the predominant primary disability reported is intellectual, the rank order changes for the self-report sample. However the samples do share four of the top five primary disabilities: Intellectual, ABI, Physical and Neurological. The absence of Autism in the self-report sample may reflect the inability of this group to communicate at the level required to respond to a questionnaire.

4.4.2 Non primary disabilities

Respondents were asked to select from an eleven item list of types of disability labelled 'Other significant disability', any or all other disabilities. The identical list was in the Carer and Person with a disability questionnaires. The items in this list are identical to those in the primary disability list.

Carer's responses

In the sample reported on by Carers, the most frequently mentioned non-primary disabilities are: Speech (16.5%; n=16); Physical 14.4%; Neurological 14.4%; and Intellectual 13.4%. Fewer than ten percent are reported to have Autism, Learning/ADD, Hearing, Psychiatric, ABI, DeafBlind and Development delay. In total 11 non-primary but significant disabilities are reported (Figure 5).

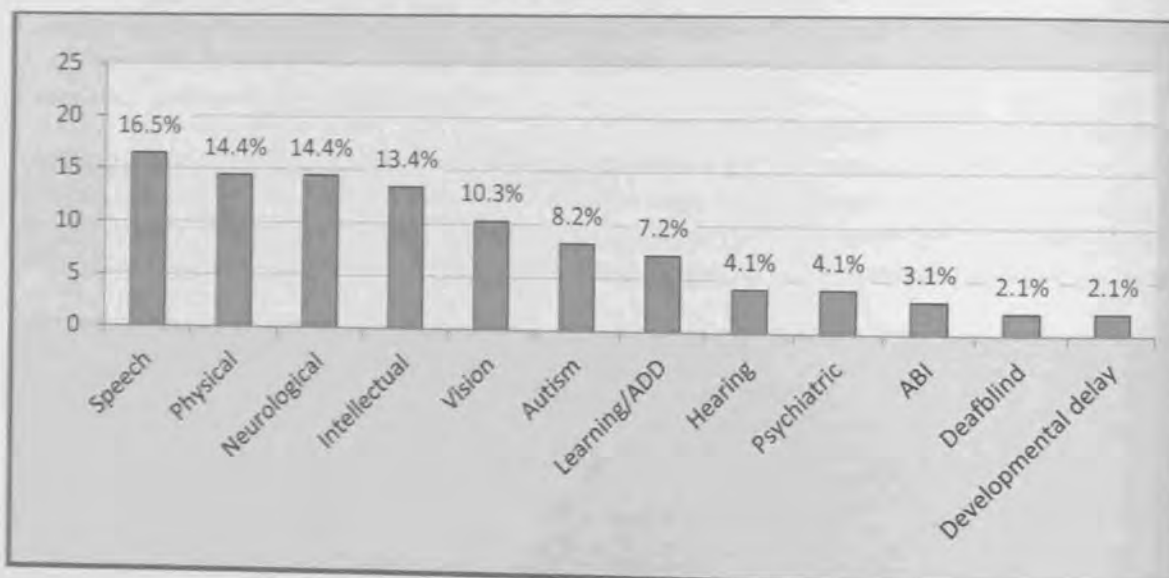


Figure 5: Non-primary disability – Carer report: Percentage of persons indicating non-primary disability.

Person with a disability self-report

While 85% reported one primary disability there is a range of non-primary disabilities. Those most often mentioned are: Speech (20.7%); Vision (17.2%); Intellectual (13.8%); Physical (13.8%); and Neurological (13.8%) (Figure 6).

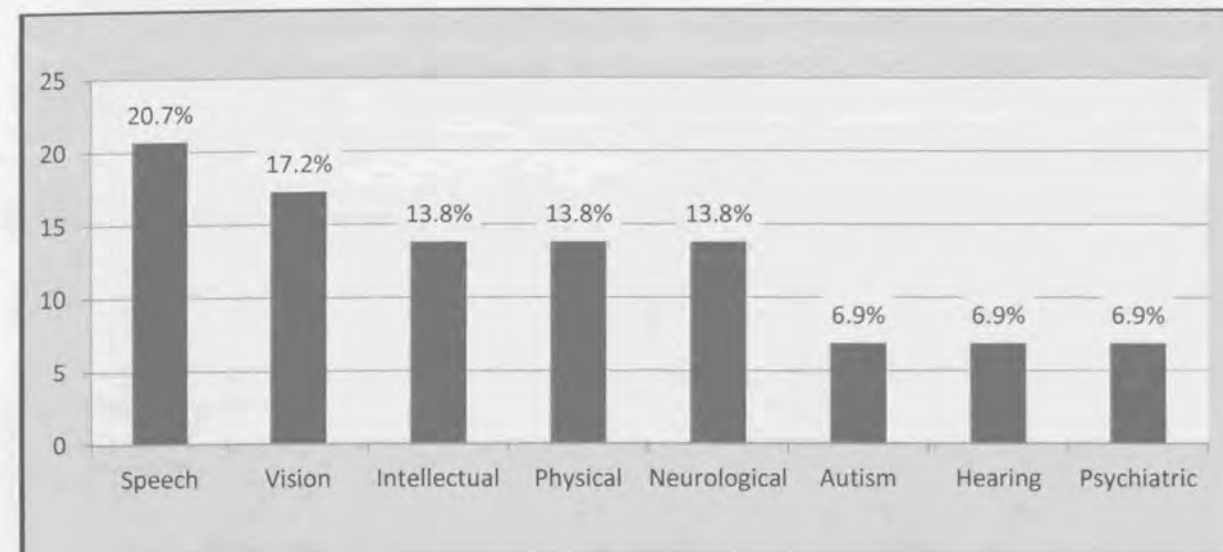


Figure 6: Non-primary disability – Person with a disability self-report: Percentage of persons indicating non-primary disability.

4.5 How most time occupied

Carers were asked 'How does the person with the disability occupy most of his/her time' and asked to select one box from a list of items (Attends secondary school; Employed part time; Employed casually; At home; Other). The person with a disability questionnaire item was asked 'How do you occupy most of your time?' and asked to select one item from a list (Employed part time; Employed casually; At home; and Other).

Carer's response

Just over half (50.7%; n=35) reportedly occupy most of their time at home; 18.8% (n=13) attend school (10.1%, n=7-Primary; 8.7%, n=6 Secondary); 10.1% (n=7) are employed (7.2%, n=5 part time; 2.9%, 2 fulltime); 7.2% (n=5) spend most time at Blue Care; and 13.0% reported 'Other' unspecified activities (Figure 7).

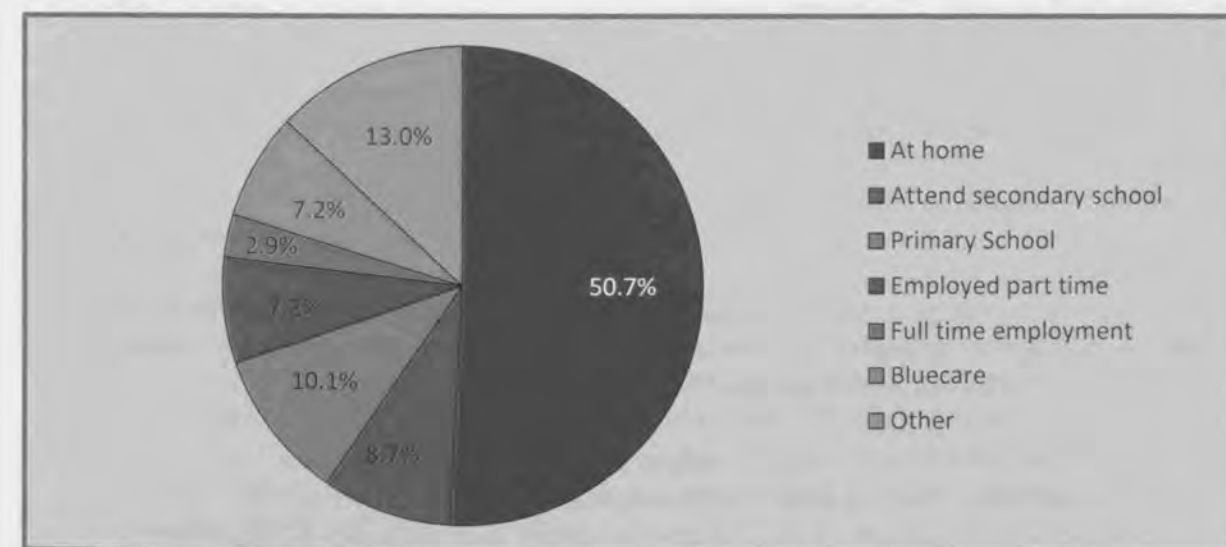


Figure 7: How the person with a disability spends most of their time – Carer's responses.

Person with a disability self-report

More than half (53.8%; n=14) of the respondents in the person with a disability sample report occupying most of their time at home, 26.9% report being employed (n=7)(15.4%, n=4 full time; 11.5%, n=3 part time) and the remaining 19% doing 'Other' unspecified activities (Figure 8).

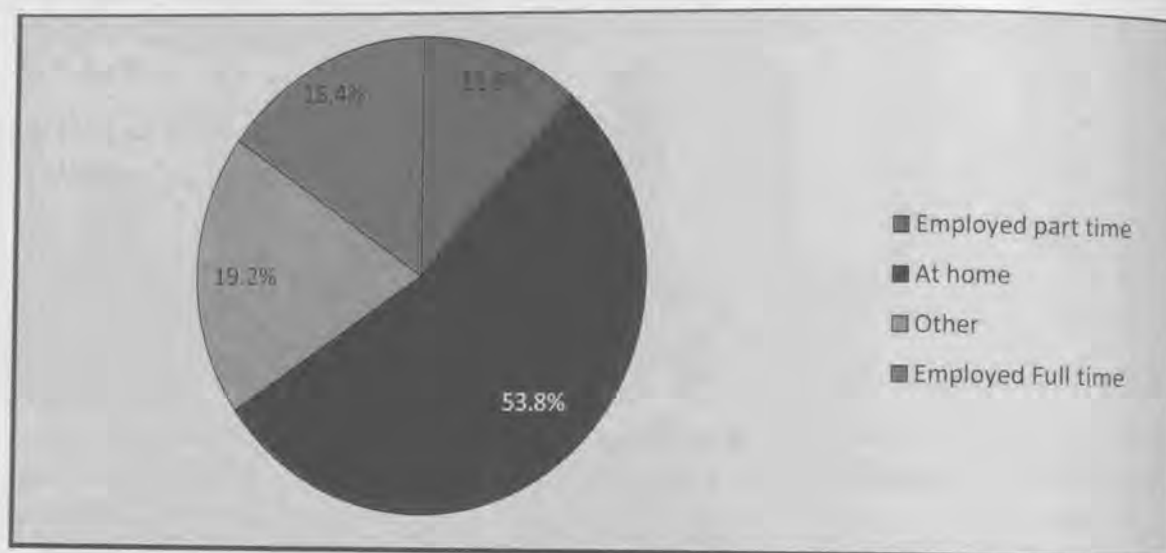


Figure 8: How the person with a disability spends most of their time – Person with a disability self-report.

4.6 Receipt of paid assistance; income; and accommodation costs

Carer's responses

Carers were asked 'Does the person with the disability receive assistance from any paid services?' (yes/no); 'Do you receive any financial assistance from the government for caring for this person/people?' (yes/no); 'What is your primary means of income support?' and asked to select from a list (Full time employment; Part time employment; Supported by spouse; Supported by other family member; CentreLink; DSQ/Other disability; Other). Results are (see Table 1):

- 57.8% of the persons with a disability receive assistance from a paid service
- 23.1% pay more than a quarter of their income on accommodation
- CentreLink is the primary means of income support for 84.1% of those cared for
- 9.5% are supported primarily by family members, and 4.8% by DSQ/Other disability income

Person with a disability self-report

People with a disability were asked 'Do you receive assistance from any paid services (yes/no); 'What is your primary means of income support?' and asked to select from a list (Full time employment; Part time employment; Supported by spouse; Supported by other family member; CentreLink; DSQ/Other disability; Other); and 'Do you pay more than 25% of your income for accommodation?' (yes/no). Results are (see Table 1):

- Almost half (47.6%) of this sample receive assistance from paid services
- 44.0% pay more than a quarter of their income on accommodation
- For 80.8% of the sample, CentreLink is their primary source of income. For one person each, the primary source of income is: full time employment; part time employment; by a family member; DSQ/Other disability; and Other.

Table 1: Carer and Person with a disability self-report on financial assistance and accommodation costs.

| | Receives assistance from a paid service | | | |
|---|---|------|------------------------|------|
| | Carer's responses | | Disability self-report | |
| | Count | % | Count | % |
| Receives assistance from a paid service | 37 | 57.8 | 10 | 47.6 |
| Pays more than 25% of income on accommodation | 15 | 23.1 | 11 | 44.0 |
| Receives assistance from CentreLink | 53 | 84.1 | 21 | 80.8 |

With fewer than two-thirds of the disability sample reported on by Carers receiving paid services it would appear that the majority of the caring required is provided by the Primary Carer. This contrasts with less than half of the disability self-report sample indicating they receive paid care. This is consistent with the youth of the Carer sample, with approximately one-quarter being less than 18 years of age.

Approximately double the percentage of the disability self-report sample pay more than one-quarter of their income on accommodation costs, when compared to the sample reported on by Carers. This is consistent with the younger age in the latter sample. Public housing rent is calculated to that not more than 25% of household income is paid on rent, so this result raised the question of the availability of public housing in the Warwick district.

More than three-quarters of both disability samples receive most income from CentreLink. For the older, more independent disability sample, with almost one-half (44%) paying more than a quarter of their income on accommodation, this implies that their disposable income would be limited.

4.7 Level of support required by the person with a disability

Respondents were asked to indicate the level of support required for the person they cared for - or for the person with the disability, what their needs for support are through the question 'How often do you need personal help or supervision with activities or participation in the following areas?'. Nine domains were listed (Self-care; mobility; communication; interpersonal interactions and relationships; learning, applying knowledge and general tasks and demands; education; community (civic) and economic life; domestic life; working) and a Likert-like scale for each domain (1=Unable to do or always needs help/supervision in this life area; 2=Sometimes needs help/supervision in this life area; 3=Does not need help/supervision in this life area but uses aids or equipment; 5=Not applicable) to indicate for each domain the level of support required. In addition to this question in both questionnaires, only the people with a disability were asked 'Do you require the assistance of a care giver - more than two-thirds (69%; n=18) answered 'yes'.

Carer's responses and Person with a disability self-reports compared

The responses to these questions are summarised in Table 2 and Figure 9 (detailed results are in Appendix 8). Because the purpose of this report is to identify the needs of people with a disability, it is the support requirements that are the focus of this section. The responses and the comparisons show:

- the people with a disability being reported on by Carers require a higher level of support than the disability sample who self-report
- the type of care that Carers provide or arrange for the provision of
- the diversity of care required by people with a disability
- that while the types of support for the two groups differ, there are similarities

More than half of both groups require support for domestic life and learning, applying knowledge and general tasks. These are fundamental requirements, so a lack of provision of support in these areas would have a significant impact.

Half or more in both groups require support with working and interpersonal interactions and relationships. Ten percent of the group reported on (10.1%) and 26.9% of the self-report group work. Interpersonal relationships are an important component of continued working life. While CentreLink is the primary source of income for the people with a disability in both groups, paid employment provides not only income but is also known to provide a measure of self-esteem. Therefore support in these two areas is important for the longer term benefits that can result.

While more than three-quarters of those reported on by Carers required support for education, only one-quarter of the disability sample do. However this is largely a reflection of the different ages of the people concerned -the youngest person with a disability to respond is 23 years.

In three of the four domains the least amount of support required is the same for both groups: mobility, communication and self-care. However for the group reported on, almost two-thirds require support with self-care, while only one-third of the self-report sample does so. Like domestic life and learning, applying knowledge and general tasks, self-care is fundamental to everyday life, and without support in this area, the challenges would no doubt be insurmountable.

Table 2: Comparison between Carer-reported and person with a disability self-reported levels of support required for the person with a disability

| Carer's responses | Person with a disability self-report |
|--|---|
| Approximately three-quarters of those being cared for require support for: - Learning, applying knowledge & general tasks - Community and economic life - Domestic life - Education | |
| Approximately two-thirds of those being cared for require support for: - Working - Interpersonal interactions and relationships - Self-care | Approximately two-thirds require support for: - Domestic life - Learning, applying knowledge & general tasks |
| Approximately half of those being cared for require support for: - Mobility - Communication | Approximately half require support for: - Working - Interpersonal interactions and relationships |
| | Approximately one-third require support with: - Community and economic life - Self-care - Communication |
| | Approximately one-quarter require support with: - Education - Mobility |

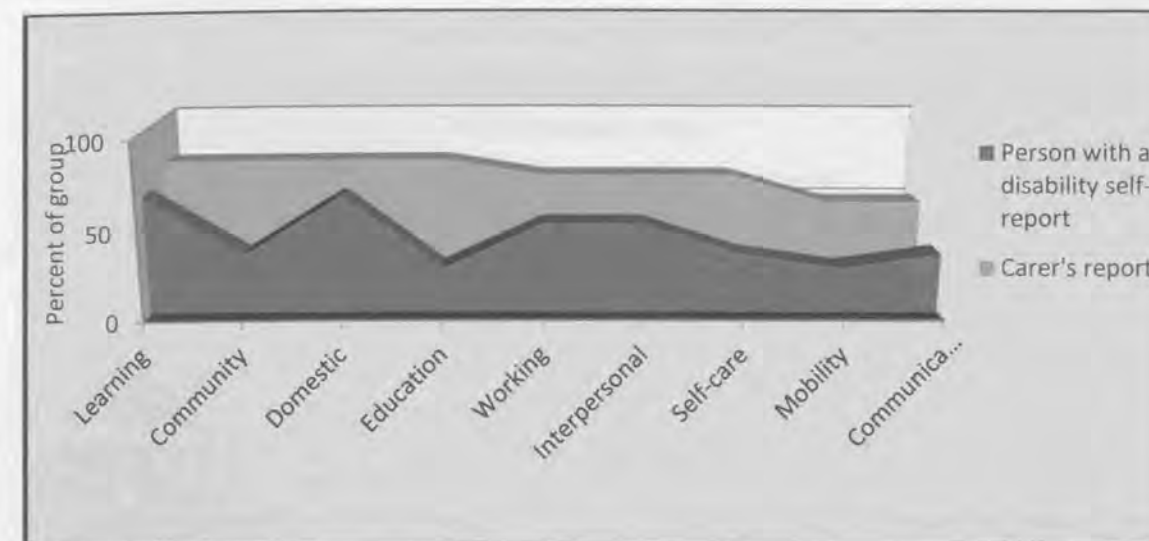


Figure 9: Level of support required - Carer's responses and Person with a disability self-report.

While only half of the group reported on required support with mobility and one-quarter of the self-report group did so; without this support, the person with the disability would be unable to conduct their everyday life.

Similar percentages in both groups require support with communication. While Carers become adept at communicating with the person they care for, without the ability to communicate effectively on their own, people living more independently may be unable to have their needs met.

Apart from education, the greatest difference in the needs of the two groups is with community and economic life. Approximately three-quarters of those cared for require support here, and by comparison, only one-third of the disability sample do.

Again this shows that the disability sample is more independent than the group reported on, and the differences reflect more than the different age groups. However half or more in both sample require support in at least four of the nine domains; half or more the sample being cared for require support in all nine domains.

4.8 Person with a disability Anxiety and Depression scores

Anxiety

The mean Anxiety score for the Person with a disability sample is 7.67. A score of above 10 is considered to be an 'abnormal' level of anxiety (Herrmann, 1997). In the Person with a disability sample 25.0% (n=6) scored an 'abnormal' level of anxiety.

Depression

The mean Depression score for the Person with a disability sample is 6.88. As with the Anxiety scale a score above 10 is considered to be 'abnormal' depression (Herrmann, 1997). In the Person with a disability sample 20.8% (n=5) scored an 'abnormal' level of depression.

When the Anxiety and Depression scales are combined, this gives a Psychological distress score, with a cut-off 12 (Pallant & Tennant, 2007); the mean for the Person with a disability sample is 14.54. In the Person with a disability sample 66.6% (n=16) scored 'abnormal' psychological distress.

5. Results – Services for people with a disability: survey results

This section reports on services for people with a disability investigated by the survey.

5.1 Accommodation/Living arrangements

It is because accommodation is so fundamental that considerable effort was expended in understanding the needs of people with a disability in this respect, through asking a range of questions. While accommodation is not in itself a 'service', frequently a particular type of accommodation or living arrangement is ideal or required for people with a disability. So it is in this sense considered a service in this context.

5.1.1 Accommodation best suited to the person with a disability

Respondents were provided with a list of possible accommodation options and asked to select the option considered to 'best suit' the person with the disability. Carers were asked 'What type of accommodation do you think would best suit the needs of the person you care for?' (Large residential – accommodating more than 20 people; Small residential 7-20 people; House/unit – living alone or sharing with other people with appropriate amounts of support; Village style – several people in unit accommodation in a supported village style environment which provides various facilities eg social, recreational; Other). People with a disability were asked 'What type of accommodation do you think would best suit your needs?', with the same answer options.

Carer's responses and Person with a disability self-report responses compared

The most frequently mentioned accommodation type, as 'best suited', for both groups is a house/unit, either alone or shared (Carer's response 38.5%; n=26; Person with a disability sample 43.5%; n=10) (Figure 10). For the Carer's this was followed by Village style supported accommodation (7-12 people)(21.7%; n=5), but the people with a disability who self-reported nominated Small residential (7-20 people) as their second preference (20.0%; n=12). The third most frequently selected 'best suited' type of accommodation for the Carer's response is Village style (7-20 people)(13.0%; n=12) and for the Person with a disability self-report it is Small residential (7-20 people)(15.0%; n=3). Neither the Carers nor the people with a disability selected Large residential (>20people). While 21.7% of the Carers selected the 'Other' category, the qualitative comments indicated there was a preference for a 'home-like' environment, with Carers referring to accommodation in 'their' home, or for the person with the disability have their own home (see Box 1). A similar percentage of the self-report disability sample also selected 'Other' and most open-ended comments suggested the same.

Box 1: Type of accommodation is 'best suited' to the person with the disability: 'Other' category – Carer's responses and Person with a disability self-report.

Carer's responses

With family (C04).

Not at the moment he is with family (C11)!

Own home ... because they all live together with me now ... (C32).

In their own home with some support (C39).

Own home (C16).

Person with a disability self-report

Already in his own home (PWD22).

Live by myself (PWD07).

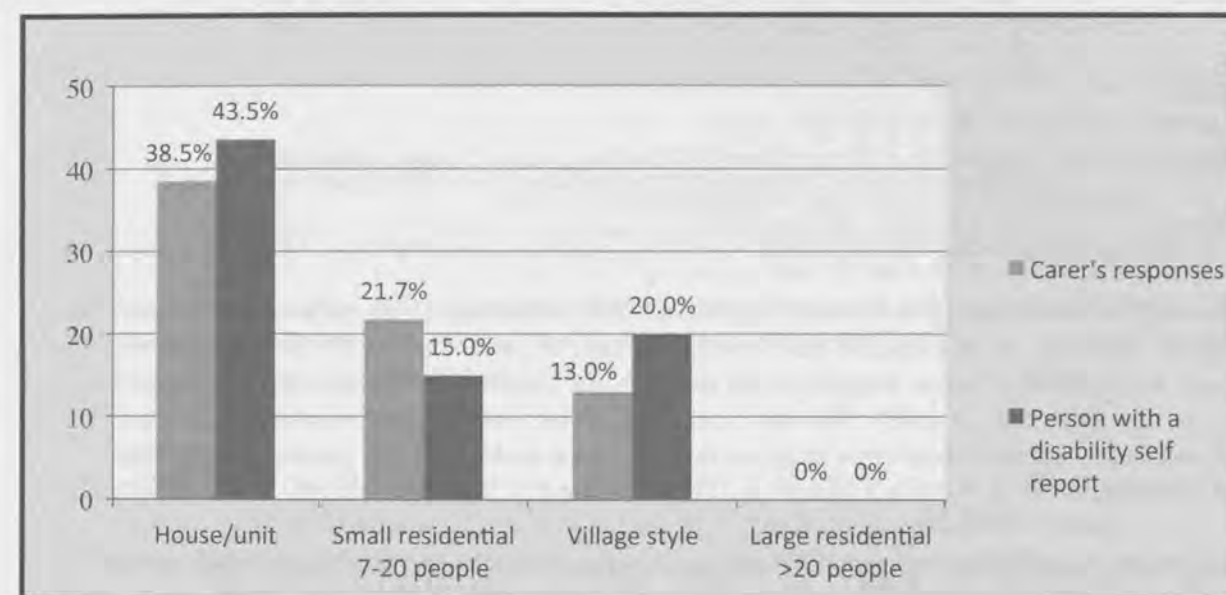


Figure 10: Accommodation best suited to the person with a disability – Carer's responses and Person with a disability self-report.

To better understand these choices respondents were asked to provide in open-ended format the reasons for this choice. The reasons that Carers gave for choosing the **house/unit** option varied (Box 2). Four comments referred to this suiting the personality of the person with a disability and two referred to this being safe. The people with a disability who chose the house/unit option indicated that family, pets and the company of others were important, with two comments about each. Other comments related to: this being the size of a family unit; the importance of being around people of a similar age; and being independent.

Box 2: Why respondents who selected the house/unit thought this 'best suited' the person with the disability.

Carer's responses

Suit personality

Sensitive to noise and others. Less people to bother (C18).

She doesn't like too many people around (C10).

This would best suit his personality (C26).

Very private person (C57).

Safe

... would allow for him to receive the care & attention he would need to be safe & happy (C40).

This would enable him to have a safe place whilst giving him the confidence he needs (C45).

Person with a disability self-report

Family

At home with family (PWD04). I live with my mum (PWD05).

Pets

You can have a pet bird (PWD06). Most places don't like pets (PWD06).

Company

Will be in a relationship (PWD16).

Then I wouldn't have to be lonely because I had no money to go anywhere and I wouldn't be imprisoned in a nursing home waiting to die (PWD04).

The reasons that Carers gave for believing that a **Small residential** (7-20) would be best suited varied (Box 3). Two comments indicated that the size/number of people was important; one comment was about the balance between independence and support and another because of the social nature of the person with the disability. The only reason given by a person with a disability for this choice related to the number of people and social aspect: 'More social with less people, small groups to talk to' (PWD08).

Box 3: Why respondents who selected the Small residential thought this 'best suited' the person with the disability.

Carer's responses

Size

Small numbers with nursing carers (C55).

X is very demanding and bossy at times so I think smaller numbers is better (C01).

Other

Because he gets on with groups of people (C30).

Independent with support (C15).

Why Carers thought a **Village style** of accommodation would be 'best suited' was largely for the social aspects this style of accommodation offers with four comments regarding this (Box 4). The only comment from a person with a disability was also about the social aspects. Three comments from Carers related to support; one chose because it was 'modern'.

Box 4: Why respondents who selected the Village style thought this 'best suited' the person with the disability.

Carer's response

Social

She is very sociable and loves outings (C27).

Greater scope for involvement in community (C24).

Because I want her to interact with other people (C14).

He likes to have friends around, going out (C06).

Support

I would like to see accommodation for people of similar ages available with proper support and recreational opportunities available (C29).

Village style sound nice – if there was enough support (C59).

It would seem more natural and able to support an individual's needs best (C23).

Persons with a disability self-report

I enjoy social activities ... (PWD15).

5.1.2 Current accommodation – of the person with the disability

Respondents were asked to select from a list where the person with a disability usually lives. They were asked 'Where does the person with a disability usually live?' (Private residence; Domestic-scale supported living; Supported accommodation facility; Boarding house/private hotel; Independent living unit within a retirement village; Residential aged care facility; Psychiatric/mental health community care facility; Hospital; Other).

Carer's responses

Over three-quarters (86.6%; n=58) of the persons with a disability reported on by Carers, not surprisingly, live in private accommodation; 4.5% (n=3) live in a supported accommodation facility and the same number are living in a hospital. Three percent (n=2) live in unspecified arrangements and one person lives in a residential aged care facility (Figure 11).

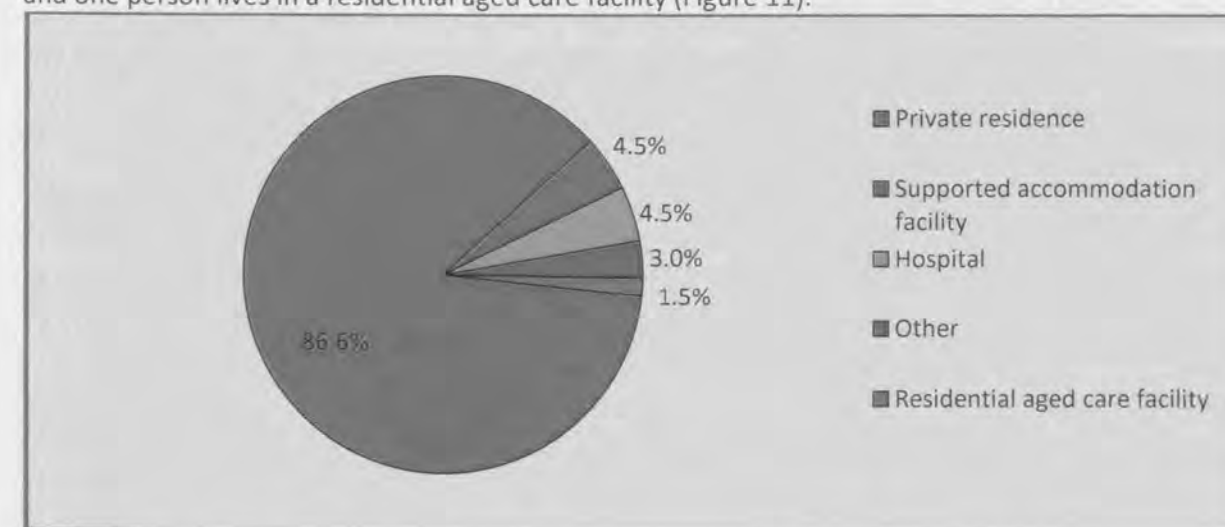


Figure 11: Type of accommodation the person with a disability currently lives in – Carer's responses.

Persons with a disability self-report

People with a disability were asked 'Where do you usually live?', with the same answer options as for Carers. Approximately two-thirds (65.4%; n=17) of these respondents report living in a private residence, and approximately one-quarter (26.9%; n=7) live in a supported accommodation facility. Less than four percent (3.8%; n=1) are living in an independent living unit in a retirement village (Figure 12).

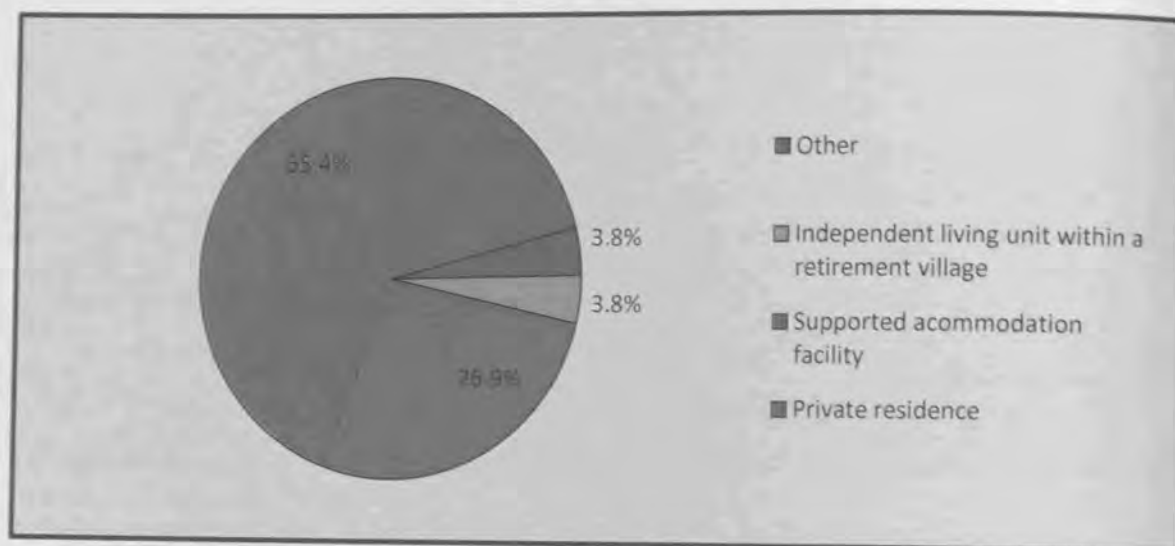


Figure 12: Type of accommodation the person with a disability currently lives in – Person with a disability self-report.

5.1.3 Current accommodation – who the person with the disability lives with

Questionnaire respondents were asked to select from a list of three items, whether the person with the disability lived alone or with others.

Carer's responses and people with a disability responses compared

Carers were asked 'Does the person with the disability usually live alone or with others?' (Lives alone; Lives with family; Lives with other). People with a disability were asked 'Do you usually live alone or with others?', with the same answer options. Not unexpectedly the majority of the Carer sample (87.9%; n=58) reported that the person with the disability lived with family. This is also where the largest group of the disability sample who self-report are living (40.0%; n=10). Only 9.1% (n=6) of those reported on by Carers live with others but 28.0% (n=7) of the disability sample who self-report live with others. Three percent (n=2) of those the Carers report on live alone but almost one-third (n=8) of the disability sample who self-report do so. The greater level of independence of the disability sample who self-report is apparent in who they live with. They are far more evenly spread between the three styles of living than those reported on by Carers (Figure 13).

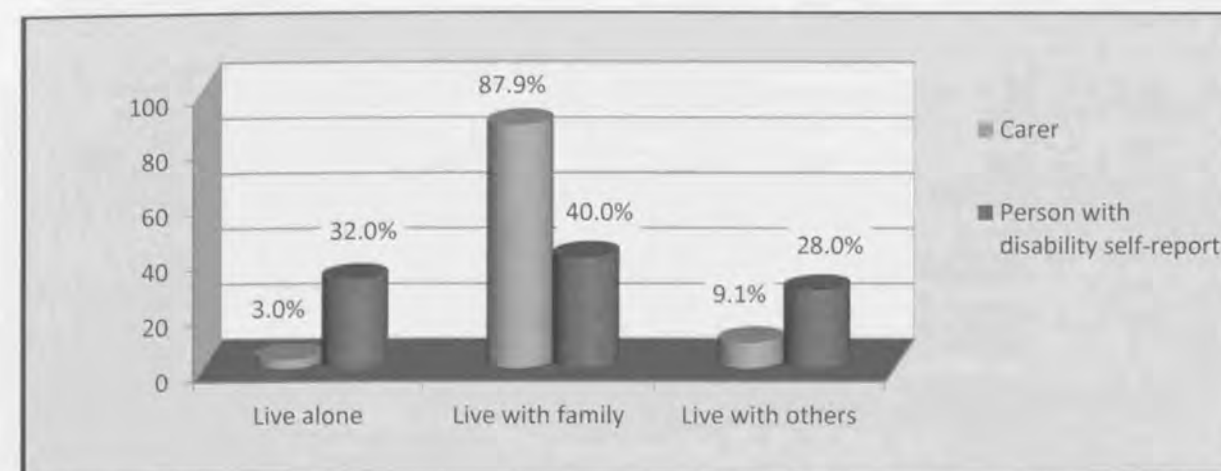


Figure 13: Who the person with the disability usually lives with - Carer's responses and Person with a disability self-report.

5.1.4 How long the person with the disability has lived in this accommodation

Respondents were asked to indicate how long the person with the disability has lived in 'this accommodation', in years. In the group reported on by Carers, this averaged 18.3 years, ranging from 1 to 50 years. By comparison the average for the disability sample is 15.8 years, but the range is the same. Half of those who Carers reported on have been in the current accommodation for 20 years or longer; one-quarter (n=14) for less than seven years and 8.0% (n=5) for just one year. In the disability sample, one-half (n=12) have lived in this accommodation for 10 years or longer; less than one-quarter (18.2% n=4) for three years and 13.6% (n=3) for just one year. So for both groups there is great diversity for the length of time lived in their current accommodation.

5.1.5 Suitability of current accommodation

An item about the suitability of current accommodation was asked, with the answer options on a 5 point Likert-like scale (5=Very suitable; 1=Very unsuitable).

Carer's response

Carers were asked 'How suitable is this accommodation for this person?' Almost half of the Carers (45.5%; n=25) reported they thought this accommodation was 'Very suitable'. Almost the same percentage (43.6%; n=24) thought it was 'Suitable'. Six percent (5.5%) were 'not sure'; 3.6% indicated it was 'Unsuitable' and 1.8%, 'Very unsuitable'. Therefore almost 90% of Carers indicated that they thought the current accommodation for the person with the disability was suitable (Figure 14).

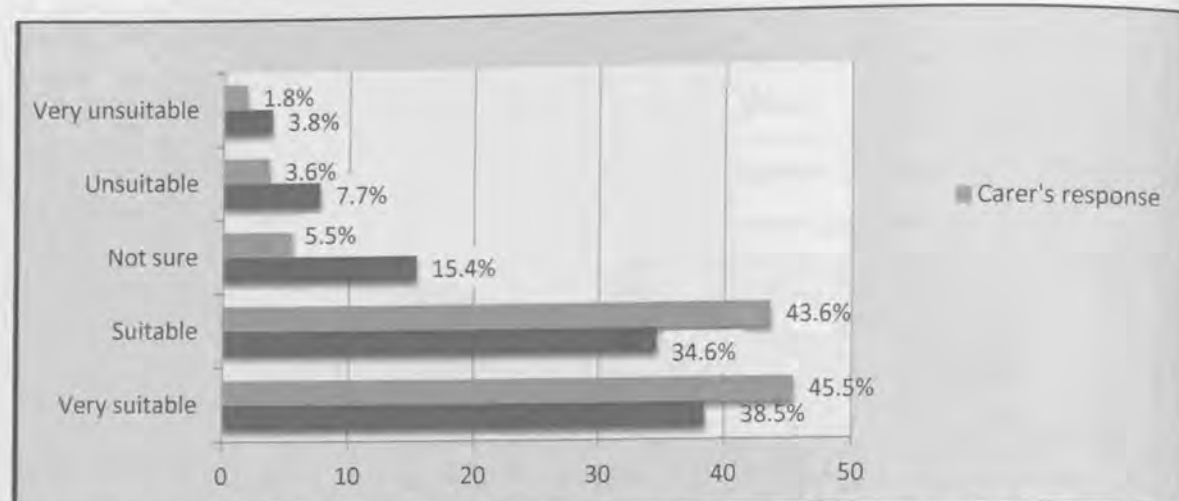


Figure 14: How suitable is this accommodation - Carer's response and Person with a disability self-report.

Respondents were asked to provide reasons for this answer, in open-ended format. Of those who indicated that they thought the current accommodation was **'Very suitable'**, nine of the fourteen comments indicated that it was because they lived with their family; for several of these the Carer indicated that it was because of the child's young age; three comments indicated that the suitability of the physical layout of the house was why they chose this response; two comments indicated that the location made it 'Very suitable' (Box 5).

Box 5: Why Carer's thought the current accommodation was 'Very suitable'.

Carer's responses

With family

He is happy, enjoys life with family (C11).
Family is best! 13 years of age (C35).
Likes to be with me ... (C57).
It's our culture to look after our own (C14).

House layout

He's able to get up and down the steps very well (C30).
Small and easy to clean and maintain (C05).

Location

Close to hospital and shops (C12).

Of the 19 comments explaining why Carers who indicated that the current accommodation was **'Suitable'**, the most frequent reasons given were that the need for a change in accommodation was expected, and the accommodation is suitable (4 comments each); followed by comments that indicated the rating was given because the person was being cared for by family, because of stress, and about the desire for more independent/life skills to be taught; (3 comments each); and two comments regarding distance (too great). So while most were remarks of a positive nature, some pointed out what was lacking (Box 6).

Box 6: Why Carer's thought the current accommodation was 'Suitable'.

Carer's responses

Change expected

Suitable now but as he and we get older maybe needs other accommodation options (C23).
It is suitable now as carer is able to monitor progress and address any short falls. Will become less suitable as carers age increases and capacity decreases (C45).
At present we can look after him but he is deteriorating and this may change (C55).

Accommodation suitable

... a well supervised, secure, staff v. Good (C54).
Everything she needs is there ... (C43).
Few steps/stairs and good bathroom/shave arrangements (C07).

With family

Parents are able to care for her (C53).
As X lives at home with family she is well looked after (C01).

Stress

He needs constant support, supervision & interaction – more than we can afford to purchase (C40).
He has behaviour problems & aggression (damages property, sometimes physically abusive) (C27).

Desire for more skills to be taught

Preparing him for more independent living and teaching living skills (C44).
It was her choice I feel they could be more proactive in advancing her life skills (C48).

One reason was given why the Carer was **'Not sure'** about the suitability of the accommodation – 'My son is comfortable in this living situation but it doesn't allow him to attend work/or activities more often because of distance. It also isn't helping him to prepare for the future' (C29). One also for the accommodation being **'Unsuitable'** – 'No bathtub, old, dusty and on railway line, does not have own room' (C51).

Person with a disability self-report

People with a disability were asked 'How suitable is this accommodation?'. More than a third (38.5%) rated it as 'Very suitable', a similar percentage (34.6%) rated it as 'suitable'; 15.4% were 'Not sure', 7.7% indicated 'Unsuitable' and 3.8% 'Very unsuitable'. So almost three-quarters indicated they found their current accommodation suitable (Figure 14).

The only comment made relating to accommodation being **'Very suitable'**, when respondents were asked to give reasons for their choice of rating, indicated that it was because this person was living with 'my mum' (PWD05). Three of the nine comments explaining the choice of **'Suitable'** accommodation were about physical aspects of the house – two positive and one indicating that changes would be desirable. Two comments were about a positive capacity for independence and two indicating that distance was a problem. As with the Carer's responses, some of the remarks indicate how the current accommodation could be improved upon (Box 7).

Box 7: Why People with a disability thought the current accommodation was 'Suitable'.

Person with a disability self-report

Physical aspects of house

I need a walk-in shower, the shower at the moment has a high step into it (PWD06).
... I designed and built this house, we love it and hope to be able to stay here (PWD01).

Independence

Learning to live independently and learning life skills (PWD02).
To be more independent, negative – mum is further away (PWD03).

Distance

Bit far away from shops/doctor, comfortable home (PWD13).
Distance from shops and Dr. (PWD15).

Of the two comments referring to the choice of 'Not sure' about the suitability of the accommodation, one comment was about the neighbours, and another noting the accommodation with more support may be required in the future.

The reasons for choosing 'Unsuitable', varied: one mentioned that mental needs were not catered for; in a similar vein another comment indicated that it was crowded, however added that 'sometimes [it] is ok to have help around' (PWD09); the third reason indicated a preference for independent living in the community.

In summary

Almost 90% of Carers indicated they thought the current accommodation for the person with the disability was suitable and almost three-quarters of the people with a disability indicated the same. The qualitative data provides insights into why this accommodation is suitable and importantly what is lacking or problematic with the current accommodation. In summary the elements making the current accommodation suitable in the Carer's view are:

- With family
- Physical structure/layout of house
- Proximity to desired services (e.g. shops, hospital)
- Adequate supervision and support
- Stress of the self-provision of care because of high needs/difficult behaviour

What is considered lacking by Carers is:

- While currently suitable, will not remain so because of ageing of carers/deterioration of condition of person with a disability
- Adequate teaching of independent living skills
- Close proximity to desired services/activities (e.g. work)
- Old, dusty, and noisy
- Lack of privacy

Elements the people with a disability reported that made the accommodation suitable:

- Physical structure/layout of house
- living independently and learning life skills

What is considered lacking by people with a disability who self-reported is:

- Suitability of the physical structure/layout of house
- Close proximity to desired services (e.g. shops, doctor)
- Crowding

The most frequently mentioned elements here are proximity to desired services/activities and the physical structure/layout of the house. Both are mentioned as assets and problems with the current accommodation. Accommodation in close proximity to shops and health services is considered an asset is does a house that promotes ease of movement within it, with the opposites identified as what contributes to making the current accommodation less suitable. An element mentioned by both groups is the learning/teaching of independent living skills.

5.1.6 How happy the person with the disability is, with the current accommodation

Respondents were asked how the person with the disability felt about their current accommodation and provided with a 5 point Likert-like scale (5=Very happy; 1=Very unhappy) to answer.

Carer's responses

Carers were asked 'How do you as a carer think the person with the disability feels about his/her accommodation arrangement?' More than half (55.2%; n=37) of the Carers reported they thought the person with the disability was 'Very happy'. Just fewer than a third (29.9%; n=20) selected 'Happy'; 10.4% were 'Not sure'; and 4.5% indicated they thought the person with the disability was 'Unhappy'; nil reported 'Very unhappy'. Carers therefore report that 85.1% of the people with the disability who they care for are happy with their current accommodation (Figure 15).

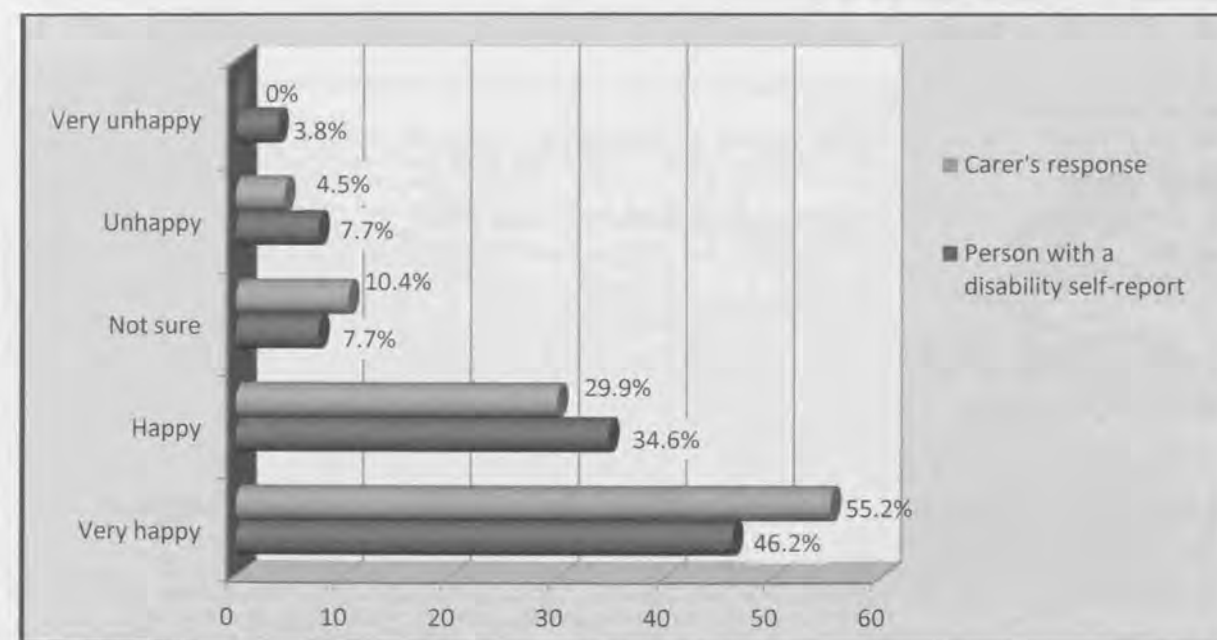


Figure 15: How happy the person with the disability is with the current accommodation – Carer's responses and Person with a disability self-report.

In order to gain insights into why the person with the disability may be happy or otherwise with the current accommodation, as perceived by their Carer or directly from themselves, questionnaire respondents were asked to give reasons for their answer.

When asked to give reasons for this response, of the 13 comments made by Carers regarding why 'Very happy' was selected, three comments each were made about: the person having their own space; being with family; and being relaxed (Box 8).

Box 8: Why Carers reported the person with a disability was 'Very happy' with the current accommodation.

Carer's responses

Own space

New home, own bedroom and bathroom, own room to enjoy their music etc. (C05).
Because he can do his own thing etc. (C32).

With family

Our son likes being at home ... (C59).
Likes to be with me (C57).

Being relaxed

He does not like change and as he has lived here for a long time feels quite comfortable (C17).
... is more relaxed at home (C57).

The Carers who indicated that the person they cared for was 'Happy', gave a range of reasons for this rating. Family was mentioned in two contexts (3 comments): two comments indicated that the person missed being with their family, and the other that they were with their family. Two comments each were about the importance of friends, and distance (Box 9).

Box 9: Why Carers reported the person with a disability was 'Very happy' with the current accommodation.

Carer's responses

Missing family

She is independent and with her friends but misses her family (C48).
Happy enough (but wants to come home). He wants to come home (we say for a visit, but he thinks permanently) (C49).

Friends

She is happy enough but also enjoys sleep-overs with her friends at respite (C27)

Distance

He is happy living at home but has to rely on me for him to attend supported work as we live on a farm x kms from Warwick and have no public transport (C29).

Of the five Carers who indicated they were 'Unsure' how happy/unhappy the person with the disability was, they said it was because of difficulty communicating with the person (Examples are: Difficult to communicate with patient due to his disorder (C54); He seems very happy – he can't express himself clearly (C30); Unable to communicate (C38). The one comment indicating that they thought the person with the disability was 'Unhappy', said it was because: '... we are all crowded ...' (C08).

Person with a disability self-report

People with a disability were asked 'How do you feel about your accommodation arrangement?' Forty-six percent (46.2%; n=12) of the people with a disability said they were 'Very happy', more than a third (34.6%; n=9) indicated they were 'Happy', 7.7% were 'Not sure', 7.7% were 'Unhappy' and 3.8% were 'Very unhappy'. In summary almost 81% of respondents with a disability reported being happy with their current accommodation (Figure 15).

When respondents were asked to give reasons for their choice of rating in open-ended format, those who chose 'Very happy', indicated this was so because of family reasons (2 comments) and that they were contented (2 comments) (Box 10).

Box 10: Why the person with a disability reported being 'Very happy' with the current accommodation.

Person with a disability self-report

Family

I can tease my sister (PWD21).
Happy because my sister and my dog are here (PWD17).

Contented

Positive – minimal maintenance etc. companionship – social activities, Negative – Nil (PWD11).
Being able to have the land that we love and a house that suited our life and family; only thing is most our family have moved away (PWD01).

The reasons that respondents gave for selecting 'Happy' about their current accommodation varied: three indicated that they are well supported; two indicated that more support was needed – respite; house management; one indicated that distance was an issue. So while respondents are indicating why they are happy with their current accommodation they are also providing reasons why it is less than ideal (Box 11).

Box 11: Why the person with a disability reported being 'Happy' with the current accommodation.

Person with a disability self-report

Well supported

Have good neighbours and caring friends who check on me (PWD15).
Happy to live with husband. Good neighbours (PWD08).
Has nice bathrooms; staff support me; people fighting (PWD20).

Support needed

House too large to manage like where I am (PWD07).
Need more respite accommodation (PWD08).

Distance

Bit far away from shops/doctor, comfortable home (PWD13).

The reason given for being 'Not sure', was that initially this person was happy, but 'due to changed circumstances now unhappy' (PWD24). Those who gave reasons for choosing 'Unhappy', mostly gave the same reasons as for the accommodation being unsuitable.

In summary

Similar percentages of Carers and people with a disability who self-reported indicate that they are happy with their current accommodation – Carers 85.1%, and People with a disability almost 80.8%. These are similar percentages to those reported for the suitability of the accommodation. Carers and people with a disability gave different reasons for being happy/unhappy with their current accommodation. Why Carers thought the person with the disability is happy are:

- They have their own space
- They are with family
- They are relaxed in their current environment

The elements that result in the Carer perceiving that the person with the disability is less happy than would be possible are:

- Missing family
- Lack of close proximity to desired locations

The reasons that the people with a disability gave for being happy with their current accommodation are:

- With family
- Are contented
- Are well supported

Why the people with the disability were less happy than would be possible are:

- Inadequate support/respite
- Lack of close proximity to desired services.

Common to both groups is the importance of family and the desire for close proximity to desired locations/services. Important points for those with a disability are being contented and well supported.

5.1.7 Independence regarding accommodation and living arrangements

Respondents were asked to indicate ('Yes' or 'No') if they would like to see the person they care for/ or themselves, continue to have the opportunity to become progressively independent in their accommodation and living arrangements. An open-ended question requesting reasons for this choice followed this question.

Carer's responses

Carers were asked 'Would you like to see the person you care for continue to have the opportunity to become progressively independent in their accommodation and living arrangement?' Eighty-three percent (83.3%) of Carers answered 'Yes' to this question. The most common reason given in the open-ended section of the question, for this choice was regarding the importance of independence (11 comments). There were an almost equal number of comments referring to ageing as a reason for wanting the person they care for to continue to have the opportunity to become increasingly independent, and those saying increasing independence was not an option (9 and 8 comments respectively) (Box 12).

Box 12: Preference for person with a disability to have ongoing opportunity to become progressively independent in living and accommodation arrangements – Carer's responses.

Carer's responses

Importance of independence

The change is what we would like to see to help him on the journey of independence as we age and for his own sense of self so his independence is not forced upon him because we have died!

So he has time to learn and adjust with our support. Important for his own self esteem (C23).

Yes, so they can be self sufficient (C58).

She wants to be closer to Warwick and her friends (C43).

Yes with assistance and motivation, support and guidance from myself and others when grow older can be independent (C51).

Important for everyone to have opportunity to grow up and leave home. Not be dependent upon parents (C35).

Ageing

I'm not going to be around forever to look after them (C12).

There will undoubtedly come a time when I can't look after her & she need to transition (C19).

As we are getting older she will need some sort of future (C01).

If something happens to us, we're getting old (C14).

Not possible

But he will always need supervision and care (C49).

Not capable of living independently (C24).

As she is deteriorating and will only get worse, there is no chance of that happening (C25).

Person with a disability self-report

People with a disability were asked 'Would you like the opportunity to become progressively independent in your accommodation and living arrangement?' More than half (52.4%) said 'Yes'. When asked to give reasons for this in an open-ended format, for three people this represented a goal, for two people this meant staying were they were; the possibility of changing circumstances for two were suggestive of greater independence; and distance from town was mentioned as an issue by one person (Box 13).

Box 13: Preference for person with a disability to have ongoing opportunity to become progressively independent in living and accommodation arrangements – Person with a disability self-report.

Person with a disability self-report

A goal

Yes I would like to be more independent and not need a 24 hour carer (PWD02).

I've always wanted that kind of accommodation (PWD19).

Yes I would like to be more independent and not have to call mum every time I kicked my toe and lose my phone (PWD03).

Staying

Yes, I would like to be able to stay here (PWD01).

Yes, do not really want to shift (PWD07).

Distance

Stuck where I am, have to get taxis all the time, want to be more independent, bit closer to town (PWD24).

Of those who said 'No' to this question, two comments indicated that they were satisfied where they were, and two inferred that their support needs would prevent this from occurring; the fifth comment indicated that more independence would result in loneliness: 'Then I'd always be alone' (PWD04).

While more than three-quarters (83.3%) of the Carers indicated that they would like the person they care for to continue to have the opportunity to become progressively independent in their accommodation and living arrangements just over half (52.4%) of the people with a disability indicated that they would like this opportunity. The Carers stressed the importance of independence even though a number indicated that this was not possible in their case. For some of the people with a disability, increased independence was a goal while others appeared to have reached that goal.

5.1.8 Expected change in accommodation needs

The questionnaire respondents were asked to indicate if they foresaw a change in the person with a disability's accommodation needs, and were given five answer options ('No, I do not foresee any change'; 'Yes within 1 year'; 'Yes within 2-5 years'; 'Yes in 5-10 years'; and 'Yes over 10 years'). They were asked to provide their reasons for this choice in an open-ended format.

Carer's responses and Person with a disability self-report compared

Carers were asked 'Do you foresee a change in this person's accommodation needs in the future?'; people with a disability were asked 'Do you foresee a change in your accommodation needs in the future?' The majority of Carers and people with a disability selected 'No, I do not foresee any change' (Carers 44.4%, n=28; Person with a disability 53.8%, n=14). The next most frequently selected option was 'Yes within 5 to 10 years, with almost one-third of Carers (30.2%; n=19) and more than one-quarter of people with a disability (26.9%, n=7) nominating it. Approximately 10% of the Carers and people with a disability indicated they expected a change within one years (Carer's response 9.5%, n=6; Person with a disability 11.5%, n=3). This represents a high level of consistency between the two groups for the responses to this question (Figure 16).

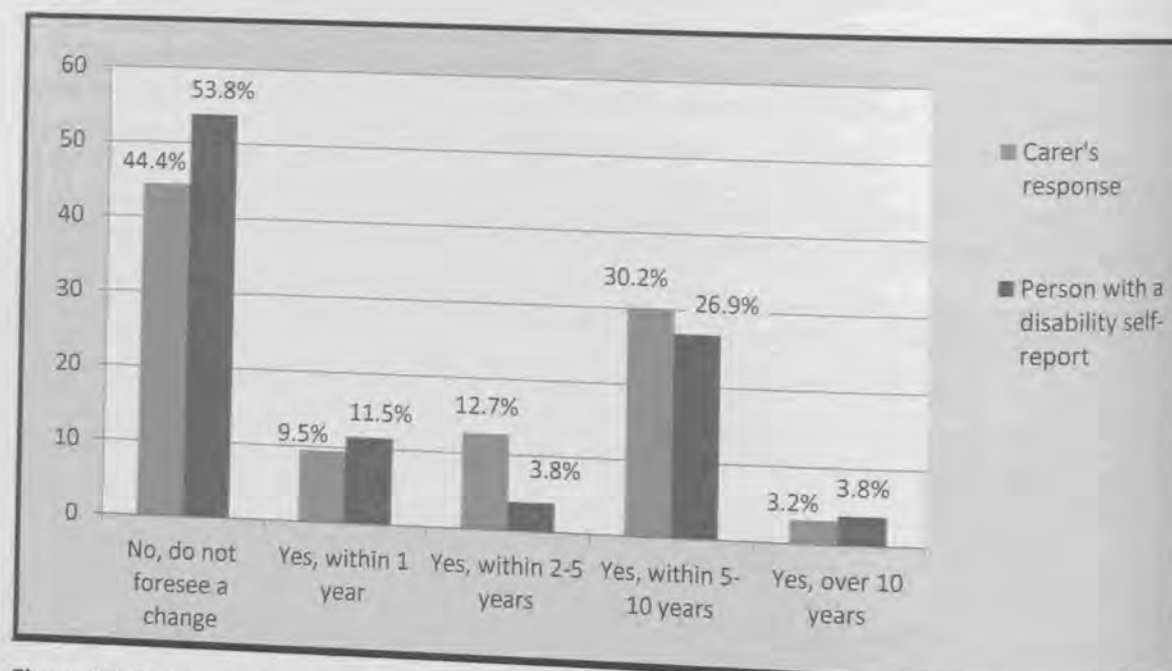


Figure 16: Foresee a change in accommodation needs of the person with a disability in the future - Carer's responses and Person with a disability self-report.

When Carers gave their reasons for their choice of answer, of the eight comments relating to 'no changed expected', three reported that it was because the person with the disability was happy and three referred to the Carer being able to continue providing care for the foreseeable future (Box 14).

Box 14: Do not foresee a change in the person with the disability's future accommodation needs - Carer's responses.

Carer's responses

Happy

He seems happy, relaxed where he's living at the moment (C30).

We live on a farm which he loves (C06).

Happy where she is (C57).

Carer to provide care for the foreseeable future

Because I am happy taking care of X until ill health stops me (C32).

Until my death (C11).

With her disabilities her life span is about 40. Depending on what happens to her health she may need to go into a nursing home when I can't look after her any longer (C25).

Only two people with a disability provided reasons for indicating that they did not foresee a change in the future accommodation needs. One remark indicated that the person was 'happy where I am' (PWD03) and the other remark was 'I don't know' (PWD06).

Of the Carers who perceived that a change to accommodation would be needed in the next **5-10 years**, the most common reasons given for this choice are because the Carer would no longer be able to provide care, and the desirability/need for independent living for the person with the disability (5 comments each); two comments indicated that changed accommodation would be needed because of the progressive deterioration in health caused by the disability (Box 15).

Box 15: Foresee a change in accommodation needs of Person with a disability in 5-10 years - Carer's responses.

Carer's comments

Unable to continue providing care

I will get older and be unable to physically care for him anymore (C58).

We the parents/carers are getting older and it is becoming too hard (C27).

Needs to be set up with peers before we are too old to look after him (C41).

Would like her to experience assisted independent living; I may not be able to physically take care of her any longer (C19).

Desirability of independent living

We feel both x could manage, with some support, to stay in the current home (C39).

He needs to be able to survive on his own (C18).

Imaging he will wish to attempt independent living. Don't know what options he will have. (C35).

Progressive deterioration

Disability is progressive in nature (C07).

The people with a disability who chose the 'change expected in 5 to 10 years' gave quite different reasons to the Carers who selected this option. For the people with a disability, five of the seven comments reported that it was because their disability is causing progressive deterioration; one referred to a relocation goal and one also reported that the Carer was aging and one reported wanting more independence (Box 16).

Box 16: Foresee a change in accommodation needs of Person with a disability in 5-10 years – Person with a disability self-report.

Person with a disability self-report

Degeneration

- Continued deterioration (PWD07).
- Disability will deteriorate as disease takes over (PWD08).
- Disability is progressing (PWD13).
- My disability is a slow degenerative condition – The care giver is also aging (PWD11).

Carers who indicated they expected a change in accommodation to be required **within the next 2 to 5 years**, reported most often that it was because of a combination of the Carer's decreasing capacity to provide care and the person with the disability's need for more independent living (3 comments). No reasons were given by the people with a disability for this time period (Box 17).

Box 17: Foresee a change in accommodation needs of Person with a disability in 2-5 years – Carer's responses.

Carer's responses

- A combination of our capacity and his choices would make this appropriate (C45).
- The change is what we would like to see to help him on the journey of independence as we age and for his own sense of self (C23).

The four remarks made by Carers for choosing 'within 1 year', had no pattern, but mentioned ageing (of parents), and the need for more support in order to continue providing care, looking for cleaner housing and a smaller house. Similarly, the reasons given by the people with a disability had no pattern. One reason was related to the physical deterioration, one who wanted to relocate out of the area and the third expressed a desire for their own accommodation, but with some support.

The two reasons given by Carers for choosing the 'more than 10 years' option were about them ageing. The only reason given by a person with a disability for this choice was mention of having ramps installed. This is consistent with remarks made about the disability progressively deteriorating.

In summary, while Carers believed that for 89.1% the current accommodation for the person with a disability that they cared for was suitable, and also believed that 85% were happy. However almost a third expected the needs of the person with the disability to change within the next 5 to 10 years. In addition more than 80% of the people with a disability reported being happy with their accommodation and more than 70% said it was suitable, more than a quarter indicated that their needs would change within the next 5 to 10 years.

5.1.9 Accommodation and respite available

Respondents were asked to select from a list, the types of accommodation currently available to the person with a disability (Long term supported accommodation with high needs and 24 hours care; Long term shared accommodation with a low level of support; Transition to care; Respite care (planned); Emergency respite care; Short term recreational accommodation; Community housing – Clusters; Community housing – Independent living).

Carer's responses and Person with a disability self-report compared

Carers were asked: 'Please indicate which of the following types of accommodation are currently available to the person with the disability; people with a disability were asked: 'Please indicate which of the following types of accommodation are currently available to you'. With the exception of respite care, consistently the Carers report lower availability of each type of accommodation than the people with a disability who self-report (Figure 17). This result is difficult to interpret. It is possible that respondents are only aware of the types of accommodation that they/those they care for currently need. Alternatively, the group cared for have more care needs.

While respondents were not asked to indicate if their accommodation needs were met, in this question, other results show that the greater majority of people with a disability in this study live in private accommodation, largely find it suitable and generally are happy there. The results from the current question though, suggest that the alternatives are few.

These results suggest that the accommodation landscape for people with a disability in the Warwick district has significant gaps.

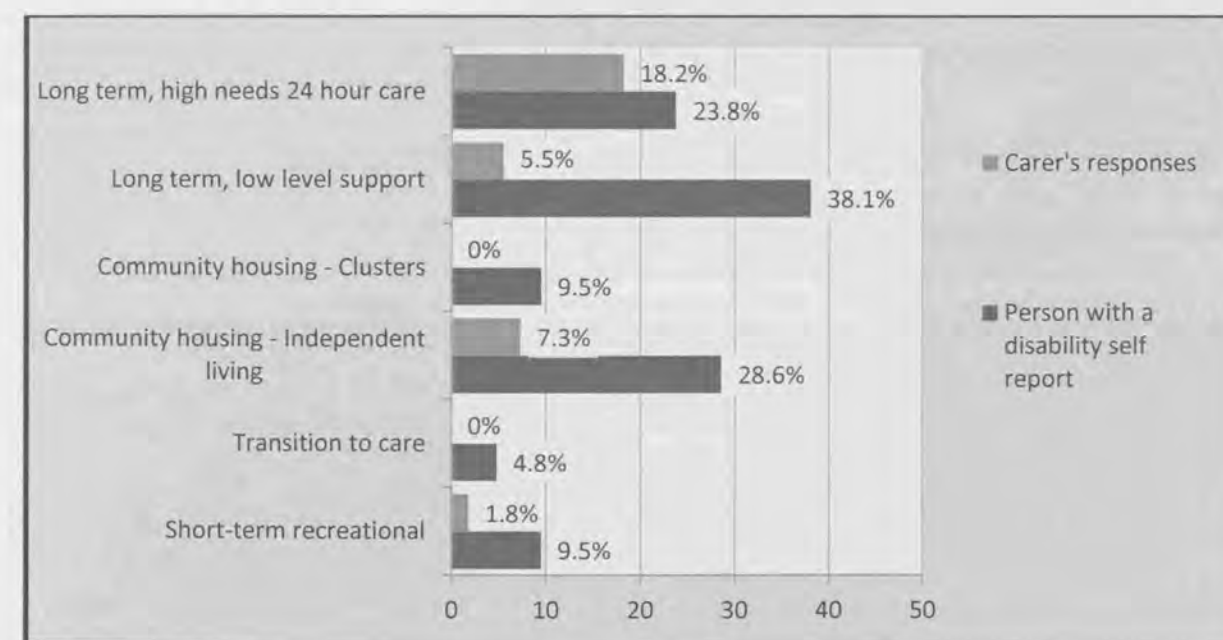


Figure 17: Accommodation currently available – Carer's responses and Person with a disability self-report.

In contrast to the more permanent types of accommodation (except short term recreational), Carers report greater availability of both planned and emergency respite care, than the people with a disability (Figure 18). Just over one-third (38.2% n=21) of Carers report having access to planned respite yet less than ten percent (9.5%; n=2) of people with a disability who self-report do. Almost one-quarter (23.6%; n=13) of Carer report access to emergency respite while 14.4% (n=3) of people with a disability do so. However it is Carers who are far more likely than people with a disability to

need respite care. It is concerning to note therefore that only approximately one-third of Carers can access planned respite, and fewer - less than one-quarter, can access emergency respite care.

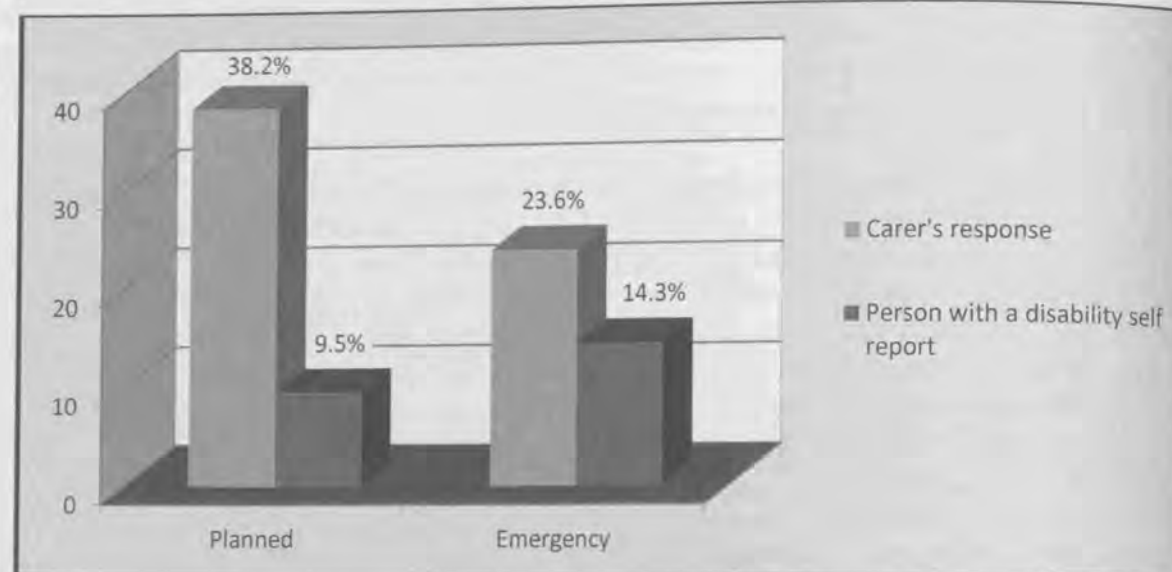


Figure 18: Respite care currently available – Carer's responses and Person with a disability self-report.

5.1.10 Current and past problems with accommodation

Carers and people with a disability were asked to provide positive and negative comments on current or past 'problems, obstacles, choices, difficulties and concerns' with accommodation.

Carer's responses

While there are diverse comments here, the most frequently mentioned issues are: limits to respite; limited long term supported accommodation; lack of choice in accommodation; lack of accommodation for special needs; limits to housing (Box 18).

Box 18: Current and past problems with accommodation – Carer's responses.

Carer's responses

Limits to respite

- Respite care needs to be planned weeks ahead (C01)
- Day respite Blue Care not very stimulating, boring (C15)
- In Warwick there is only limited respite available (C19)
- Need to plan a long way ahead for respite (C55)

Limited long term supported accommodation

- No long term available particularly without a 'package' (C24)
- We need more supported accommodation in Warwick (C44)
- No suitable supervised accommodation available (C29)

Lack of choice in accommodation

- There's not a lot of places for people with a disability in the country (C06)
- Lack of choice regarding type of service, high demand/lack of availability from few providers (C58)
- There is no recreational accommodation, no emergency care, little respite and no real transition option (C45)
- No future option in Warwick! (C35)

Lack of accommodation for special needs groups

- No aged care accommodation for men with disability in Warwick (C05)
- Accommodation is unable to administer medication, therefore it isn't really a rest for me (C20)

Limits to housing

- Because of bad behaviours and mood swings the house has to be suitably adjusted eg Perspex in vulnerable windows ... (C49)
- Showering – needs to be more hand rails in the house ... (C42)
- ... need bigger house with more rooms and bathtub and heating and cooling (C51)

Person with a disability self-report

When people with a disability were asked this same question, they also spoke of limits to accommodation in Warwick. Comments were mainly about availability; and house structure (Box 19).

Box 19: Current and past problems with accommodation – Person with a disability self-report.

Person with a disability self-report

Availability

- It was difficult to get into supported accommodation in Warwick (P02)
- Affordability and available of suitable accommodation (P07)

House structure

- Floors cement without the proper thickness of rubber backed carpet online increase pain of osteoarthritis in lower spine and legs (P04)
- I would like a place that I could get around in, wheelchair height and access to everything and walk-in shower (P06)
- Mobility issues are a concern (P13)

5.1.11 What is impacting on future accommodation needs

Carers and people with a disability were asked in an open-ended format question, 'Please tell us what is impacting upon the future accommodation needs'.

Carer's responses

The most frequently issue Carers mention is lack of availability; this is followed by lack of choice; what will happen when the Carer is able to provide care; the level of care required; and independence (Box 20).

Box 20: Impacts on future accommodation needs – Carer's responses.

Carer's responses

Lack of availability

- Availability and affordability (C40)
- Availability when needed, probably at short notice (C43)
- No suitable supervised accommodation available (C29)
- Lack of accommodation for her age group, only aged care and mentally disabled available (C15)
- Availability of appropriate accommodation/care (C26)
- Lack of accommodation options (C23)

Lack of choice

Lack of choice regarding type of service ... No appropriate long term care facilities for high care needs especially for children, poorly run services (C58)
His need will become high care and there is only aged care available (C55)

Carer unable to provide care

Upon my death! (C11)
If I am no longer able to care for my daughter, I worry about what will happen to her (C19)
If anything happens to us ... who will look after him and his brother and sister (C06)

Level of care required

High care level required (C17)
She is starting to progress on a downhill (C42)

Independence

If she can become independent or not (C10)
Being able to look after herself (C57)

Person with a disability self-report

When people with a disability responded to this question, most comments were about funding, but mobility issues and declining health were also mentioned (Box 21).

Box 21: Impacts on future accommodation needs – Person with a disability self-report.

Person with a disability self-report

Funding

Great need for more funding to run these & more of these types of (supported) accommodation (P02)
Lack of funding for support worker (P19)
Getting cheap accommodation through Qld Housing and getting help to do some things (P09)
Lack of accommodation for young disabled; lack of government (at all levels) support (P08)

Mobility

Lack of mobility

Declining health

Declining health (P04)
I have crippling arthritis and about 36 other disabilities to cope with (P06)

5.2 Day Activities

Respondents were asked to select from a list of activities, firstly those that the person with the disability/themselves would participate in if they were available, then which of this same list of activities is currently available to them.

Carer's responses

Carers were asked 'Listed below are the types of day activities that adults with a disability may wish to participate in. Please indicate which of these activities the person you care for currently would participate in if they were available'. Figure 19 shows that for the Carer report group demand outstrips supply with day activities. It is apparent that there are gaps with the availability of activities. The percentages that Carers report their person with the disability WOULD participate in if available is higher than for percentage reported for the AVAILABILITY of that activity for all activities listed except 'Day activities – Other'. The largest gaps are with recreational activities (73.7% and 35.2%) recreational trips (64.9% and 25.9%) and Skills for independent living (43.9% and 9.3%). However no less important are gaps with Long hours day care (15.8% and 3.7%), School holiday day care (8.8% and 1.9%) and Education for literacy and numeracy (31.6% and 20.4%).

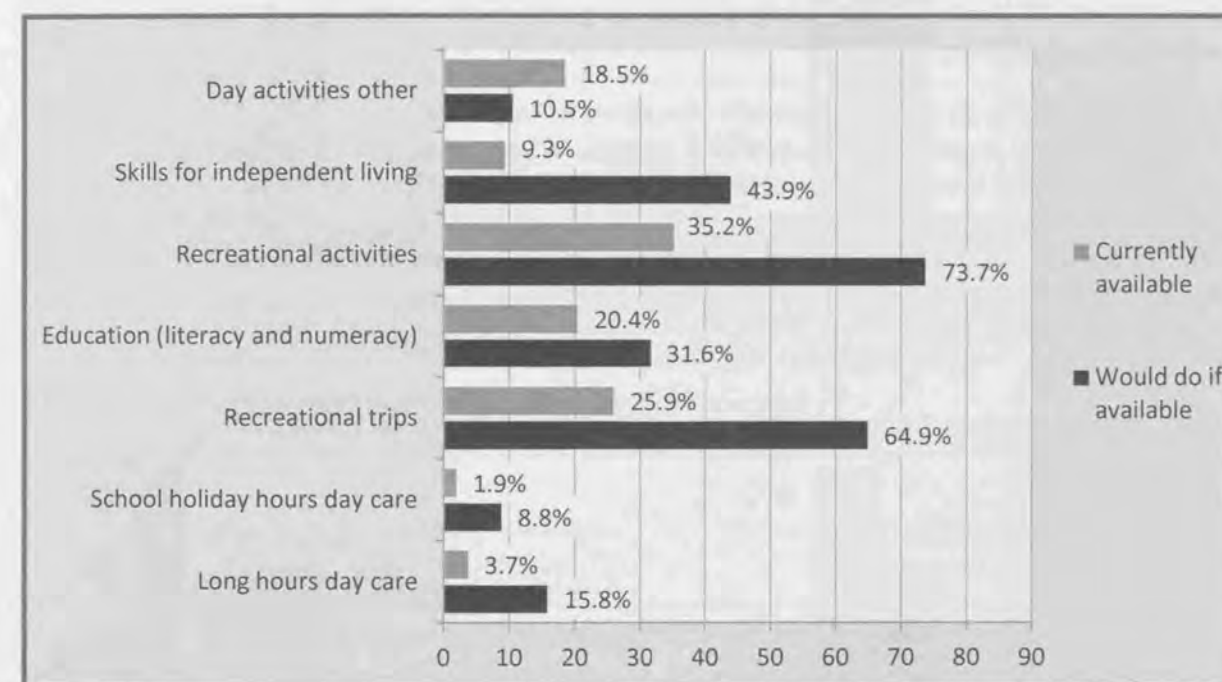


Figure 19: Activities - what is available and what the person with a disability would participate in – Carer's responses.

Person with a disability self-report

People with a disability were asked 'Listed below are the types of day activities that adults with a disability may wish to participate in. Please indicate which of these activities you would participate in if they were available'. The results from the disability sample reflect a very different situation for this group (Figure 20), when compared to that reported by Carers. The difference is that while demand outstrips supply for four of the five types of activity (Recreational trips; Recreational activities; Skills for independent living; Other Activities), the difference is very small when compared to the Carer's responses. However the largest gap is in an area that is of fundamental importance for a sample where many are living independently – Skills for independent living (40.9% and 23.8%).

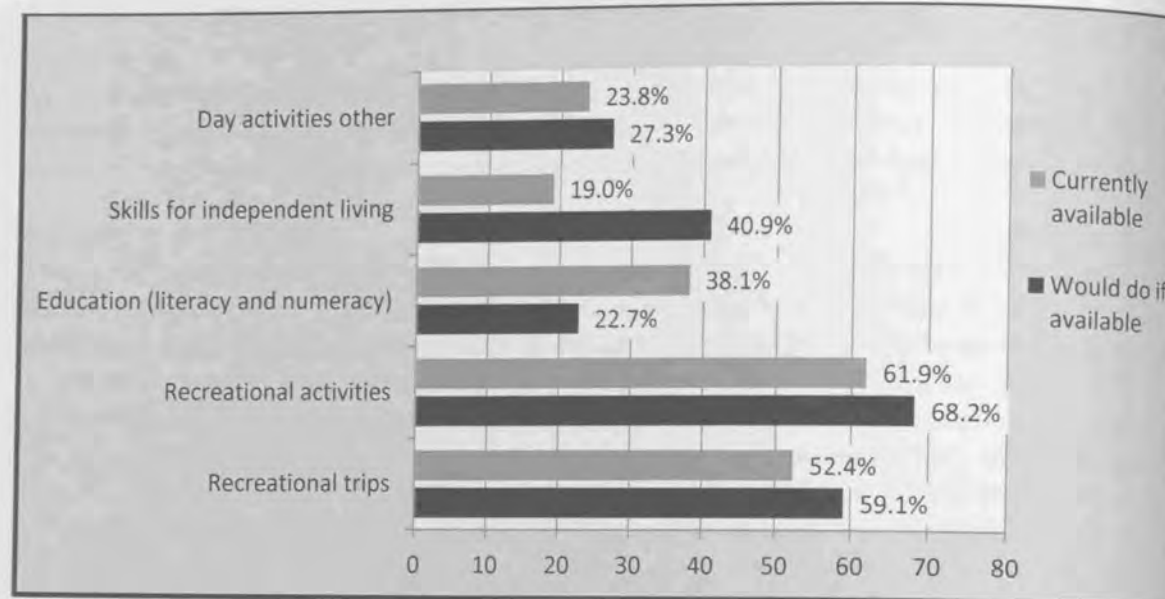


Figure 20: Activities - what is available and what the person with a disability would participate in - Person with a disability self-report.

The study demonstrates that for these samples, there are significant unmet needs for day activities for people with a disability in the Warwick district. While the largest gaps in services for day activities are in the provision of recreational opportunities (trips and activities), as reported by Carers and the self-report disability sample, of more fundamental importance are the unmet needs for day care (long hours and School holiday) for the Carer sample and opportunities to learn skills for independence reported by Carers and the disability sample.

5.3 Transport

The respondents were asked to select from a list (Usual car travel; Public transport [e.g. bus, train]; Transport purpose built for a person with a disability [e.g. Maxi taxi] the type of transport the person they care for/themselves currently require, then which types on the same list are currently available

Carer's responses

Both Carers and the people with a disability report that transport needs are largely met. Almost all of those who require usual car for transport are able to access this and all those who require taxi travel are able to. There are gaps with public transport and purpose built transport. The supply of public transport and purpose built transport is reportedly greater than the supply (Figures 21 and 22).

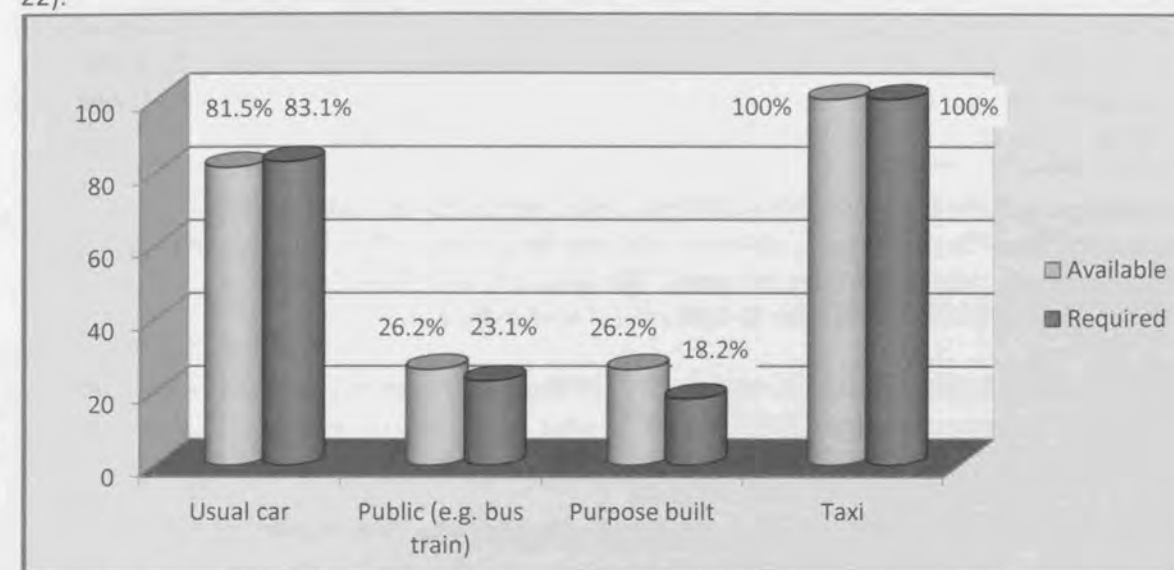


Figure 21: Transport available and required – Carer's responses.

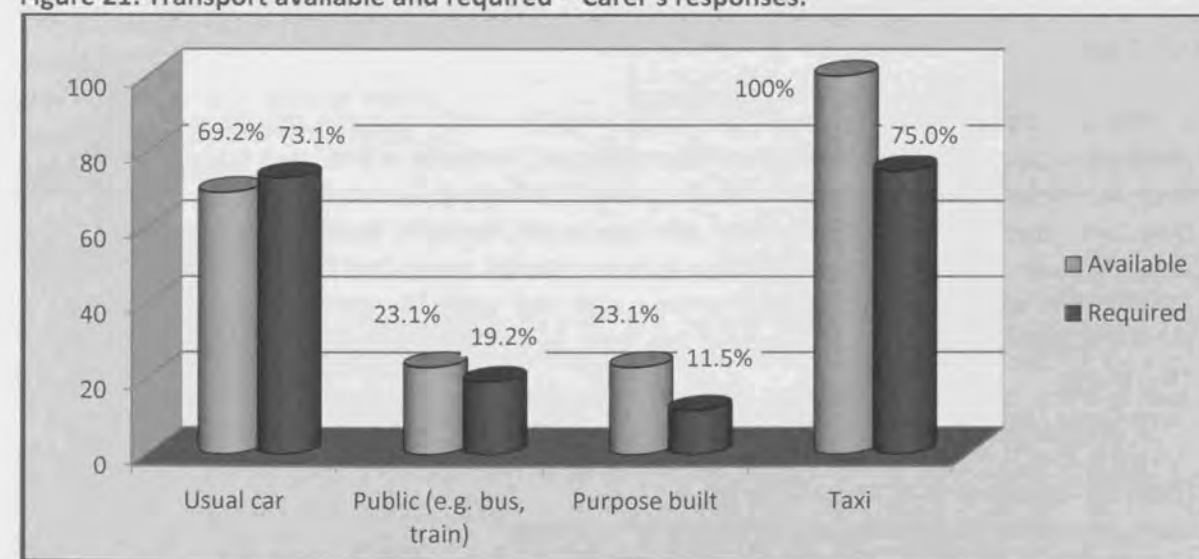


Figure 22: Transport available and required – Person with a disability self-report.

6. Results – Services for people with a disability: interview results

In an effort to identify existing services Carers were asked to indicate services they currently access for the person with a disability they care for, and Key informants were asked what services exist for people with a disability.

6.1 Services used by Carers for people with a disability

Carers were asked 'What services do you currently access for the person with a disability that you care for?' The most frequently mentioned services are: day activities; and planned respite. Also mentioned are: physiotherapy; personal care; Homehelp, access to a wheelchair, shopping; subsidised lawn mowing; transport; and Meals on Wheels. One Carer took the opportunity to comment on the poor quality of care available, another the lack of services, and a third that the person cared for would not access a particular service because of the cost of transport. One person spoke of the stigma attached to seeking services.

Five of the Carers and one person with a disability spoke about day activities. Due to a disagreeable experience one Carer has withdrawn his/her child from day activities. Most interviewees mentioned attending Blue Care, usually two days per week. The Uniting Church Friends, a social group, was also mentioned. These day activities appear to operate as Carer respite.

Five of the Carers also spoke about planned respite and appear to have worked it into their routines; one mentioned the cost as an issue. A Carer with a child who is high need can only access respite outside the local area, at considerable cost and with a lot of coordination.

6.2 Current services for people with a disability

Key informants were asked to identify services that are currently available to people with a disability – 'What services are currently available to people with a disability in the Warwick district?'. Services identified are:

- Endeavour – supported employment (primarily for people with an intellectual disability, not physical); supported accommodation; in-home support for those in their own home; casual drop-in care; post-school services
- Blue Care – day respite; overnight/short stay respite but limited to those without high care needs because of staff shortages (3 beds); in-home respite; supported accommodation; learning and life skills program limited to those without high care needs because of facilities.
- Rules that prevent people from accessing the same type of service from different providers e.g. day respite.
- Community Options – supported accommodation (two houses); in-home respite where person comes to home of Carer; transport
- Disability Services – local area coordinators
- Warwick Supported Employment Service has shut down.
- Uniting Church Friends (ex-Crossroads) – social activities/trips
- Education – Warwick East special education unit; Warwick High School
- St Vincent de Paul – accommodation.
- Carers Queensland – support to parents and Carers; guest speakers; cultural competency training; mentor program
- Parent to Parent – Carer support; training.
- Headspace and Lighthouse

6.3 Service desired and service gaps

In order to elicit what services are required, Carers were asked to list the services they 'desired' ('Considering your circumstances, are there services that you wish you could access?') while Key informants were asked to report service gaps ('What do think are the gaps in services for people with a disability in the Warwick district?').

6.3.1 Services desired by Carers

Table 3 lists services that Carers desire (in brackets the number of Carers that listed it). This is detailed through the use of quotes, following.

Table 3: Services desired - Carer's responses.

| | |
|---|--|
| Accommodation – supported, permanent, high care (3) | Transport – non emergency medical (2) |
| Accommodation – transitioned care (3) | Transport – a car (2) |
| Accommodation – independent (1) | Transport – reimbursement of petrol costs (1) |
| Respite – overnight for person with high care needs (1); short term for person with high care needs (1) | Transport – instead of taxis (1) |
| Respite – overnight in facility planned (1); overnight in-house planned (1) | Transport – wheelchair accessible ambulance (1) |
| Respite – day, for person with high care needs (1) | Parenting advice for parents of children with disabilities (1) |
| Respite – holiday (1) | Financial support – loan/advance (2) |
| Live in Carer (1) | Central point for information (2) |
| Day activities – for person with high care needs (1) | Support for Carers (2) |
| Day activities centre (3) | Practical help for Carers (1) |
| Day activities centre – for person with high care needs (1) | Recognition for Carers (1) |
| Day activities – age appropriate (1) | Understanding the system (1) |
| Paediatric occupational therapist (1) | |
| Mental stimulation (1) | |

Day activity centre:

An activity centre ... which could be great in a perfect world. If there was a big shed ... that enabled a lot of disabled people to come out there for day time activities, but focused on high-care kids, because there's nothing here for high-care kids ... it takes an extra person ... they have to be supervised all the time. ... big activity centre where they can do lots of things, like maybe bus rides, lunch outings, movies, to the library, have somebody come in and play music with them ... pottery, scrapbooking, heaps and heaps of things that's in our community now ... we'd know that they'd be right. Maybe they could stay and have lunch and tea ... access the occasional overnight stay. That would make my life happier. And hers too. ... X is intellectually disabled and physically disabled ... she can't talk and she can't walk, but she's switched on enough to want to get something out of life herself ... She's not happy having nothing to look forward to, as I'm not. ... even though these kids are severely disabled, they still get excited and like to look forward to something. So they're not deaf, dumb, blind and stupid ... she loves to be excited about something ... something like ... the aged-care up there ... I would like to see something like that for disabled persons ... where you've got plenty of qualified workers (C03).

... in the UK ... something similar to that ... the kids went to school, then school progressed to activity centre with respite care. So there was a progression ... we don't seem to have that in Australia. It seems to be that disabled people, that the responsibility's gone back to the family and that the government aren't helping. Just in that one area. And our kids don't seem to progress to anywhere and they even say that with the kids that are accessing Blue Care and government-funded homes here in Warwick, that there's no progression ... There's nothing for them to go to as they get older ... if they've been going to Blue Care, that's where they stay. Or once they move out to the home, then they can't access Blue Care so they stay there ... We're not going from A to B to C to D. ... They're just letting them rot in one spot (C03).

To move on. To progress. We've finished school now. We need to go on to something else (C03).

Support group for Carers:

I would like to see some sort of support group where you don't have to pay to become a member. I've only just found out there is one in Toowoomba but again the one here it's no good because it's at 9 o'clock in the morning till 11 or something, well I'm with her, so I could go but that means she gets nothing done and it's no good coming in and giving her breakfast at 12 o'clock, she can't be left all day so I could go there, so that does me no good because I can't attend it (C06).

... even if there was a mother's group or something, like we used to do when kids are at preschool or something, have a cup of coffee ... (C08).

Recognition for Carers:

... I think that there's a government mentality that while we're quiet they just throw a bit of money at us from time to time and we'll be thankful with that, but I think at the end of the day, there's got to be some sort of recognition from higher above that if we all put our hands up and said no where not doing this it's too hard, there'd be a lot of people that need looking after all of a sudden (C08).

Understanding the system:

... I think it's earmarked, this year we're going to fund lots of people with not too desperate need, that they don't need a whole lot of help to do things, they can shower themselves or whatever, it's cheaper for us to set up a series of smaller houses with limited care, or another year it might be we're going to fund a couple of people with really significant needs, and you've just got to meet what they're looking for at the time. It's just like applying for a job, they know what they're looking for that year and if you send up the right flags in your application, if the right person is helping you write it and you say the right things, and that's what they're looking for then you'll get help (C08).

In order to identify a high priority need Carers were asked 'if there was just one service that you could have, that you don't currently have, what would it be?'

Three Carers named a Day activity centre – frequently called a Learning and Lifestyle Centre. It was mentioned that this could be a productive and/or meaningful outlet for those unable to attend

Endeavour either at all or for those who were unable to when their health deteriorated. One Carer mentioned time apart from the person he/she cared for, another mentioned swimming, yet another, a Speech Therapist.

6.3.2 Services gaps for people with a disability

Key informants were also asked to identify service gaps. They report gaps in: accommodation; respite; post school services/training for independent living skills; employment; services for older people with disabilities; and transport.

Service gaps for people with a disability:

- Accommodation
- Respite
- Post school services/ training for independent living skills
- Employment
- Services for older people with disabilities
- Transport

Accommodation: When accommodation was mentioned, interviewees indicated that there was an absence of accommodation for younger people with a disability or that provides high care, for example with retirement villages and hospitals not having the credentials to care for people with disabilities. Following are comments from key informants that portray these difficult situations.

... that person was high care needs like an ABI ... he would have to go to the only place that can take him which is a place like the Oaks or an aged care facility ... There's a need for places like that but not for young people with a disability because they can't meet the needs that the young people have. It's the last place you can send them but it's the only place at the moment that they can go ... (KI02).

It's very difficult for people who are planning for this aging process ... For example, I'll be 62 this year; I could quite happily [retire] and move into any one of a thousand retirement villages ... can't take X ... no-one can go there unless they're aged 55 as a minimum. ... You can't even plan for a transition that involves you going there and the person that you are caring for going there ... they haven't got around to thinking about that yet. ... if you don't include it you force these people to make difficult and desperate choices – they have to start thinking about relinquishment for example, they have to start thinking about how we can get ourselves out of this, our health is failing, we've got other things we want to do with the balance of our life ... what can we do with little Johnnie who by now is big Johnnie ... (KI02).

There are no high care facilities in Warwick ... I know of three children that would qualify for that; there are undoubtedly more ... If they need to go away for specialised care then those young adults either have to go to places that can deal with them which would be Toowoomba or metropolitan Brisbane like ladies with MS have to do or they simply are passed around amongst the family or some accommodation has to be made ... such as the emergency department of the hospital or something like that. ... However, I think what would happen is that the aged care facility ... would go "Oh no, we have people with aged care certificates; we don't have people with disability certificates – they're different certifications and therefore we can't fit you in" (KI01).

... So there's definitely a need for more accommodation services here for people who as they get older ... know that their son or daughter is living somewhere that they're being looked after and taught some skills while they're not living at home anymore (KI01).

Respite: Comments about respite revolved around the lack of respite available for people with high care needs, but it was also noted that there was an absolute limit in what was available for low support respite.

There is no respite for very high care people that I'm aware of (KI03).

... here's only one real respite place and that's Blue Care. It only has three beds; it struggles to deal with high care needs people because of the rules relating to how those people have to be cared for ... (KI02).

... Blue Care wouldn't cover everybody that's here in Warwick ... because I'd imagine they're limited, they've only got 365 days in a year and if families are only allowed so many days and how many families are there that are wanting respite ... situations might arise where a family member is sick and they need respite in an emergency situation, I don't know how much of that is out there. I'd imagine that Blue Care tries to accommodate that, but I know Endeavour doesn't have any respite services at the moment. So there's probably a gap in that area as well (KI01).

Post school activities & skills for independent living: A key informant noted that while one organisation provided this type of activity he/she believed it was close to capacity.

So what do they do? Well the only thing they can do is go home. There would be facilities at Blue Care for a Learning and Lifestyle centre but I think that's close to capacity. There are no other Learning and Lifestyle centre facilities ... in terms of a structured program where these young people can go to improve their life skills, to improve their social skills, to correct learning deficiencies or slowness ... It is community – extended family groups do over two-thirds of the work; probably three quarters of the work ... (KI02).

Employment: The need for more places for supported employment was raised and some of the difficulties faced by people with a disability in open employment were mentioned. The social benefits of supported employment are highlighted.

Supported employment

We need more placements, we are limited to the placements that we are given by the federal government, ... we do have a waiting list for people to come in ... we are at capacity, and so with our 37 placements, so we feel that we could cope with more placements so it's just a matter of getting the government to acknowledge that and provide us with more placements so that we can provide employment opportunities for more people. (KI01).

... it's a pretty secure environment and they are very stable, very reliable in fact. So probably a lot more reliable than some other people out in the workforce. And they love to come to work, which is another great thing, they are very enthusiastic, they want to be here, it's a social network for them, it's a whole environment for them, so we need those new places, because we don't lose people at the other end (KI01).

... they are with their peers, so they make a lot of their social arrangements themselves here at work, so coming to work here creates also a social network for them, they go to the

movies outside of work together, they go down town and have lunch and dinner and all that sort of stuff together. So they form a bit of a social network themselves (KI01).

People with disabilities in open employment

... sometimes get people ... aren't treated very well in open employment, they're bullied or given jobs that are very demeaning, or people aren't very tolerant of their lack of skills or ability, and taking the time to train and teach ... people with disabilities those skills, so they end up coming here because they're just not treated very well in open employment. So that's been our experience with a few of our supported employees (KI01).

... I think he was medically blind ... He worked at X – they took him on and did a bit of community work for him ... I don't think that's continued because I think what's happened is that it's too hard for them to have him cared for ... and where he was working that job or that area has changed and the kind of work he'd now have to do requires better sight so I think they've struggled to keep him on. There are a couple that are involved in the livestock industry who do a little bit at the sale yards for the sheep or for the cattle or down at the Pig and Calf but this is not a job; this is something to do on a Wednesday or a Tuesday or something – it's not really a job (KI02).

Older people with disabilities: Like a shortage of structured activities for younger people with a disability, it is stated there are no activities for older people with disabilities, specifically those beyond retirement age. The existing services for aged people are considered unlikely to be able to accommodate older people with a disability. The lack of independent living skills training is mentioned again.

... there's nowhere for people who ... for ... medical reasons or aging reasons, become non-productive or their skills deteriorate to a point where they can't come to work anymore, there's nowhere for them to go during the day ... there needs to be a day service here ... do a little bit of vocational work, your leisure activities, even some independent living training, cooking skills and things like that, that can still be worked on even if they're older or have some medical limitations, just somewhere to keep them ... active during the day rather than just sit there and do nothing (KI01).

... when you're 65 when you're a male – you pass out of the state's administrative control ... into the federal's responsibility. ... Where do they go then? What can they do? What programs are run specifically to meet the needs of aging people with a disability? The answer is not very much – structured. There are organisations like church groups, for example you see Uniting Church, UC Friends and other church-driven organisations which run bus tours and trips ... but they're once a quarter type things (KI02).

I know of no structured seniors program for people with a disability in any of the areas here. In fact, I think that if you were a senior with a disability you would struggle to be part of a standard seniors program due to the special needs that you would bring to that group ... (KI02).

Transport: Transport is raised as an issue because many people rely on taxis for transport and these are very costly. In addition no bus service operates at times that suit people attending supported employment, and in wet weather preference is often given to people without a disability.

... work in the industrial estate, there's actually no bus service that's at a time that would suit ... they did a study into it, but I don't know what happened from it ... come to work in private vehicles, pushbikes or a taxi ... some ... earn less than the taxi costs them to come to

work ... We've only got one taxi service in Warwick, so they've got a bit of a monopoly, and the public transport, there's no bus that comes out here (KI01).

... accommodation service relies heavily on the taxis ... get the guys to their appointments, because you can't expect staff to use their own car all the time ... we have about half a dozen taxis come here at 6 minutes past 4 to pick our guys up when they finish, but if it's raining, they also get a lot of calls from downtown and quite often our guys are still sitting here at 4.30pm waiting for their taxi to come (KI01).

But it's based on the HACC guidelines, and they have limited funds. So once again it doesn't meet the need. It's meant to be, you can take someone to a doctor's appointment now, but that's up until the last review of the HACC guidelines that wasn't possible, it was only for social (KI03).

6.4 The impact of service gaps on people with a disability

Key informants were asked how they thought the lack of services they identified impacted on the people with a disability. Anxiety, social isolation and lack of community integration are identified – shown in quotes below. Poor wheelchair access and its impact in the town of Warwick is highlighted.

Impact of service gaps on people with a disability:

- Anxiety
- Social isolation
- Lack of community integration
- From poor wheelchair access

Anxiety: When arrangements, in this case transport arrangements, go awry, this creates anxiety for the person with the disability and in some cases for the Carers as well.

Well they get quite agitated and we've got parents ringing to say 'my son or daughter isn't home yet'; it affects the staff ... if we've still got people sitting here at 4.30pm, we can't leave, so we've got to wait for the taxi to come and get them. And it gets them quite agitated because it's out of routine. 'My taxi comes at 10 past 4 every day, I'm still sitting here at 4.30, where is my taxi?' ... maybe mum or dad's made a doctor's appointment for 4.30 in the afternoon ... It has that knock on effect. The parents might have to come and get them, which they didn't plan on doing. We've had taxis forget people all together, still be sitting here at a ¼ to 5 and the taxi has forgotten to come and get them ... It doesn't happen very often ... that has a bit of a knock on effect (KI01).

Social isolation: The lack of structured activities available for people can result in a level of social isolation both for the people with the disability and for the Carer.

Young people with a disability have just as much right to socialise and just as much right to go out and meet different people and do different things as everybody else does. Like everybody else, they need the opportunity to do that. ... I think it's very important. It's like never having holidays. If people never have a holiday, never ever take time out to sit down and just look at the rose garden ... you just become so introverted that you lose your social networking ability and that's as important for people with a disability as it is for everybody

else. That's the benefit that you get out of a higher degree of interactivity as simply as a social event (KI02).

Isolation is the biggest thing I believe, they don't get the opportunities that we do to build relationships, have friends, learn how to be independent. Because if they're not getting enough access to our learning and life skills programmes, then they're not reaching their potential, so they are not getting the same benefits that everyone else in the world gets. That's I think the biggest affect on them, and the same applies to the parents. If the parents are bound to the house, or to their child, then they're not having a normal lifestyle either ... Communities are losing out, and I think that's the biggest thing (KI03).

Lack of community integration: It is claimed that the lack of structured activities for people with a disability results in them being inadequately integrated into the community, which is perceived of as a loss for all.

... this is equally as important – is that it presents people with a disability in the wider community so that they can be seen and observed by members of the wider community as being part of the community. Only when they can effectively act in the wider community can that wider community see the value in the work that they do and, in turn, give the people with a disability that sense of community value that they deserve (KI02).

If people knew what happened at Endeavour ... and they could see what these people did – they'd be far more accommodating to the kind of work that's done ... unless you've got a personal involvement with these people or with a family that has someone like this, it's largely missed. You've seen them – "Oh yeah, there go those funny kids in the bus again" – but you don't know anything about them. If you were engaged with them, if you see them socially, if you actually meet them at an event that isn't work-related; it's social – then you get the opportunity to see a bit more of them in a different sense. ... It's necessary that that happens ... being involved in a wider social and community ... there'd be benefits for both the community and people with a disability – big benefits (KI02).

Poor wheelchair access:

I did write to ... the mayor. He is pretty hopeless and he basically said 'Tough shit'. ... I said most of the shops I can't get into because there is always a bit of lip or something or a step ... I can't go in. ... There is only one place that X and I have to go. I am sick of going there ... we have lunch there quite often or tea and it always the same and you know what is on the menu. You know everything, you know everyone who works there. It is alright but it is a bit monotonous. How long have we been doing that? Six years or something (PWD01).

... accessing things and especially toilet blocks and things like that because I reckon if you go in a wheelchair ... how would they access that if they've got to push a wheelchair and then open the door. ... they say we can't put a ramp in here because it's heritage listed there's fold away ramps ... they'd write them off against their tax and they're going to get it back anyway ... so they're really not paying anything. So it's very frustrating for me as a Carer that she can't access some of the places that we would like to go (C06).

7. Results – Service delivery

This report documents what services are known by participants to be available and the organisations that provide them. To elicit from Carers their views on service delivery they were asked who 'should' provide/fund services, and 'how' to provide disability services in a small rural community. To complement this Key informants were asked what barriers to service delivery they believed existed.

7.1 Who 'should' provide/fund services

Carers and people with a disability were asked two questions: 'In your view who should be providing services for people with a disability?' and 'Who should fund services for people with a disability?' As the responses to these questions were similar, the results are combined. In summary most Carers perceive that government should fund the services and they should be provided by accredited organisations. However some thought funding could be provided by local groups, banks and or one's self. Examples of these comments follow.

Accredited organisations to provide services

... NGOs, and government funding people should run them, because they're accredited for doing these things ... It's a huge job to become accredited, but if people like Blue Care, or Endeavour, or Community Options, or even Vinnie's have a house now in town, so even they've become accredited to do this sort of work ... (C04).

There is a DON ... everyone's qualified and it looks to be running fairly well. Blue Care is a non-government organisation. ... there are care-plans in place, so it must be accredited ... (C03).

And they should have a minimum standard, grade 12 at least, and preferably they will have done some study or something in aged care. If they've got some aged care behind them they might be able to handle disability, you would hope (PWD01).

Government to fund services

... government has obligation, responsibilities to citizens ... Whether that's on an equity justification or it's social justice, equality ... so many different reasons for providing those services. ... Whether or not it's going to come down to a state or federal funding thing, that's up to someone else other than me but if we want people with disabilities to become productive members of society then we need to put the money in, particularly early intervention. So if all the government rhetoric and discourse is over labour markets and productivity, that's what they need to be doing, that's their obligation to do that ... So it's their job. Obviously you get the charities and welfare groups and things like that but I don't necessarily think that they should happen. Obviously they're government funded as well so it's just very much a division of responsibility I guess (C01).

I just think the government have to look after everybody in their community. They're forgetting the disabled people. ... There's people that really need help ... There's a story recently of a lady who is so elderly she had to go into a nursing home, but there was nowhere for her daughter to go for many, many months ... they say they give billions of dollars to disabilities but we never see that. That goes to administration. That keeps somebody in a job ... but it doesn't come ... to the people who need it (C03).

... I think ... probably all government departments should be helping out a bit more than they are (C07).

I think it should be somebody who gets the funding from the government ... places like Blue Care that already have the van ... why can't the government give them extra money to use that van ... So, yeah, something like that. But government can pay. I mean, I believe Blue Care do have a committee that do fund raising so that that can also be in it. ... something like that: an organisation like Blue Care that ... the government will help fund (C02).

... both NGOs, and government funding people should run them, because they're accredited for doing these things. They know the system (C04).

Local community groups, banks, companies and self to provide/fund

... community groups like the Granite Belt Support Service are able to self-manage a lot better and therefore cater to their local needs more because they know the community, they know what the needs are. I know the Disability Workforce Council is actually working under that premise at the moment ... community groups do know their community better and what's needed (C01).

I'm not certain it will be fixed by federal bureaucracy either but it may – if you get more local input into how it's administered, I think ... (KI02).

... we all say well the government's got all this money but I suppose that if every subgroup in the community put their hand out to the government for money there'd be no money left there either, so I don't know, the banks always seem to be making millions of dollars of profit, maybe they could sponsor something for a change, give something back to the community for a change. ... Yes the big companies that are, you know ... And they, if they had a, like a stockpile or something that you could access and pay back to or something (C08).

The person themselves should, but even though I can fund everything for myself because I worked all my life, a lot of others haven't worked and haven't done anything and they shouldn't be treated differently, but I suppose the government has to then (PWD01).

7.2 How to provide disability services in a small rural community

Carers were asked: 'In a small rural community it is more difficult to provide the range of services that would be available in the city. What ideas do you have about how more services could be provided for people with a disability, in the Warwick district?' It is because Carers are those best acquainted with the services for people with a disability, that they were asked for their perspective on how such services could be provided in a small rural community. Key informants also commented here. The responses to this question were varied depending on how it was interpreted.

The most common approach mentioned was through collaboration. Also mentioned are lobbying for funding; offering incentives/rural service and having a central point for information. Some interviewees spoke of how collaborations could be brought together and others detailed existing collaborations.

How to provide disability services in a small rural community:

- Collaboratively
- Lobbying for funding
- Incentives to attract professional staff
- Central point for information

Proposed collaboration:

I think it's about people working together. I really think there needs to be more collaboration, more support and people working together. You don't need to have, like the school bit, and then the post school bit and then the adult bit, supported accommodation, you need to be from the time that a person is born or diagnosed or, and it can happen to anybody any time, you know a disability, from that time they need to be supporting that person and the family all the way through as a life pathway sort of thing, no different to what I suppose we do for ourselves as well in terms of planning and stuff like that, it just needs to be a bit more intensive planning (KI04).

... there was a bequeath from an estate ... about eight hundred thousand dollars, so that helped. So then the government put some more money towards it then Endeavour did, so they've got this wonderful facility. So I imagine it's finance, but again, if they got a better idea of how many people are here who need the service, then they might be more inclined to look towards starting one in this area (C04).

Endeavour have a learning and lifestyle centre ... we feel that if we buddied up with someone like Endeavour ... if Endeavour took the cudgel and ran with it, they would have the finances to set funding up like that, then they would obviously get government support as well ... (C04).

... the learning and lifestyle centre, if that was a day service every day for people to access ... we could get the spinners and weavers involved and the painting groups in town involved in it, and you know, get a whole range of different community groups involved, which would expand the horizons of the people who are going there. They'd probably be drawn in to different areas of social activity within town (C04).

I'm not sure how we do it better at the top but I think it is about government departments even coming together better and having that interagency support as well (KI04).

Existing collaborations:

Respite ... either in the home or in the centre ... where HACC and disability funding work together like this, so that's what's keeping a lot of people at home. We have a young fellow who's becoming quite high care, his parents both have jobs and won't be able to look after him fulltime, and we are helping to keep that family unit together with a combination of HACC and disabilities, if the HACC is taken away then the family won't be able to cope and he will be placed into aged care residential, because there's nowhere else for them to go at this stage, and that would be tragic for the whole family (KI03).

... there could be some more [social activities], we've actually run some community dances ... Some of them come, some don't, we do coffee club and stuff like that ... our goal always was that if we could match people together and friendships could develop ... during our day activity programme, and then we could bring them in overnight so they could say I want to come in with Mary she's my friend, and so they come in together and book two rooms and have a wonderful time together, and then if it was possible for them to be able to meet independently in the community that's part of our goal as well to see if we can support the building up of friendships and then encourage them to have those friendships outside of the organisation (KI03).

... Transport services are run by Community Options ... that came about because we had a community transport partnership that was developed ... goes back to probably 2003, 2004. We set up a partnership between Community Options, Blue Care, the ambulance and St Vinnie de Paul bus. So that partnership is still in existence, and it still meets every three months I think ... (KI03).

Incentives:

... OT who works for ... Education Queensland, and whilst she gets paid ... there's just not a great deal of incentive to stay here when she's got this wonderful qualification that can take her anywhere, why choose Warwick over anything else? So there needs to be some sort of reason for people to come to a regional area (C01).

Central point of information:

It needs a more central base. ... that was partly what we were trying to do with DAGFORCE, was make a central base ... they could say, "Hey, look, there's this problem. Where do I get information about it?" ... like a database place and have different organisations come in from time to time, so that if people wanted to come in and learn things it was there. I think that is what is needed, is something like that, for people to know where to go and how to get the information. I wouldn't know where to go and get the information from (C02).

7.3 Barriers to service delivery

Key informants were asked 'What do you think are barriers to service deliver/provision for these people – locally, and state-wide?' A key point made by interviewees is that lack of funding is a barrier, but also how funds are prioritised, with issues being raised about government covering themselves and funds being spent on administration rather than services, and how services compete against each other for funding. The second barrier identified was a lack of awareness of the needs of people with a disability. One interviewee felt the two are related. The third barrier is the 'rules of engagement', where one Key informant highlighted government priorities and practices, and the challenges related to meeting funding criteria. Part of this is 'fitting inside the square'. The final barrier is the stoicism and pride of rural people and the stigma associated with seeking help.

Barriers to service delivery:

Funding:

- Lack of funding
- How funds are prioritised and spent
- Competition for funds

Lack of awareness of people with a disability

Engaging with government

Stoicism and pride

Stigma

Funding - how much and how it is spent:

Probably boils down to money a lot of the time, financial ... to provide day services and accommodation services ... we've got 37 employees now who range in age from 16 or 17, right up to 60, there's a new batch coming through this year, it's not like some drop off the other end to make way for those new placements. ... once we get someone, we've got them

for 40 years, and so we need new placements to come through, because that natural attrition doesn't always happen ... We don't have a high turnover of supported employees – once they come, they usually stay for a long, long time (KI01).

Money it's all about money, really ... because there's not enough money. ... we could take a whole lot more people if we could get more money. If we were better funded ... there's no funding opportunities coming up. ... So it's a matter of Disability Services being given a greater priority, so that it's got a greater chance of getting a better allocation of funds ... only way for Disability Services to get more money is to get better promotion and publicity so that the government focuses more on the need (KI03).

I think the biggest single barrier is the inappropriate use of funding ... this doesn't mean that the programs are unfunded; it just means that the funds are not applied with the benefit of the person with the disability at the top of the tree. I think there's a "Cover your arse" philosophy that works and then once we've done that once or twice and we make sure there's not even a hair on our bum that's exposed, then we might put out a glossy brochure and get the marketing shit up to speed ... and the ministerial releases ... and we send people out to talk to people in the field about how good all this is and we spent this, that and the other, there's probably \$5 left in the tin and we'll have morning tea (KI02).

I think the administrative costs of service provision and delivering things are higher than they need to be and because of that, organisations like Endeavour and Blue Care and others have to use economies of scale. If you like, the rules force them to building bigger, larger centres in regional areas instead of smaller, more effective centres in rural areas where the littler, smaller groups need more fine-tuning adjustment, where the program's got to be adapted to suit the requirements of the 15 people here not the 1,500 people there.(K02) ... with the insurance scheme [NDIS] ... it's going to take a long time to implement it, but in the end hopefully it will be done well and it will cater to the needs of everybody, and there'll be enough money to go around, and I guess that the governments way of saying "hey look we recognise that there is need in this area, we understand that there are carers who are really struggling, we understand that there are people with disabilities who aren't reaching their potential, and are socially isolated and all of that type of stuff. But we can't give you any more funding, so let's look at a whole different system and that's where this insurance has come from", because it works well in America (KI03).

... that was probably one of the biggest issues ... Home and Community Care is all about keeping people with disabilities, frail aged, mental illness or whatever it is, in their own homes longer, and they're just isn't enough money for that service ... To me it seems ridiculous. We have home community care services to keep people and like I said, 75 percent of the care is being done by the carer, or the parent, so only 25 percent, and we don't have enough money to have somebody to come in and help that carer when they need it, so then they fall over and they end up in hospital themselves and the person they care for ends up in a nursing home or in respite or something like that while they try to work out whether we can get them well enough to take on the caring role again, but just how much it costs for that short period of time. ... you know what most carers take their respite for? To go and do their shopping. Very rarely do they ever go and get their hair done, they use their respite time to go and do their shopping and pay the bills. So if there's not enough funding to actually sustain the carer in the home, we're going to be in big doodoo because the number of carers are reducing and the number of needs is increasing, so unless we get that bucket a little bit higher, that's why we like the National Disability Insurance Scheme (K04)

Prioritisation I think ... if you're investing that money into home and community services, you're sustaining people and you're sustaining communities, making communities that care and the caring role is valued in the community. ... Caring is not valued in our community really. Mother's are not even valued, let alone carers, but if you're investing in that. Do you know how much it costs to keep a person, you know like, I will say this story because, you know Martin Bryant the guy that shot all of those people down at the Port Arthur disaster in Tasmania. He has autism, or Asperger's syndrome, how many times did his mum ask for help when he was a little boy and never got it, how many times did he, in his own way, ask for help. It might have been inappropriate behaviour or whatever else like that, but do you know how much it costs to keep somebody like Martin Bryant in jail, half a million dollars a year. Now if we'd invested ... We have families who are, they just can't do the caring role. If we invested \$50,000 in somebody that I know and gave that \$50,000 they would have been able to sustain, make alterations to the house, modify their house do whatever they needed to do to keep that person home, that child's now in care \$250,000 to \$300,000 a year (KI04).

Coordination/Competition:

... all Disability Services are competing against each other, and when you look at Toowoomba ... there was only one [house] for years and years, and just in the last three years we've got three houses, and ... I think it was because we had people in crisis situations who were having to abandon ... the people they were caring for, and that's a crisis situation, and I think that helped put the spotlight on Warwick a little bit, and that's why we got those houses (KI03).

Awareness:

... awareness a little bit in the government, sometimes we have politicians come and visit and they weren't aware of what we do or what we provide, and their eyes are quite opened once they've been here. We are very well supported by Bruce Scott and our local member Lawrence Springborg, they get involved which is good (KI01).

... I guess the government has got a lot on their plate, they've got unemployment and they've got all sorts of other issues, global financial crisis, housing, you know all that sort of stuff. But I think sometimes we do get pushed aside a little bit, and maybe unless you get a member of parliament or someone who has got a personal experience, and has that member in their family or whatever, it's not a personal agenda for them, or a priority. But if you get someone who is very supportive and everything, then sometimes it can come to the forefront a little bit (KI01).

... probably comes down to the squeaky wheel gets the oil to a degree. Because there's certainly been a lot of people who, parents in particular who've been really active, politically active in getting the spotlight on Warwick and getting on consumer groups, representative groups, and lobbying groups and stuff like that and that's important (KI03).

Rules of engagement:

I think that the biggest barriers are the rules of engagement that are set by the various people that control the regulations. I'm quite critical of the state government in this because it spends an enormous amount of time producing lovely brochures telling you all about all the wonderful things that they're doing but it never bloody does them. There are brochures in there about the ten year plan and "Help us do this" and it's a load of crap because not

only do they not believe it, they don't even attempt to do it. It's extremely frustrating because if you listen to the succession of ministers talk about this – and I have – and I've been to community cabinet meetings and I've talked to them and they've talked to me and we have listened to what had to be said and we've said what had to be listened to but there have been no real changes as a result of those sorts of discussions (KI02).

... service providers must meet extraordinarily complicated and complex accreditation criteria. There is ... more time spent on accreditation and meeting criteria and filling in forms and ticking boxes and having the appropriate piece of paper to say that what you do in case the toilet blocks up and stuff like that – there's more time spent on getting all this stuff done than is necessary. This doesn't mean that you throw it all out the window because that's not what I'm trying to say (KI02).

... I think the bureaucracy ... has protected itself to the 'nth and it has not delivered on what it says to do. All you need to do to be certain of it is to just get a disability services brochure and read it; it says all the most wonderful things in the world about how fantastic and "We are committed to... and this is" ... none of it ever happens; well not here anyway. ... I think all that stuff is just hype and it's regrettable because ... these people can't advocate for themselves either. ... without advocacy they struggle; they don't vote usually so that's another struggle ... They're batting from a couple of yards behind the stumps ... they need a bit of a hand up but the bureaucrats don't help them I don't think. I think that's where the major reason for the inefficiencies in the state-run system is. I'm not certain it will be fixed by federal bureaucracy either ... (KI02).

... I think that what happens is that the senior state bureaucrats look at Warwick as being part of the region ... "let's look at the Darling Down region" ... Toowoomba, Warwick ... Chinchilla, Miles ... Goondiwindi, ... and they'd say ... there's 275,000 people ... there are 10,000 people with a disability; that represents this and our budget is that ... we're seeing whatever the percentage is and that's all good ... what tends to happen is that a lot of that is centred in Toowoomba. If you take everybody else out of that and just look at Toowoomba, you'll suddenly find that Toowoomba's at about 2.9 – or whatever the percentage is – of services for people with a disability and everybody else is about five but they never do the numbers that way ... we need to get those statistics drilled down so that they're representative of where the people with the disability are; exactly what was said here in this thing called the "Productivity Commission's Enquiry Report" which said and I'll quote it ... "It's inevitable. What you receive in assistance depends on where you live not what your disability is" – you have to have something that's got national standards and entitlements so that you can correct it. ... I don't see that there's any reason why Warwick or the Warwick area cannot have that. ... we know that there are enough people that could use it – the one that's sitting there that Blue Care's got is full and we know that there are people coming forward (KI02).

Fitting inside the square: The important point made in the following quote raises an important and difficult to address issue – the rules that govern funded disability services are complex and do not necessarily work in ways that enable access to these services.

... nobody has sat down and said "Well hang on X, the bus that goes out here to bring old people in from Leyburn and the other one that runs over there that picks up people from Yangan and Swanfels ... why don't we get involved and see if we can pick up some people who have got mobility issues with a disability?" Why don't they? I don't know whether it's a funding issue, I don't know whether no-one's told them or asked them – I can't imagine that

– but it's probably got to do with the fact that they don't qualify under some funding support to deal with this. It's probably also got to do with the fact that it's not just the person you've got to take; you've got to take the Carer as well. So "Oh hang on, we can take this person but we can't take that person because they're not old enough" – or too old or able to move or not able to move or whatever ... There's too much of this fitting inside the square and no flexibility of the boundaries. Transport and transport-related issues in rural areas are very, very important. They're probably just as important as getting respite and support because you've got to be able to get people to go, to move around – they have to socialise, they have to get out, they have to meet other people, they have to do all of the things that normal people do. That's really all that we're asking for people with a disability; they need to have exactly the same kinds of opportunities as everybody else and they're not getting that because they're disadvantaged, not necessarily because of disability but through their disability and because of where they live they don't get access to things that other people do. That needs to be looked at (KI02).

Pride/stoicism: While only one person spoke of the pride of rural Queenslanders perhaps preventing them from attempting to access services/support, there is a lingering thread throughout this report that is consistent with this idea.

... in the senate enquiry that was recently held ... recommendation number eight – the committee said, and I'll quote out of this: "The committee was seriously concerned by evidence suggesting that as many as 25% of carers are not linked in with CentreLink and therefore are not receiving any payments to which they are entitled. The committee therefore recommends that CentreLink review its communication strategy with respect to carers and engage local disability service providers more directly" ... In rural Queensland ... they're very stoic people – they don't go looking for hand-outs, they keep family matters to themselves and they just accept their lot and say "Well that's the cards that I've been dealt" – bit like no rain and the crop's fail – "you just get on with it and away you go again" (KI02).

... So you're finding that there's a lot of elderly people who have looked after their children for 50, 60 years and they've never ever accessed services because they've just seen it as their duty (KI03).

... like a lot of country folk – that you just tighten the belt a notch or two and knuckle down and get on with it (KI02).

Stigma:

... some families, I know for myself, it took me years before I actually asked for help, because I had three other children, I was a mum, why couldn't I cope with this one? It was reinforced in the community from other family members right down, that it's your child you're supposed to cope. So when it's a child that your caring of (KI04).

'So when he was little there was no respite because you didn't go and ask for help because that means you're not coping and you're not a good mum, so there's that whole stigma of asking for help, so it makes it a little bit difficult you don't want to admit that it's not going so well. I'm going just a little bit insane (C08).

7.4 Barriers to completing survey questionnaire

Key informants were asked to indicate what barriers there may have been for people to complete the questionnaire. While the list of possible barriers to completing the survey is diverse, most of these are well recognised reasons.

Time:

... the most one I was told, haven't had time so there's that time thing (KI04).

Don't know what to ask for:

... the fact that people with disabilities and their families have been asked so many times what they need and want and they don't necessarily know, it's like me trying to answer your questions this morning, I don't know what I don't know. ... If they don't know the service is out there and they don't know what to ask, a lot of families just think this is my lot in life and so until we actually get in there and help them with that, it's not going to change (KI04).

Literacy skills & support:

the literacy skills of some of the families. I don't think some of them would have been able to read them. I think they really needed help to actually fill them out to get a really rich feedback from those people, you really needed somebody to actually help them fill them out (KI04).

there would also perhaps have been some people who had some difficulty filling out the form – forms can be frightening. It may be that that was one of the reasons (KI02).

So they really do have to be user friendly, with support available (KI03).

Language:

The questions themselves I thought were pretty good except the little bit of academic language tone (KI04).

So they really do have to be user friendly, with support available. So, but I've not heard anything negative about them. So other than those barriers which are probably common to all surveys, I don't know of any others (KI03).

No actions from previous surveys:

... this would be about the fifth or the sixth attempt in the last 20 years to raise the awareness of people with a disability in the Warwick area, all of which have met with a resounding "Oh, that's nice, thanks for coming but we'll get back to you" and they may just say "Well, why are we doing this? What's going to happen? I'm sick and bloody tired of filling out these frigging forms" and they go off and they go into a bucket and they come back and nothing changes. There is an air I think of despondency particularly from a place like Warwick ... (KI02).

Apathy:

I guess some people would have just said "Mm, it's not worth the effort" (KI02).

Didn't hear about survey:

I also think that we may have failed to reach a few because they didn't listen to the radio or read the papers or because they're not on anyone's list (KI02).

I've not heard anything negative about it, and, but I'm hoping that it's got out to everyone (KI03).

Stoicism:

There's a sense of "Oh well, we'll just get on with it, we always have, we've always had to so we'll do that". which is unfortunate but I think there would have been some of that (KI02).

Denial of disability:

"What disability". "I've got three eyes – what's going on?" That's a bit unfair but you know what I mean. I think there would have been some of that too; I couldn't quantify any of those things but I suspect that both of those reasons would have meant that there were some people who felt that the form didn't apply to them ... or because they don't believe that they have a problem ... (KI02).

Desire for privacy / suspicion:

I think some of them would have said "Well you know, little Johnnie will be all right; the family will look after him – we don't need any interference from you people. I know about the survey but thanks but no thanks. I'll deal with it" (KI02).

Organisations ... people are suspicious of them I suppose. No matter how good you are, it's still the department or when it comes to even the LACs help as best they can, but they're still employed by the department. We're an organisation and non government organisation, an NGO, but we're still an organisation that might be saying to these people we know you want 15 hours, but we can only give you six. So we're kind of perceived as being the baddie as well probably (KI03).

Not aware of any:

So other than that I only had one or two queries, that was it. So I think the majority of them were very straight forward and very happy with them (KI01).

I'm not aware of any, I would imagine it would be seen as a positive thing (KI03).

8. Results – The Future and Final comments: interview results

8.1 The Future

Carers were asked 'As you age, what are your main concerns about the person with the disability who you care for?' For all Carers it is the future care of the person with the disability. In addition some wondered about their physical capacity to care, about having a life for themselves and that they are constantly concerned about the future. Other issues raised are: employment; independence; the uncertainty of the future; having no back-up and day activities.

Future care: The key point made by Carers is that they are aware of no reliable option for the provision of care for the person they care for, when they are no longer able to do it and this is a constant concern. Intermingled with this one can hear their reluctance to burden another family member, the need for their child to have some supervision because of their vulnerability and their desire to have some retirement or time for themselves at some point. In addition there is the issue of their diminishing capacity to provide care because of age or ill health. Two have experienced Blue Care service and are critical, so are reluctant to use this service.

Well what's to happen to them when I die (C05).

That's very difficult, because as she's deteriorating I won't be able to keep looking after her. So, she'll have to go into a nursing home. Unfortunately, because of her age, they won't take them, but because of her disability they may take her. ... Otherwise, I just hope that I'm still able-bodied enough to still look after her. ... But yeah, I just hope that I've still got the strength to keep going (C02).

... when I think of people who are in their seventies and eighties caring somehow for a disabled person, they need to know before they die that their person is being looked after. So if you had something like The Oaks ... I'm sure it would put some people's minds to rest. I'm not at that stage yet. ... there are people out there who are very elderly, that need care themselves. I don't know how they're coping. I think it'd be a terrible thing to have; to be on your deathbed and then wondering well, who's going to look after her? ... I don't know what would happen to X. I suppose I'd have to put the burden back onto Y ... my daughter ... I guess she'd, I don't know. She'd have to cope somehow (C03).

That he has somewhere stable to live, before we get too much older. That's our main concern, but that he's well looked after in a supported accommodation environment (C04).

We all put in and paid a third of having a solar put on the house to help cut down the costs for the future years and I thought well that will help to reduce electricity bills as time goes on, at least if I'm gone it makes it a bit more affordable for them, they can stay here. I don't know how we'd go for trying to get somebody to come in, whether they'd have to pay somebody give them a wage or whether just them paying for food and that, would the house be sufficient, and then if there was somebody that was on the pension perhaps just a few dollars or something a week. But they would need some sort of supervision to assist them with forms and making decisions ... No, just that it is a constant worry wondering what's going to happen when I'm not here to look after them because there's too many people around to take advantage of them (C05).

I would be worried about putting the burden on our daughter to look after him when we can't because she deserves better, to have a life, she's prepared to have him for weekends but not full time. X is in his O's now and I'm in my Y's and not particularly well most of the time with blood pressure and one thing or another, and he's getting bigger and more of a handful, so we need to eventually, work towards an independent place, away from us. For him personally, he would be better in a small group, one or two, with a Carer, so he doesn't annoy everybody too much the way he is. Somewhere where he can be safe and secure and monitored, so that he doesn't make bad choices, which he will, because he doesn't handle money and that's part of the problem as well, what is he going to be able to afford and what funding is going to be available. It's a bit of a mine field. It's on your mind all the time (C08).

Every time my other half wants to change jobs or whatever so, okay, what's going to happen now, how long is this going to be, are we going to be right, are we going to have something left over when we get to retirement to buy him into a place, and how much is it going to take out of us before we get to that stage where he's... how far down and exhausted and worn out are we going to be before we can set him up, so we still have some kind of retirement as well, where we can get to the end. Like with all of us with kids like X, that wasn't our plan when we set out to have kids you know. It was going to be a caravan and a trip around Australia, but that's not going to happen now, so everything changes (C08).

8.2 Final comments

Both Carers and Key informants were asked if they had any 'final comments'. This was an opportunity for interviewees to raise any points they wished to make that had not emerged during the interview, or to recap on what they have said. Table 4 shows the points made in response to this question.

Table 4: Points re-iterated and new points made from the Final comments.

| Points re-iterated | New points |
|---|--|
| More support for Carers (4C) | Local government a driver for service planning |
| Central point for information | Have respect |
| Raise community awareness | Activities for children in the family who do NOT have a disability |
| More short term respite | Limited staffing for respite care |
| Inadequate funding for services | The need for flexibility around service delivery (for providers) |
| Transitioning to care | |
| Aging carers | |
| The need for short term financial assistance | |
| The need for Carers to be flexible and gentle | |
| Services for small children with disabilities | |

9. Discussion and Conclusions

Summary of results

The results of this needs analysis for people with a disability and their Carers in the Warwick district, has confirmed results of earlier research. And, because it is the first comprehensive attempt to investigate disability needs in this geographical area, the output is a more thorough and nuanced description. A comparison between what Carers and the people with a disability indicate are needed through this report, and the services listed in the Disability Resources Directory, shows glaring gaps.

Due to the purposive sampling approach the results of this study cannot be generalised to the broader disability/Carer community in the Warwick district. However it is the consistency of results that gives this study its strength and enhances the legitimacy of the results. There is consistency:

- Between the results of this study and earlier research in the same geographical area, spanning almost 20 years
- Between the results in the survey and the interviews in this study
- Between the results in the two survey samples in this study

A key finding of this study is that there is a need to plan for services for people with a disability and their Carers – to meet the significant gaps identified in this study, and previously. It is apparent that many Carers in this small rural community have been managing without services, though only a few by choice. Related to this point is one raised several times in the study – there is a need for a central point for information about disability services. A comparison between the list of services that Key informants report and those in the Disability Resources Directory indicate that even those in the best position to know what the services are, do not have a comprehensive knowledge.

One quote captures much of the angst that Carers in this study expressed: 'What will happen when I die?'. In general Carers report that important services – respite care and accommodation are limited, or entirely absent for people with some types/levels of disability. Less than a quarter of the Carers report being able to access emergency respite and just over a third, planned respite. Low or nil access was reported by Carers for the various types of accommodation that a person with a disability may require.

While some day activities are available, again this is very limited and only caters for some of the population of people with a disability. Day activities could provide Carers with much needed respite from their 24/7 role, and the people with a disability with opportunities to learn independent living skills, or at least to use their time productively. It is of concern that five of the eight Carers interviewed report that they continued their caring role because they 'had no choice' – there was no one else to do it. Implicit here is that there are no services as backup. Carers report emotional, social and financial costs to caring, resulting in fatigue, mental stress and the lack of a social life or the expectations of having one. Another quote expresses this sentiment 'This is our life until we die ...'. The anxiety, depression and psychological distress scores in this study that are higher than for the general population are consistent with the Carer's concerns and predicament.

The majority of Carers and people with a disability report that although their current largely private residential accommodation is suitable and they are happy, both groups indicate that it is within the next 5 to 10 years that the accommodation needs of the person with the disability will change. For Carers in general this is because of their declining ability to provide care and for the people with the disability, it is because of their declining health.

In this study more than 80% of Carers and people with a disability were reliant primarily on CentreLink for income support; just over half are Sole carers. In addition 44% of the people with a

disability spent more than a quarter of their income on accommodation, and those who need to travel to the Endeavour workshop by taxi may struggle financially. While this is not a representative sample, service providers do need to consider the capacity to pay.

Key result areas

As the focus of this report is to identify what the needs of people with a disability and their Carers are, this section of the discussion is written with specific reference to service delivery and gaps.

Carers and respite

An important insight from this study is that caring for a person with a disability is continuous – it is 24 hours a day, seven days a week, 365 days a year; it is physically demanding and the difficult behaviours encountered require patience; it is unpredictable because it revolves around the health, wants and needs of the person with the disability, and because service provision can be erratic. What is keeping those Carers interviewed in this study going, when life gets very difficult, is that there is no one else to do the caring. The 'costs' of caring are emotional, social and financial. Carers who completed the questionnaire report levels of psychological distress higher than the general population.

Access to key services that would provide Carers with support is limited or non-existent in the Warwick district. There is limited out-of-home respite, planned and emergency, and no respite for those with high care needs; limited access/nil to long hours day care and School holiday care; and limited access to day activities for those who have completed their formal schooling. Inadequate respite in the Warwick district was first reported almost 20 years ago and was identified in the 1995, 2007 and 2009 reports (Cavaye, 2009; Department of Anthropology and Sociology, 1995; Warwick & District Accommodation Support Group, 2007). The difficulty accessing services when formal schooling had been completed was also reported in 2009 (Cavaye, 2009).

It appears though that there are Carers who do not access services now because they have learnt in the past to manage without them; for others their pride prevents them from asking for help; but the stigma of disability is also a barrier. Previous research has identified a variety of factors which may influence the uptake of respite. Attributes such as the severity of the disability, the level of care required, impairment in communication, family size and stress levels, and lack of social supports have been associated with lack of uptake (Chan & Sigafos, 2000) but not consistently so (Mac Donald, et al., 2007). A lack of knowledge of available services and how to access them, confusion over funding availability and options, and lack of variety and flexibility of services have been associated with limited uptake (Doig, et al., 2009).

Day activities

In this study the need for more day activities was mentioned in several ways. One half to two-thirds of respondents in the current study report being able to access recreational trips and activities but only 20 to 40% can access the learning of skills for independent living. Australia wide, between 94 and 97% of persons with a disability (mild to profound) participate in a social activity within their home within a given 3-month period, and 88-93% of persons with a disability participate in a social event outside the home within a given three month period, although in general, persons with higher levels of restrictive disability participate to a slightly lesser degree (ABS, 2011b). Persons with a disability are less likely than those without a disability to attend or participate in a sporting event or attend a cultural event or venue (ABS, 2011b). Persons with a disability spend less time engaged in social and community interactions than persons without a disability, but spend more time in recreation and leisure activities (ABS, 2011b).

While attendance at day activities potentially provides the Carer with respite, the emphasis in this study was on the need for and the importance of the person with the disability having the opportunity to learn independent living skills. While Carers acknowledged that greater independence may not be possible for their child, like any parent they are keen for the learning opportunity to be available. The importance of learning independent living skills was associated with the need for the child/adult child to move out of the family home into some other accommodation when the Carer is no longer able to provide care.

Community access (where day activities fit) provides opportunities and support for persons with a disability to participate in social activities within their community, including the development of life skills, learning opportunities, and recreational activities (SCRGSP, 2011, p. 14.6). In Queensland in 2008-9 it is estimated that 8,922 consumers utilised disability specific community access services (AIHW, 2011).

On completion of formal secondary schooling persons with a disability are less likely to move into either further education or employment than cohort members without a disability and generally remain in the workforce for a substantially shorter time period (AIHW, 2008).

Employment

A need for more supported accommodation places is identified in this study. In the current study approximately one-quarter of the self-report disability group are employed. Of all persons with a disability aged 15-64 living in households in Queensland, 75% are employed in some capacity, 4% are unemployed, and 20% are not in the labour force (ABS, 2011a). Comments were made in this study about discrimination in the workplace towards people with a disability. This is reflected in nearly half of all complaints made to the Human Rights and Equal Opportunities Commission (HREOC) and Federal courts under the Australian Disability Discrimination Act pertaining to discrimination on the basis of disability (Darcy & Taylor, 2009). However the majority were about access, including both physical access to public and private facilities and information provision about accommodation options for persons with a disability. Transport complaints were predominantly related to the public transport (e.g. bus and train) but also included taxis and increasingly air transport.

People with a disability

How the current study was constructed provided information on two groups of people with a disability – those who the Carers reported on and people with a disability who completed the questionnaire themselves. The latter group is older and appears to be more independent than the former group.

While the samples in this study are purposive and therefore the results cannot be generalised to the larger population, there are similarities with the broader disability population. In this study the most common disabilities reported are Intellectual, Physical, Neurological and Acquired Brain Injury. By comparison in 2008, the most frequently reported type of disability was Intellectual (28%), followed by Psychiatric (18%) then Physical (16%) (AIHW, 2011). While most people had one disability two-thirds of those being cared for and almost half of the self-report disability group had more than one disability.

Their Carers

In the current study, the largest group of Carers are parents, but almost one-quarter of the people with a disability who self-report have a spouse as Carer. In 2008-9 users of Commonwealth State/Territory Disability Agreement and National Disability Agreement (CSTDA/NDA) funded services across Australia numbered 266,066. Thirty-nine percent of these service users had an

informal carer, and for 34% of those the informal carer was the primary carer. Rates for having an informal carer were higher as the location of the person with a disability grew more isolated (i.e. Major city/Inner regional/Outer regional/Remote/Very remote). Thirty-nine percent of persons with a disability living in a Major city had an informal carer; 42% in an Inner regional location; 43% in an Outer regional location; 48% in a Remote location; and 60% in a very remote location (SCRGSP, 2011, Table 14A2). Approximately half (45%) of primary carers were aged 25-44, an additional one third (35%) aged 45-64 (SCRGSP, 2011, Table 14A3). In this study almost one-third (32.7%) are under 50 years and almost one-third (29%) are 60 years or over.

Assistance required

Approximately half of both disability groups in the current study received assistance from a paid service. In a 2009 ABS survey of all people receiving assistance, more than three-quarters received help from informal sources-typically family members, and approximately two-thirds from formal sources (ABS, 2009) (note people may receive help from both formal and informal sources). In the same survey more than two-thirds of people with a disability reported they did not get sufficient assistance with mobility, self care, or health care.

The proportion of the group being cared who require assistance is higher than the older more independent sample, and they also require more support in all areas of life. One-half or more of all the people with a disability in this study require support with: learning, applying knowledge and general tasks; community and economic life; domestic life; working; interpersonal interactions and relationships; self-care; mobility; and communication.

In this study approximately half of all of the people with a disability spent most of their time at home. Almost one-fifth attended school in the Carer sample and in the self-report disability sample more than one-quarter were employed.

Accommodation

Accommodation is a fundamental requirement. In the current study while the majority of people with a disability who live in a house/unit, largely find it suitable and generally are happy with this arrangement, there are few alternatives in the Warwick district. In particular, there is no accommodation for people with high care needs available locally, nor for older people with a disability, or younger people with a disability.

Legislative changes in Australia in the mid 1980s led to deinstitutionalisation and a subsequent increase in community based accommodation for persons with a disability. In 2003 a total of 105,600 Australians with an intellectual disability and severe or profound limitations were living in cared accommodation (e.g. aged care facilities or supported care facilities specific to persons with a disability). Twelve percent of these people were aged under 65 years (AIHW, 2008).

Research into the accommodation needs of carers and person with a disability in Toowoomba, Queensland reported only limited long-term accommodation options for adults with an intellectual disability and had insufficient resources to accommodate the growing number of people with a disability who would require alternative care when their carers were no longer able to continue the task (Eley, et al., 2006). Research has found that services in addition to those needed for the general ageing population are required for people with a disability who are ageing (Ellison, et al., 2011). However the provision of care in the home is strongly associated with owning one's home (Beer & Faulkner, 2008). In 2003, the largest proportion of unmet need for accommodation and respite for persons with a disability was for people with an intellectual disability (not exclusive of related diseases) (AIHW, 2008).

Transport

In the current study survey respondents indicated that transport needs were largely met. However it was in the interviews that transport service gaps were identified. In particular, in Warwick there is limited public transport, and people with a disability are somewhat reliant on taxis services which are expensive for people such as these on a limited income, and taxis are not always reliable. Also identified were specific transport gaps for people with mobility issues. Some interviewees indicated that reimbursement of petrol costs would be advantageous, others said having a car would be.

The National Census ascertains the use of transport by persons with a disability by asking them to indicate how they travelled in the last journey they made in the two weeks prior to the census. Of all persons with a disability living in a household in Queensland, approximately half indicated they were the driver of a vehicle and one-third were passengers for the last journey. Six percent walked or used another method and 5% used public transport. Four percent had not made a journey in the preceding two weeks (ABS, 2011a). When only persons with a core activity limitation were considered (78% of all persons with a disability) the distribution of proportions across the sample remained very similar. Ninety percent of persons with a disability indicated their transport needs were fully met, 6% that they were partly met, and 4% that they were not met at all (ABS, 2011a).

Anxiety and depression scores

The 28% of Carers and 25% of people with a disability who scored 'abnormal' levels of anxiety is consistent with Shepherd et al's (1966) finding that 30 to 40% of a general populations suffers from anxiety that would benefit from clinical intervention, although it contrasts with Crawford et al's (2001) 12.6% of a general adult population scoring here, and a prevalence of 13.9% with anxiety disorders in Meltzer et al's (1995) survey of a general population. The mean anxiety score for Carers (8.14) and those with a disability (7.67) in this study is higher than for others: Spinhoven et al (1997) where the mean scores of three general adult populations ranged from 3.9 to 5.9; and Crawford et al's (2001) result of 6.4. In previous research mothers of disabled children showed significantly higher scores on the anxiety, depression and total HADs scales than mothers with children who were not disabled (Al-Eithan, Robert, & Al-Saeed, 2010). The anxiety mean score for mothers with disabled children was 8.7, and 4.9 for those whose children were not disabled, which is very similar to the mean scores in the current study.

The 18.9% of Carers and 20.8% of people with a disability scored 'abnormal' levels of depression. This compares with Crawford et al's (2001) 3.6%. The mean score for depression in the current study for Carers (6.44) and people with a disability (6.88) is higher than Crawford et al's (2001) 3.68, or Spinhoven et al's (1997) range for three studies of 3.4 to 4.6. The mean depression score for mothers of disabled children was 7.7, compared with 5.4 for mothers of children who were not disabled (Al-Eithan, et al., 2010). Again the mean for depression in the current study is consistent with this.

Impact of unmet need

Spall, et al. (2005) looked at the quality of service delivery following reforms in policy and funding in the Queensland disability sector. Findings highlighted cutbacks in quality and quantity of in-home and centre-based respite and domestic care due to funding shortfalls. These reductions in service availability placed increased financial burdens on carers and persons with a disability and increased the difficulty of obtaining aids (e.g. wheelchairs), which adversely affected carer and person with a disability quality of life.

In a recent study based in one Australian State, Nankervis, et al. (2011) interviewed staff from services and institutions involved with persons with a disability who had been relinquished into long-term respite care in the preceding 12 months. These interviews supplemented information from

client files to provide insight into why families relinquish care of persons with a disability. Relinquishing parents were characterised by physical exhaustion, depression, and feeling emotionally overwhelmed. The authors concluded that the provision of specific services - marriage counselling to strengthen family relationships, parental training in strategies such as prevention and management of challenging behaviours, and additional respite - had the potential to delay or prevent relinquishment of care of persons with a disability into care. Nankervis et al. noted however, that additional respite alone was not believed to be sufficient to prevent relinquishment.

In New Zealand it is reported that that carers experienced moderate to severe financial difficulties due to lack of information which prevented them from accessing entitlements, and significantly impacting on the carer being able to maintain employment (Jorgensen, et al., 2010).

Consequences were noted for other family members: carers noted that additional responsibilities were often placed on siblings of the person with a disability; and parental attention given to other offspring was reduced (Jorgensen, et al., 2010). Carers also reported social isolation due to demands of the carer role, consistent with the current study.

Central point of information

A point raised in several contexts in the current study is the need for a central point for information about disability services. It was also reported in the 2009 study (Cavaye, 2009).

Responsibilities for service provision and delivery

Most of the data for this study was collected prior to the announcement of the NDIS. Participants perceive that government holds most responsibility for funding services but that they are best delivered by accredited providers.

How to deliver services in a rural community

Collaboration is the answer most people gave and they were able to report existing collaborations and made suggestions for future ones.

Conclusions

While the issue remained unstated, a key gap is the planning for services for people with a disability. Carers reported being constantly concerned about what would happen to the person they care for if/when they were unable to continue providing care - because they have no current alternatives and there are no services planned that could provide this care, in their stead. This is the issue that concerns Carers most - the future!

There are notable service gaps for people with a disability and their Carers in the Warwick district. Many of these have been previously reported, with the gap in respite care first identified almost 20 years ago. This is a service that has the potential to be a key support for what in this study are distressed Carers, tiring under the burden of care, with no solutions on the horizon, and for many, little else apart for their Carer role. There are also key gaps in the provision of day activities and accommodation.

10. Recommendations

Priority One - Establish or increase the following services

These recommendations are in rank order.

1. Create a central point for information about disability services.

While this point is not the strongest point made, it is the top priority because without access to information about what services exist, people with a disability and the Carers, will not be able to access services that do exist. A key argument here is that not even the Key informants could provide a comprehensive list of the services available in the Warwick district, for people with a disability. While the responsibility for this service does not inherently lie with any one organisation, this is a service that needs to be sustainable. Because people with a disability and their Carers access specialist and generalist services, but in a specified geographical location, a logical choice to host this service is local government.

2. Develop a plan for the current and future provision of disability services

This is a key recommendation. Not once was planning for the provision of disability services mentioned by respondents. However the *lack* of a plan is apparent in so many of the comments made by people with a disability, their Carers and the Key informants. While it is clear that there is a high level of commitment and interest in providing for the needs of people with a disability and their Carers in the Warwick district, equally, service delivery appears to be fragmented and sporadic.

3. Collaborate for service delivery: Revisit existing collaborations and develop further collaborations to enable scarce services to be provided.

4. Address respite care service gaps

Some respite is available for people with a disability; it is well used and appreciated by Carers, but access is quite limited. In addition there are significant gaps where limited or no respite is available. These gaps are:

- d. Emergency respite
- e. Planned respite
- f. Respite for people with a disability with high care needs

5. Address accommodation gaps

There is some long term supported accommodation in Warwick, but it is limited. There appears to be no long term supported care for people with high care needs, and little or limited independent accommodation. A primary concern for many Carers in this study is what will happen to their child when they are no longer able to provide care, anticipated to happen in the next 5 to 10 years. While they want the security of knowing there is future care, they may not be ready to relinquish their role of primary carer yet. Therefore, transitional accommodation – places specified as such in supported accommodation – would provide the opportunity for the Carer and the person with the disability to make this move over a long period of time, as is required. Key accommodation gaps are:

- a. Long term supported, high care
- b. Independent living accommodation

6. Create a day activities centre

The value of a day activities centre is that it provides two services in one – respite for Carers and a potentially a productive use of time for the people with a disability. The people in this study want more opportunities for people with a disability to learn independent living skills – this is associated with the need for some of these people to learn to become more independent when their current Carer is unable to continue providing care. It is also because the current options are limited. The recommendation is for a day activities centre:

- a. To provide respite for Carers

- b. To provide people with a disability with constructive activities
- c. To teach independent living skills

7. Employment: Provide more supported employment places in the Warwick district.

8. Transport:

While most (but not all) transport needs appear to be met, specific problems with possible solutions have been mentioned. These are:

- a. Investigate the possibility of public transport being available to transport employees of the Endeavour Workshop
- b. Investigate how collaborations between service providers could improve transport options within and outside the town of Warwick
- c. Investigate how increased transport options could be created to meet the needs of people with mobility issues

9. Mobility: Investigate improving wheelchair access to commercial premises in Warwick

Priority Two – further investigate the following:

10. Respite

- a. Long hours
- b. School holiday
- c. Age appropriate

11. Day activities

- a. For elderly people with a disability
- b. Age appropriate activities

12. Investigate how Carers can be supported directly.

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12. Appendices

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Appendix 1: Maps

Warwick Shire Local Government Area (1994-2006)



Figure 1: Map of the Warwick shire.
Map provided by Southern Downs Regional Council

Southern Downs Regional Council (2006 onward)



Figure 2: Map of the Southern Downs Regional Council
([http://www.southerndowns.qld.gov.au/page/Council Information/](http://www.southerndowns.qld.gov.au/page/Council%20Information/) accessed 16/11/11)

Appendix 2: Publicity

Table 1: Dates and type of publicity items

| DATE | ITEM | |
|----------|--|----------------|
| 21/05/11 | Warwick Daily News | Online version |
| 14/06/11 | Free Times article | Online version |
| 14/07/11 | Free Times Article | Online version |
| 21/07/11 | Warwick Daily news | Online version |
| 23/07/11 | Warwick Daily news | Online version |
| 29/07/11 | Warwick Daily News | Online version |
| 15/08/11 | Warwick Daily News | Front Page |
| 01/08/11 | Interview with David Iliffe (not NDIS) | AM band only |
| 11/08/11 | NDIS interview (references study) | FM band |
| Replayed | Interview with David Iliffe (not NDIS) | AM/FM bands |

Daily News

Analysis gives hope to carers

Toni Somes | 21st May 2011

Warwick and District Disability Support Group president Peter Stacy has welcomed vital government funding for a disability needs analysis survey.

A NEW university research project examining the needs of disabled people in Warwick is offering hope to local carers.

Warwick and District Disability Support Group (WDDSG) president Peter Stacy announced this week his group had received vital government funding for a disability needs analysis survey.

"Our group has been lobbying for funding for this research project for three years and finally we have got lucky," he said.

More than \$29,800 has been offered to the WDDSG from the Gambling Community Benefit Fund for the survey.

Mr Stacy said this would be the first time a comprehensive disability needs analysis survey had been undertaken around the Warwick region.

"We really need this information so we can lobby government to improve or develop specific services here," he said.

"It will give us a comprehensive understanding of what disabled people of different ages and stages need in terms of local support and infrastructure.

"In the past we have written reports and talked to people but what has been missing – until now – is hard data."

He said the survey would be undertaken by the University of Queensland.



"There will be questionnaires people can fill in without giving their names or addresses," Mr Stacy said.

"University researchers will then do follow up interviews with anyone wishing to discuss their needs or particular situation in more detail."

UQ postdoctoral research fellow Jenny Moffatt said the survey had the potential to become a powerful tool for organisations like WDDSG to lobby government.

"I congratulate the WDDSG on securing funding for this research because I realise how important it is to have hard data," Dr Moffatt said.

"Governments tend to understand numbers."

The research project reference group will include WDDSG members, as well as representatives from the Endeavour Foundation, the Southern Downs Regional Council and the Department of Communities.

Mr Stacy said the project, which was expected to take between six and seven months, would initially focus on the former Warwick Shire area.

"But if there are people caring for family members with disabilities from outside that area we would sincerely welcome their input," he said.

A passionate disability services advocate, Mr Stacy said the survey offered hope for those people caring for family members or friends with special needs.

"My wife Christine and I are the full-time carers of our son Leigh, who has Down syndrome," he said.

"Being part of this survey gives us a chance to have our say and to assemble some statistics we can use to lever government to improve the future for people like Leigh."

He said the data collated during the survey would be available to other Warwick organisations representing people with disabilities.

For more information or to be part of the WDDSG disability needs analysis survey contact 4667 1909 or 0408 674 634 or p.c.stacy@bigpond.com

Tuesday, June 14, 2011



Disability survey to show deficit in care

A survey on the needs of people with disabilities in Warwick should hit the streets later this month. Warwick and District Disability Support Group president Peter Stacy is hoping residents will take the time to fill out this survey, which will provide the necessary facts for funding applications in an effort to start addressing these needs.

Mr Stacy said there were many unmet needs in the local disability sector, including the need for a learning and lifestyle centre, which will provide educational support for people with disabilities once they leave school.

"All the children with disabilities coming through school, when they turn 18, have nothing. Some of the building blocks that need to be put there aren't there at the moment," he said.

Mr Stacy said, unfortunately some people with disabilities end up in an aged care facility because there is nowhere else for them to go.

"This is tragic when you read about it or hear about it but it will be more tragic if we don't do anything about it," he said.

"It directly or indirectly affects everyone's lives in Warwick."

Another unmet need, which he believed will be identified in the upcoming survey, is the need for more respite beds in Warwick. At the moment, there are only three respite beds in the Rose City.

Mr Stacy wants carers and parents of local people with disabilities to fill out the survey, which does not ask for names and addresses, but focuses on your unmet needs.

He believed the survey results would be announced in December or January.

The questionnaire will be conducted by the University of Queensland.

The disability support group has been granted nearly \$30,000 through the Gambling Community Benefit Fund to conduct the needs analysis.

For more details or to participate in the survey, contact Peter Stacy on (07) 4667 1909.

Story: Rebecca Brown

Thursday, July 14, 2011



Surveys now out



People with disabilities, or their carers, are urged to pick up a needs analysis input survey, which are now available around the district.

The survey will show the needs of people with disabilities in the old Warwick Shire Council area and will hopefully provide the catalyst to receive government funding for necessary changes in the local disability sector.

The questionnaire is available at multiple locations around the district to make it easier for people to pick

up a copy. These locations include the Southern Downs Regional Council Library, the Southern Downs Regional Council Mobile Library, State Member for Southern Downs Lawrence Springborg's office in King Street, Warwick, the Department of Communities office in Guy Street, Warwick, the reception at the Condamine Medical Centre, the Allora Pharmacy, the Caltex Station in Wallace Street, Warwick, and Killarney's St Vinnies Store.

Warwick and District Disability Support Group Inc (WDDSG Inc) president Peter Stacy said the group hoped hundreds of locals would complete the survey, which does not require any identification details, so they could analyse the best information possible.

Mr Stacy said surveys should be posted in the supplied postage paid envelopes by the end of this month.

This will allow results to be collated by November.

If you need a survey posted to you, contact Peter Stacy on 0408 674 634.

Story: Rebecca Brown

Survey could help disabled | Warwick News | Local News in Warwick

Daily News

Survey could help disabled

Kerri Burns-Taylor | 21st July 2011

Tags [lawrence springborg](#), [university of queensland](#), [warwick disability group](#)



Peter Stacy is encouraging people with a disability or their carers to take a few minutes to complete a survey that he hopes will bring better access to facilities and services.

Kerri Burns-Taylor

WARWICK residents with a disability and their carers are being urged to spend a few minutes completing a survey that could potentially increase the facilities and services available in the area.

The Warwick Disability Group has worked tirelessly over the past few years to gain funding for a study to identify the current needs for the disabled community and their families.

President Peter Stacy said people can take part in the study – conducted by the University of Queensland – by spending a few minutes completing a questionnaire regarding their circumstances.

The results will be used to identify gaps within the services offered within the community and will be able to be used at a later stage to obtain funding and support to fill those gaps.

Member for Southern Downs Lawrence Springborg yesterday said he considered the project to be a fantastic idea and urged people to get behind it.

"This is an enormous credit to the Disability Support group," he said.

"It has been a real labour of love and the whole idea of trying to find out that the need is for disability support in the community is fantastic."

Mr Springborg said people are falling through the cracks and said the solution was a combination of self-help and government assistance.

Once the results are compiled, Mr Springborg said they would also be a valuable tool for council in terms of developing future planning and evaluating needs.

In 2006 there were 1069 individuals with disabilities identified within the former Warwick Shire, equating to about 5.27% of the population.

Mr Springborg said while many of those individuals were taken care of by parents or others, there was a concern about what would happen when that was no longer possible.

"Some of these people are happy to carry the burden while they're able-bodied, but the concern is what happens when they're no longer able to care for the person they love?" Mr Springborg said.

Mr Stacy said he hoped the results would open the door to greater resources for disabled people, making the transition during such a time much easier for those involved.

Pick up the disability needs questionnaire at: Caltex Service Station (Wallace St), Warwick Library and Mobile Library, Lawrence Springborg's office (King St), Department of Communities office (King St), Condamine Medical Centre, Allora Pharmacy, St Vinnie's Killarney.

For more information call Peter on 0408 674 634.

Survey to help find disabled needs | Warwick News | Local News in Warwick

Daily News

Survey to help find disabled needs

Kerri Burns-Taylor | 23rd July 2011

Tags



Christine and Peter Stacy, Dawn Scrymgeour and Lawrence Springborg.

Kerri Burns-Taylor

THE heart-wrenching question of "who will take care of my children when I'm gone?" is one that some parents ponder for far too long.

Parents of children with disabilities often spend much of their lives fearful of where their children will end up when they're gone and the pressure can be increased by a lack of local resources.

But the Warwick Disability group is striving to ease the minds of these parents and has invested in a

study to identify the needs in the area as a step towards providing better access to services.

Parents Peter and Christine Stacy and Dawn Scrymgeour say they have serious concern over what will happen to their disabled children when they are no longer able to take care of them.

They are fearful a sudden illness or accident could leave them unable to fulfil their round-the-clock duties in taking care of their children and have a devastating effect on those they love most.

"Without a proper transition it would be devastating to them," Mr Stacy said.

"When someone dies there is always going to be suffering but we should be trying to minimise that and a good transition reduces the shock and prepares them better.

"They might not like it and they may wish things were different but at least they won't be devastated."

After working tirelessly for funding for the past four years the group has now invested \$30,000 in a study that will help identify the needs of local disabled people and their carers.

The group believes a learning and lifestyle centre would also be an invaluable asset to the disabled community, especially to those who aren't suitable or are unable to attain employment.

Mrs Scrymgeour – whose two daughters are employed at the Endeavour Centre – said the installation of a learning and lifestyle centre would provide people with disabilities the chance to socialise and learn while also providing carers and parents with the down time they deserve.

Now disabled people and their families are being given to make a real difference in not only their lives, but also the lives of others with just a few minutes.

The group is on a strict timeline and is urging people to get in quick and complete the survey.

Once compiled, the results will create a tool that will be used to gain funding to improve the lives of all local disabled people and their carers.

Help make a difference. Pick up the disability needs questionnaire at:

Caltex Service Station (Wallace St)

Warwick Library and Mobile Library

Lawrence Springborg's office (King St)

Department of Communities office (King St)

Condamine Medical Centre

Allora Pharmacy

St Vinnie's Killarney

For more information call Peter on 0408 674 634

Warwick News | Local News in Warwick
MS sufferer calls for more services

Kerri Burns-Taylor | 29th July 2011

Warwick Daily News



Wendy and Guy Sugden stick together.

Kerri Burns-Taylor

WENDY Sugden's shocking diagnosis with MS was not easy to accept and she constantly ponders what the future holds for her when her beloved husband is no longer around.

At the time of diagnosis she said she "was really pissed off and I just kept thinking 'why did I get it?'"

"At night I would use my brain and really concentrate and think 'tomorrow I'm going to get up and walk'.

"But I've stopped doing that now and I have accepted it but I still get frustrated sometimes when I can't do something I want to do.

"I have a lovely dog and a lovely husband who loves me and I love him very much.

"Sometimes I can't understand why he loves me so much," she said.

The couple said they would like to see more facilities available to both people with a disability and their carers.

Mrs Sugden is considered a high-care person and her husband is on hand 24 hours a day to fulfil almost any need.

Both would like Mr Sugden to be able to take more breaks but said in Warwick there are limited options available.

Mrs Sugden can access temporary respite but is either placed with elderly people or those with a mental disability.

While she concedes she is happy to go wherever she can to provide her hard-working husband with some rest, she said she would like to be able to interact with people of her own age and intellectual capacity.

Mr Sugden is planning a rare week-long fishing trip with friends and Mrs Sugden will spend some time at the Killarney Aged Care facility.

Although the disease has left her in a wheelchair, Mrs Sugden's wit and alertness have not wavered, despite the occasional bout of short-term memory loss.

Having spent the past 11 years caring for his wife on a daily basis, Mr Sugden said he also fears what would happen to his wife if he were unable to care for her.

"What if something happens to me – if I get hurt or sick?" Mr Sugden asked.

"Where do I go? I thought about that the other night," Mrs Sugden said.

"Would I go to the MS house in Brisbane? But then I would be too far away from Guy."

The Warwick Disability Group is conducting a survey to identify and address the needs of people and their carers in the Warwick area.

The deadline is fast approaching and those eligible to participate are being urged to do so as soon as possible.

Pick up your form at: Caltex Service Station (Wallace St), Warwick Library and Mobile Library, Lawrence Springborg's office (King St), Department of Communities office (King St), Condamine Medical Centre, Allora Pharmacy and St Vinnie's Killarney.

For more information call Peter on 0408 674 634.

Daily News

Endeavour helps disabled people

Kerri Burns-Taylor | 15th August 2011

Tags

PEOPLE with disabilities looking for work

Kerri Burns-Taylor



in Warwick lack employment opportunities despite a Federal Government focus on getting them back into the workforce.

Endeavour Industries in the Industrial Estate is at capacity with 37 supported employees, and has seen an increase in capacity of just four places in more than 10 years.

Endeavour employees (front) Dave Gossow, Les Davies, Toby Frost, Kellum Doherty, (back) Mason Hartwell and manager Terry Politch enjoy going to work each day but other disabled people don't have that opportunity.

Customer service manager Lisa Wilson said Endeavour provided an invaluable opportunity for people with disabilities to develop skills and personal relationships in a supportive environment.

While Mrs Wilson said she would like to see more placements made available to the people on their waiting list, she said the decision to expand was out of Endeavour's hands.

"We have been at capacity for quite some time now. We certainly feel we have the capacity to provide employment opportunities for more people, but that decision is in the hands of the Federal Government," she said.

"In Warwick I think we are the only employment service for people with disabilities and I guess there are limited choices available."

Mrs Wilson said the Endeavour employees get more than just a pay cheque from their job.

She said it also provided the opportunity for personal growth, social networks and friendship, and the clients genuinely enjoyed coming to work each day.

"I think most of these guys would come to work even if they didn't get paid," she said.

Christine Stacy's son Leigh is employed at the Endeavour centre and she said a learning and lifestyle centre – where people with disabilities could meet, socialise and take part in games and activities – would help.

"If we had a learning and lifestyle centre more people would retire when they should and it would stop the clogging," she said.

Toby Frost has worked at the Endeavour centre for just over a year.

Mr Frost said he was bullied in his previous job and was happier in his new role.

"It's a lot better here because there is the bestest boss I've ever had," he said

An extensive study is under way to identify the needs of people with disabilities and their carers in the local community.

Get your copy at the Caltex Service Station (Wallace St), Warwick Library and Mobile Library, Lawrence Springborg's office, Department of Communities office, Condamine Medical Centre, Allora Pharmacy, St Vinnies Killarney or contact Peter Stacy on 0408674634.

WARWICK DISABILITY SURVEY FOR BLOG 3

David It's a very important survey, if you like, which is happening in the Warwick area at the moment of people with a disability and carer's of people with a disability in that area. The survey is being undertaken on behalf of the Warwick and District Disability Support Group. This is a group that's aimed at raising awareness of the plight of young people with a disability so that deficiencies and resources can be highlighted and that's what this survey is all about, to identify where those unmet needs are in the Warwick community. Peter Stacy is with the Warwick and District Disability Support Group and he joins me on the line now. Peter, good morning. Welcome.

Peter Good morning David, thank you for the call. How are you?

David Peter I am very, very well. This is a pretty important survey, I would imagine. Tell me how it came about? You got a grant from the government?

Peter Yes we did. We were able to get a Gaming Grant, for want of a better word, which enabled us to fund the University of Queensland to undertake this research. We need the data to be able to lobby government and government organisations to provide the services that are needed to look after people with a disability and their carer's in this part of the world, so that's really the main purpose for getting this exercise done. We know for example that about 5.3% of the population, this is from the last Census data, have a severe or profound core activity disability. But, we don't have the services to address that. And until we have some hard data to be able to put before people from the various government agencies, they thank us very nicely for our kind words, but they just move on. So we need to be able to provide hard information to get this stuff addressed.

David Peter, this survey will give you that information on paper and it will give you evidence to take along to the powers that be, but you must know anecdotally that the situation is not overly good, I suppose, for a lot of people in that situation.

Peter Well, of course, we do know this, but we can't put the hard data there. Interestingly enough, what we intend to do with this, is publish the results. Historically what happens when you get data such as this, it ends up in a filing cabinet somewhere and whilst you may be able to put it to a short term use, in longer term and for other groups and other organisations within the area they don't get access to it. We saw that as a shortcoming, so we intend to publish this, it will be presented probably to the Southern Downs Regional Council. We hope it will be incorporated in their Futures Plan, but more importantly it will be available to other members of the community to use for their purposes, so, there is a fair bit there. The people we try to reach are the people that are very hard to reach. They're a pretty stoic lot these people that live in rural communities, they don't go looking for handouts, they keep themselves to themselves and their business is kept to themselves and when they're faced with an adversity such as this, they tend just to tighten their belts, get the family group a little closer together and get on with it. They don't tell you about it.

David Given that, I suppose you are a little bit concerned that people will receive this survey and not take the time to fill it out.

Peter Well, they mightn't even go looking for it. There was a Senate References Committee Meeting, it actually met in Toowoomba in December last year, you may remember it. It's just presented its report to the government and it's concerned that up to 25% of people don't even contact

Centrelink when they have people with a disability that they're to care for. So if 25%, or thereabouts, of them don't even bother to tell Centrelink, you can just imagine how many people they would present to the Department of Disability Services and that's really the issue. We want these people, not to identify themselves, just to tell us what they need. Because of that we have made allowances for the forms to be in locations outside of Warwick, so for example, if you are in the Killarney side of town, the forms are at St. Vinnies store, if you are over on the other side or out towards Leyburn and Allora, they are at the pharmacy in Allora. They're at the reception for [Condamine] *0:04:22 Medical centres, someone has to go to the doctors. If someone's in Warwick and has to go to the hospital, then Caltex on Wallace Street has these forms. They are with the travelling mobile library that goes around all these small rural communities, [Cannonvale and Yangan] *0:04:38 and what and you can get a form there. If you are in Warwick for any other reason, you can get them from the council, mobile library. You can get them from Lawrence Springborgs' office or you can get them from us. You have our contact numbers there, so if people need the form, then I would hope that they could get access to it and they do need to send it in. The university has a short timeframe; we need to get the stuff in. They need to do their work to produce this data and from that, I hope that we can lobby the departments to ensure that the services that are needed are provided. We don't have a lot of services in Warwick, there aren't many things that are there and that's probably because the need hasn't been expressed.

David Indeed. Good luck in getting people to respond to this survey. If people miss those details, they can give us a call. I will have to leave it there, but I appreciate your time and let us know how things go – stay in touch.

Peter I would love to do that. Thank you David.

David Thanks Peter, much appreciated. Peter Stacy from the Warwick & District Disability Support Group. News time, it's half past seven.

Supporting disabilities in Warwick & surrounding areas

WARWICK & DISTRICT DISABILITY SUPPORT GROUP

**INVITES PEOPLE WITH A DISABILITY AND/OR CARERS OF
PEOPLE WITH A DISABILITY TO STATE THEIR NEEDS.**

If you require further
information please call
Peter Stacy (Chairman)
07 46671909

Warwick & District Disability Support
Group

University of Queensland
Researchers are compiling a "Needs
Analysis Survey" register in the War-
wick region.

Forms are available at:

Lawrence Springborg's Office, King Street,
Warwick

Alora Pharmacy

Department of Communities Office, Guy
Street, Warwick

Warwick Library

Warwick Library Mobile Bus

Condamine Medical Centre

Caltex On Wallace

Killarney - St Vincent De Paul Office

Appendix 3: Questionnaire returns and publicity dates

Table 2: Questionnaire returns and publicity dates.

| Date | Received | Publicity |
|----------|----------|--|
| 21/05/11 | | Warwick Daily News article (NP) |
| 14/06/11 | | Free Times article (NP) |
| 18/07/11 | 1 | |
| 19/07/11 | 8 | |
| 20/07/11 | 3 | |
| 21/07/11 | 2 | Warwick Daily News article (NP) |
| 22/07/11 | 2 | |
| 23/07/11 | | Warwick Daily News article (NP) |
| 25/07/11 | 5 | |
| 26/07/11 | 2 | |
| 27/07/11 | 18 | |
| 28/07/11 | 1 | |
| 29/07/11 | 3 | Warwick Daily News article (NP) |
| 01/08/11 | | ABC Regional radio interview (AM only) |
| 02/08/11 | 10 | |
| 03/08/11 | 4 | |
| 04/08/11 | 4 | |
| 05/08/11 | 6 | |
| 09/08/11 | 4 | |
| 11/08/11 | | ABC Regional radio interview (NDIS) |
| 12/08/11 | 4 | |
| 15/08/11 | 8 | Warwick Daily News article (NP) |
| 16/08/11 | 2 | |
| 17/08/11 | 1 | |
| 18/08/11 | 2 | |
| 19/08/11 | 4 | |
| 23/08/11 | 1 | |
| 24/08/11 | 2 | |
| TOTAL | 97 | |

Appendix 4: Content of Questionnaire packages

The questionnaire package included:

- An introductory letter from the president of the Warwick and District Disability Support Group
- Participant information sheet
- Participant consent form
- Questionnaires (reproduced in Appendix 6)
- Reply paid envelope.

Introductory letter from the president of the Warwick and District Disability Support Group Inc

**WARWICK & DISTRICT DISABILITY SUPPORT
GROUP Inc**
ABN 32 455 699 456

Postal address: 20283 New England Hwy, The Glen, 4370
Telephone: 4667 1909
Email: p.c.stacy@bigpond.com

Warwick District Disability Needs Assessment

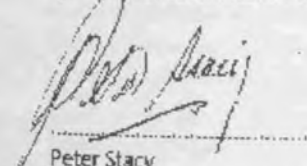
Introductory letter from the President of WDDSG Inc

For some years we have been aware that there are people in our community with a disability who do not have enough support. We have obtained funds from the Community Gambling Benefit Fund and have engaged the University of Queensland to conduct a study on our behalf to identify services, and gaps in service provision to people with a disability and their carers. We will then use this research report to help government and non-government organisations in the Warwick district with their planning for disability support services.

We are asking all carers of people with a disability and adults with a disability, in the northern part of the Southern Downs, to complete a questionnaire. The University will also want to interview some people. Neither carers nor people with a disability will be identifiable in the report the University will give to the Warwick District Disability Support Group Inc.

The university will also create a Resource directory for disability services in the Warwick district. The report, combined with the Resource Directory will show what services there are for people with a disability and their carers, and what is needed – it will show the gap.

Thank you in advance for your participation. Should you have any questions or would like to speak to someone about the project please contact me.



Peter Stacy
President
Mobile: 0408 674 634



The University of Queensland
Rural Clinical School Research Centre,

Project title: Disability Needs Analysis for the Warwick District

Information sheet

Investigators

Dr. Jennifer Moffatt, Postdoctoral Research Fellow, Rural Clinical School Research Centre, School of Medicine, University of Queensland.

Project

Unmet needs in the disability sector have been identified in the Warwick district in 1994, 1995, 2007, and again in 2009, through research investigating broader issues. The purpose of this study is to identify services, and gaps in service provision to disabled persons and their carers, to assist government and non-government organisations in their planning.

The information for the study will be collected from questionnaires and interviews with people with disabilities, and their carers, living in the Warwick district, and from existing data sources. We would like to invite you to participate in this study and to contribute your opinions and views through a questionnaire and possible interview. The questionnaire will ask you about your needs as a carer or person with a disability, and whether those needs are met by the services currently available within the Warwick district. A small number of participants will be further interviewed by the principal researcher. In the interview you will be asked questions about the provision of services for persons with a disability living within the Warwick district. The information you provide will be invaluable in helping us research this area. The interview will take approximately 45 minutes; it will occur at a time and place of your convenience and will consist of a series of questions about the service requirements of disabled persons and their carers. The interview will be digitally recorded. All information relating to your participation in this project will be immediately de-identified by the researcher, and held securely in this de-identified format. Reporting about the project and any results used for publications will be aggregated so that no individual is identified.

Involvement in the study is voluntary and participants may withdraw from the study at any time if they wish to, without consequence. Your answers to all questions will be confidential. The results from the study will be reported at the sector level. This study adheres to the guidelines of the ethical review process of the University of Queensland and has been approved by the University of Queensland Behavioural and Social Science Ethical Review Committee (Reference number 2010000667). Whilst you are free to discuss your participation in this study with the project staff, if you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 07/3365-3924. Information on the project can be obtained by contacting Dr Jennifer Moffatt (07/4631-5455 j.moffatt@uq.edu.au).



The University of Queensland
Rural Clinical School Research Centre,
School of Medicine

Project title: Disability Needs Analysis for the Warwick District

Consent form

Investigators

Dr. Jennifer Moffatt, Postdoctoral Research Fellow, Rural Clinical School Research Centre, School of Medicine, University of Queensland.
Ms Donna Rouse, Project Officer, Disability Needs Analysis Study, Rural Clinical School Research Centre, School of Medicine, University of Queensland.

This research project has been approved by the University of Queensland Behavioural and Social Science Ethical Review Committee. The investigators conducting this research project abide by the principles governing the ethical conduct of research and, at all times, avows to protect the interests of all participants. This form and the accompanying *Information Sheet* have been given to you for your own protection, and contain an outline of the proposed study. Your signature below will indicate that you agree to participate in the study.

I agree to participate in the above project and in doing so acknowledge that:

1. I have read the associated Information sheet outlining the nature and purpose of the project and the extent of my involvement, and have had these details explained to me. I have had the opportunity to ask further questions and am satisfied that I understand what is involved in the project.
2. I have been informed as to the nature and extent of any risk to my health or well being.
3. I am aware that participation in this project will not result in any direct benefit to me.
4. I have been informed that participation in this study is voluntary and that I may withdraw from the project at any time without consequence to me.
5. I am aware that I may request further information about the project.
6. I understand that in respect of any information obtained during the course of the project, confidentiality will be maintained and that I will not be identified in any way in any documents produced from this project, without my explicit permission.
7. This study adheres to the guidelines for the ethical review process of the University of Queensland. You are free to discuss your participation in this study at any time with the project manager, Dr Jennifer Moffatt (07/4631 5455). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 07/3365 3924.

Date:

Participant's name: Signature:

Appendix 5: Interview variables matrix

Table 3: Interview variables matrix

| | Town | Age of carer | Age PWD | Disability type (main) | Relationship | Carer Sex |
|-------|-----------------|--------------|---------|------------------------|--------------|-----------|
| CARER | Town 6 O/T 2 | 27 | 5 | Intellect 3 | Parent 6 | Female 6 |
| | | 45 | 18 | Physical 2 | Spouse 1 | Male 1 |
| | | 45 | 20 | ABI 1 | Friend 1 | |
| | | 50 | 31 | Multi 1 | | |
| | | 50 | 38 | Autism | | |
| | | 57 | 40 & 48 | | | |
| | | 59 | 57 | | | |
| | | 76 | 63 | | | |
| PWD | Town 2 | | 57 | Physical 1 | | Female 1 |
| | | | 65 | Physical/psychological | | Male 1 |

Appendix 6: Questionnaires

Carer Questionnaire

RURAL CLINICAL SCHOOL RESEARCH CENTRE
PO BOX 496,
DARLING HEIGHTS,
QLD 4350
PH: 07 4631 1648



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

Warwick District Disability Needs Assessment

Questionnaire for Carers

Q1 Primary carer details

To assist us to understand you as a carer, we would like some information about yourself. The first section asks for general details.

- a) What is your postcode?
- b) In what year were you born?
- c) What is your gender? ☐ Male ☐ Female
- d) For how many years have you provided care for a person/s with a disability? years
- e) What is your relationship to this person/people?
(Please tick one box) ☐ Parent ☐ Friend
☐ Sibling (brother or sister) ☐ Other (describe)
☐ Other relative
- f) Are you the sole carer for this person/people? ☐ Yes ☐ No
- g) Do you receive any financial assistance from the government for caring for this person/people? ☐ Yes ☐ No
- h) What is your primary means of income support?
(Please tick one box) ☐ Full time employment ☐ CentreLink
☐ Part time employment ☐ DSQ/Other disability
☐ Supported by spouse ☐ Other
☐ Supported by other family member

Q2 Details of the person/people with the disability whom you care for

We would like you to describe the person that you care for. If you care for more than one person, write numbers of people in the box. For example for person 1, write 1 in the box; for person 2, write 2 in the box. Multiple boxes are provided for some questions.

- a) What is the postcode of the person with the disability? Person 1
 Person 2
- b) What is the year of birth of the person with the disability? Person 1
 Person 2

c) What is the gender of the person with the disability?

☐ Male ☐ Female
☐ Male ☐ Female

d) How does the person with the disability occupy most of his/her time?
(e.g. Endeavour, therapy centre, school)

☐ Attends secondary school
☐ Employed part time
☐ Employed casually
☐ At home
☐ Other

(If more than 1 person, write numbers in the boxes, e.g. 1, 2 and so on)

e) Does the person with the disability receive assistance from any paid services? ☐ Yes ☐ No

f) What is the primary means of income support received by the person with the disability?

☐ Full time employment
☐ Part time employment
☐ Supported by spouse
☐ Supported by other family member
☐ CentreLink
☐ DSQ/Other disability
☐ Other

(If more than 1 person, write numbers in the boxes, e.g. 1, 2 and so on)

g) Does the person with the disability pay more than 25% of his/her income for accommodation? ☐ Yes ☐ No

h) What are the primary and other significant disability groups of the person with the disability?

Primary disability group

Please tick only 1 box

- ☐ Intellectual
☐ Specific learning/ADD (other than intellectual)
☐ Autism – including Aspergers' Syndrome
☐ Physical
☐ Acquired Brain Injury
☐ Neurological – including Epilepsy and Alzheimer's Disease
☐ Deafblind – dual sensory
☐ Vision
☐ Hearing
☐ Speech
☐ Psychiatric
☐ Developmental Delay – only valid for a child aged 0-5 years

Other significant disability

Please tick all that apply

- ☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐
☐

Q3 The level of support needed by the person/people with the disability whom you care for
How often does the person with the disability need personal help or supervision with activities or participation in the following life areas?

The person can undertake activities or participate in this life area with this level of personal help or supervision (or would require this level of help or supervision if the person currently helping were not available).

The levels of help or supervision are:

- 1) Unable to do or always needs help/ supervision in this life area
- 2) Sometimes needs help/ supervision in this life area
- 3) Does not need help/ supervision in this life area but uses aids or equipment
- 4) Does not need help/ supervision in this life area and does not use aids or equipment
- 5) Not applicable

Please indicate the level of help or supervision required for each life area (rows a-i) by ticking only one level of help or supervision (columns 1-5).

a) Self-care (e.g. washing oneself, dressing, eating, toileting) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

b) Mobility (e.g. moving around the home and/or moving around away from home, including using public transport or driving a motor vehicle, getting in or out of bed or a chair) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

c) Communication (e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

d) Interpersonal interactions and relationships (e.g. actions and behaviours an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

NOTE: In the following questions 'not applicable' is a valid response ONLY IF the person is 0-4 years old

e) Learning, applying knowledge and general tasks and demands (e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Question continues over the page

f) Education (e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

g) Community (civic) and economic life (e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

NOTE: In the following questions 'not applicable' is a valid response ONLY IF the person is 0-14 years old

h) Domestic life (e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping cooking, home maintenance) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

i) Working (e.g. actions, behaviours and tasks to obtain and retain paid employment) ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Q4 Current living arrangements

Now we would like you to tell us about the current living arrangements of the person with the disability.

a) Where does the person with a disability usually live?

- ☐ Private residence
- ☐ Domestic-scale supported living
- ☐ Supported accommodation facility
- ☐ Boarding house/private hotel
- ☐ Independent living unit within a retirement village
- ☐ Residential aged care facility
- ☐ Psychiatric/mental health community care facility
- ☐ Hospital
- ☐ Other

b) Does the person with the disability usually live alone or with others?

- ☐ Lives alone
- ☐ Lives with family
- ☐ Lives with others

c) How many years has this person been living in this accommodation? years

d) How suitable is this accommodation for this person (Please tick one box)

☐ Very suitable ☐ Suitable ☐ Not sure ☐ Unsuitable ☐ Very unsuitable

c) Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects

d) How do you as a carer think the person with the disability feels about his/her accommodation arrangement? (Please tick one box)

☐ Very happy ☐ Happy ☐ Not sure ☐ Unhappy ☐ Very unhappy

e) Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects

Q5 Future accommodation needs

a) Do you foresee a change in this person's accommodation needs in the future? (Please tick one box)

☐ Yes within 1yr ☐ No, I do not foresee any change

☐ Yes within 2-5 yrs

☐ Yes in 5-10 yrs

☐ Yes over 10 yrs

b) Would you like to tell us more about your reasons for this choice?

c) Would you like to see the person you care for continue to have the opportunity to become progressively independent in their accommodation and living arrangement? ☐ Yes ☐ No

d) Would you like to tell us more about your reasons for this choice?

e) What type of accommodation do you think would best suit the needs of the person you care for? (Please tick one box)

☐ Large residential – accommodating more than 20 people

☐ Small residential – 7-20

☐ House/unit – living alone or sharing with other people with appropriate amounts of support

☐ Village style – several people in unit accommodation in a supported village style environment which provides various facilities (e.g., social, recreational)

☐ Other

f) Would you like to tell us more about your reasons for this choice?

Q6 Accommodation availability/needs

a) Please indicate which of the following types of accommodation are currently available to the person with the disability (Please tick all that apply)

- ☐ Long term supported accommodation with high needs and 24 hour care
- ☐ Long term shared accommodation with a low level of support
- ☐ Transition to care
- ☐ Respite care (planned)
- ☐ Emergency respite care
- ☐ Short term recreational accommodation
- ☐ Community housing
 - ☐ Clusters
 - ☐ Independent living

b) It is important for us to know of the problems, obstacles, choices, difficulties and concerns you have now or had in the past with accommodation needs. Please comment on both

positives and negatives of these needs

c) Please tell us what you see is impacting upon the future accommodation needs of the person you care for

Q7 Day activities

a) Listed below are the types of day activities that adults with a disability may wish to participate in. Please indicate which of these activities the person you care for currently would participate in if they were available? (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Long hours day care (7am-7pm) | <input type="checkbox"/> Recreational activities |
| <input type="checkbox"/> School holiday hour day care | <input type="checkbox"/> Skills for independent living activities |
| <input type="checkbox"/> Recreational trips | <input type="checkbox"/> Other |
| <input type="checkbox"/> Education (literacy and numeracy) | |

b) Please indicate which of these day activities are available now. (Please tick all that apply)

- | | |
|--|---|
| <input type="checkbox"/> Long hours day care (7am-7pm) | <input type="checkbox"/> Recreational activities |
| <input type="checkbox"/> School holiday hour day care | <input type="checkbox"/> Skills for independent living activities |
| <input type="checkbox"/> Recreational trips | <input type="checkbox"/> Other |
| <input type="checkbox"/> Education (literacy and numeracy) | |

Q8 Transport

a) What type of transport does the person you care for currently require? (Please tick all that apply)

- ☐ Usual car travel
- ☐ Public transport (e.g. bus, train)
- ☐ Transport purpose built for a person with a disability (e.g. Maxi taxi)

b) Which of the types of transport that the person you care for can use, are available to you now. (Please tick all that apply)

- ☐ Usual car travel
- ☐ Public transport (e.g. bus, train)
- ☐ Transport purpose built for a person with a disability (e.g. Maxi taxi)

Q9 Your Feelings

The following section asks about your feelings at the moment. Tick the box that best describes your feelings right now, and try to answer without spending too much time thinking about your response.

a) I feel tense or 'wound up'

- ☐ Most of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Not at all

c) I get a sort of frightened feeling as if something awful is about to happen

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little but it doesn't worry me
- ☐ Not at all

e) Worrying thoughts go through my mind

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

g) I can sit at ease and feel relaxed

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

b) I still enjoy the things I used to

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

d) I can laugh and see the funny side of things

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

f) I feel cheerful

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

h) I feel as if I am slowed down

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

Needs Assessment Questionnaire – Carer

i) I get sort of frightened, like feeling 'butterflies' in the stomach

- ☐ Not at all
☐ Occasionally
☐ Quite often
☐ Very often

j) I have lost interest in my appearance

- ☐ Definitely
☐ I don't take as much care as I should
☐ I may not take quite as much care
☐ I take just as much care as ever

k) I feel restless as if I have to be on the move

- ☐ Very much indeed
☐ Quite a lot
☐ Not very much
☐ Not at all

l) I look forward with enjoyment to things

- ☐ As much as I ever did
☐ Rather less than I used to
☐ Definitely less than I used to
☐ Hardly at all

m) I get sudden feelings of panic

- ☐ Very often indeed
☐ Quite often
☐ Not very often
☐ Not at all

n) I can enjoy a good book or radio or TV program

- ☐ Often
☐ Sometimes
☐ Not often
☐ Very seldom

Are you happy to be contacted for a follow-up interview?

Name

Address

Phone number

Your final comments are?

.....
.....
.....

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
Please place this and your signed consent form in the Reply Paid envelope provided and post it.

Person with a disability Questionnaire

RURAL CLINICAL SCHOOL RESEARCH CENTRE
PO BOX 496,
DARLING HEIGHTS,
QLD 4350
PH: 07 4631 1648



THE UNIVERSITY
OF QUEENSLAND
AUSTRALIA

Warwick District Disability Needs Assessment

Questionnaire for Person with a disability

Q1. Personal details

To assist us to understand you as a person with a disability, we would like some information about you. The first section asks for general details.

a) What is your postcode?

b) In what year were you born?

c) What is your gender?

☐ Male ☐ Female

d) What are your primary and other significant disability groups?

Other significant disability

Please tick only 1 box

Please tick all that apply

- | | |
|--|--------------------------|
| <input type="checkbox"/> Intellectual | <input type="checkbox"/> |
| <input type="checkbox"/> Specific learning/ADD (other than intellectual) | <input type="checkbox"/> |
| <input type="checkbox"/> Autism – including Aspergers' Syndrome | <input type="checkbox"/> |
| <input type="checkbox"/> Physical | <input type="checkbox"/> |
| <input type="checkbox"/> Acquired Brain Injury | <input type="checkbox"/> |
| <input type="checkbox"/> Neurological – including Epilepsy and Alzheimer's Disease | <input type="checkbox"/> |
| <input type="checkbox"/> Deafblind – dual sensory | <input type="checkbox"/> |
| <input type="checkbox"/> Vision | <input type="checkbox"/> |
| <input type="checkbox"/> Hearing | <input type="checkbox"/> |
| <input type="checkbox"/> Speech | <input type="checkbox"/> |
| <input type="checkbox"/> Psychiatric | <input type="checkbox"/> |

e) How do you occupy most of your time? (e.g. Endeavour, therapy centre, school)
(Please tick one box)

- ☐ Employed part time
☐ Employed casually
☐ At home
☐ Other

f) Do you receive assistance from any paid services? ☐ Yes ☐ No

g) Do you pay more than 25% of your income for accommodation? ☐ Yes ☐ No

h) What is your primary means of income support?
(Please tick one box)

- ☐ Full time employment
☐ Part time employment
☐ Supported by spouse
☐ Supported by other family member
☐ CentreLink
☐ DSQ/Other disability
☐ Other

Q2 The level of support you require

a) Do you require the assistance of a care giver? ☐ Yes ☐ No

b) What is your relationship to your primary care provider?

- ☐ Child
☐ Sibling (brother or sister)
☐ Other relative
☐ Friend
☐ Other (describe)

How often do you need personal help or supervision with activities or participation in the following life areas?

Indicate whether you can undertake activities or participate in this life area with this level of personal help or supervision or would require this level of help or supervision if the person currently helping were not available.

Please indicate the level of help or supervision required for each life area (rows c-k) by ticking only one level of help or supervision (columns 1-4).

Question continues on the next page

The levels of help of supervision are:

- 1) Unable to do or always need help/ supervision in this life area
- 2) Sometimes need help/ supervision in this life area
- 3) Do not need help/ supervision in this life area but use aids or equipment
- 4) Do not need help/ supervision in this life area and do not use aides or equipment

c) Self-care (e.g. washing oneself, dressing, eating, toileting) ☐ 1 ☐ 2 ☐ 3 ☐ 4

d) Mobility (e.g. moving around the home and/or moving around away from home, including using public transport or driving a motor vehicle, getting in or out of bed or a chair) ☐ 1 ☐ 2 ☐ 3 ☐ 4

e) Communication (e.g. making self understood, in own native language or preferred method of communication if applicable, and understanding others) ☐ 1 ☐ 2 ☐ 3 ☐ 4

f) Interpersonal interactions and relationships (e.g. actions and behaviours an individual does to make and keep friends and relationships, behaving within accepted limits, coping with feelings and emotions) ☐ 1 ☐ 2 ☐ 3 ☐ 4

g) Learning, applying knowledge and general tasks and demands (e.g. understanding new ideas, remembering, problem solving, decision making, paying attention, undertaking single or multiple tasks, carrying out daily routine) ☐ 1 ☐ 2 ☐ 3 ☐ 4

h) Education (e.g. the actions, behaviours and tasks an individual performs at school, college, or any educational setting) ☐ 1 ☐ 2 ☐ 3 ☐ 4

i) Community (civic) and economic life (e.g. recreation and leisure, religion and spirituality, human rights, political life and citizenship, economic life such as handling money) ☐ 1 ☐ 2 ☐ 3 ☐ 4

j) Domestic life (e.g. organising meals, cleaning, disposing of garbage, housekeeping, shopping cooking, home maintenance) ☐ 1 ☐ 2 ☐ 3 ☐ 4

k) Working (e.g. actions, behaviours and tasks to obtain and retain paid employment) ☐ 1 ☐ 2 ☐ 3 ☐ 4

Q3 Current living arrangements

Now we would like you to tell us about your current living arrangements.

a) Where do you usually live?

(Please tick one box)

- ☐ Private residence
- ☐ Domestic-scale supported living
- ☐ Supported accommodation facility
- ☐ Boarding house/private hotel
- ☐ Independent living unit within a retirement village
- ☐ Residential aged care facility
- ☐ Psychiatric/mental health community care facility
- ☐ Hospital
- ☐ Other

b) Do you usually live alone or with others?

- ☐ Live alone
- ☐ Live with family
- ☐ Live with others

c) How many years have you been living in this accommodation?

years

d) How suitable is this accommodation for you? (Please tick one box)

- ☐ Very suitable
- ☐ Suitable
- ☐ Not sure
- ☐ Unsuitable
- ☐ Very unsuitable

e) Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects

f) How do you feel about your accommodation arrangement? (Please tick one box)

- ☐ Very happy
- ☐ Happy
- ☐ Not sure
- ☐ Unhappy
- ☐ Very unhappy

g) Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects

Q4 Future accommodation needs

a) Do you foresee a change in your accommodation needs in the future? (Please tick one box)

- ☐ No
- ☐ Yes within 1yr
- ☐ Yes within 2-5 yrs
- ☐ Yes in 5-10 yrs
- ☐ Yes over 10 yrs

b) Would you like to tell us more about your reasons for this choice?

c) Would you like the opportunity to become progressively independent in your accommodation and living arrangements? ☐ Yes ☐ No

d) Would you like to tell us more about your reasons for this choice?

e) What type of accommodation do you think would best suit your needs? (Please tick one box)

- ☐ Large residential – accommodating more than 20 people
- ☐ Small residential – 7-20
- ☐ House/unit – living alone or sharing with other people with appropriate amounts of support
- ☐ Village style – several people in unit accommodation in a supported village style environment which provides various facilities (eg social, recreational)

☐ Other

f) Would you like to tell us more about your reasons for this choice?

Q5 Accommodation availability

a) Please indicate which of the following types of accommodation are currently available to you (Please tick all that apply)

- ☐ Long term supported accommodation with high needs and 24 hour care
- ☐ Long term shared accommodation with a low level of support
- ☐ Transition to care

List continues over page

- ☐ Respite care (planned)
- ☐ Emergency respite care
- ☐ Short term recreational accommodation
- ☐ Community housing
 - ☐ Clusters
 - ☐ Independent living

a) It is important for us to know of the problems, obstacles, choices, difficulties and concerns you have now or had in the past with accommodation needs. Please comment on both positives and negatives of these needs.

b) Please tell us what you see is impacting upon your future accommodation needs?

Q6 Daily activities

a) Listed below are the types of day activities that adults with a disability may wish to participate in. Please indicate which of these activities YOU would participate in if they were available. (Please tick all that apply)

- ☐ Recreational trips
- ☐ Education (literacy and numeracy)
- ☐ Recreational activities
- ☐ Skills for independent living activities
- ☐ Other

b) Please indicate which of these day activities are available to you now. (Please tick all that apply)

- ☐ Recreational trips
- ☐ Education (literacy and numeracy)
- ☐ Recreational activities
- ☐ Skills for independent living activities
- ☐ Other

Q7 Transport

a) What type of transport do you require? (Please tick all that apply)

- ☐ Usual car travel
- ☐ Public transport (e.g. bus, train)
- ☐ Transport purpose built for a person with a disability (eg Maxi taxi)

b) Which of the types of transport that you can use, are available to you now? (Please tick all that apply)

- ☐ Usual car travel
- ☐ Public transport (e.g. bus, train)
- ☐ Transport purpose built for a person with a disability (eg Maxi taxi)

Q8 your feelings

The following section asks about your feelings at the moment. Tick the box that best describes your feelings right now, and try to answer without spending too much time thinking about your response.

a) I feel tense or 'wound up'

- ☐ Most of the time
- ☐ A lot of the time
- ☐ From time to time, occasionally
- ☐ Not at all

c) I get a sort of frightened feeling as if something awful is about to happen

- ☐ Very definitely and quite badly
- ☐ Yes, but not too badly
- ☐ A little but it doesn't worry me
- ☐ Not at all

e) Worrying thoughts go through my mind

- ☐ A great deal of the time
- ☐ A lot of the time
- ☐ From time to time, but not too often
- ☐ Only occasionally

g) I can sit at ease and feel relaxed

- ☐ Definitely
- ☐ Usually
- ☐ Not often
- ☐ Not at all

b) I still enjoy the things I used to

- ☐ Definitely as much
- ☐ Not quite so much
- ☐ Only a little
- ☐ Hardly at all

d) I can laugh and see the funny side of things

- ☐ As much as I always could
- ☐ Not quite so much now
- ☐ Definitely not so much now
- ☐ Not at all

f) I feel cheerful

- ☐ Not at all
- ☐ Not often
- ☐ Sometimes
- ☐ Most of the time

h) I feel as if I am slowed down

- ☐ Nearly all the time
- ☐ Very often
- ☐ Sometimes
- ☐ Not at all

Needs Assessment questionnaire – Person with a disability

i) I get sort of frightened, like feeling 'butterflies' in the stomach

- ☐ Not at all
☐ Occasionally
☐ Quite often
☐ Very often

j) I have lost interest in my appearance

- ☐ Definitely
☐ I don't take as much care as I should
☐ I may not take quite as much care
☐ I take just as much care as ever

k) I feel restless as if I have to be on the move

- ☐ Very much indeed
☐ Quite a lot
☐ Not very much
☐ Not at all

l) I look forward with enjoyment to things

- ☐ As much as I ever did
☐ Rather less than I used to
☐ Definitely less than I used to
☐ Hardly at all

m) I get sudden feelings of panic

- ☐ Very often indeed
☐ Quite often
☐ Not very often
☐ Not at all

n) I can enjoy a good book or radio or TV program

- ☐ Often
☐ Sometimes
☐ Not often
☐ Very seldom

Did you receive any assistance from a carer to complete this questionnaire?

☐ Yes ☐ No

Are you happy to be contacted for a follow-up interview?

Name.....

Address.....

Phone number.....

Final comments:

.....
.....
.....

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
Please place this and your signed consent form in the Reply Paid envelope provided and post it.

Appendix 7: Interview guides

Interview guide - Carer

Interview guide - carer

ID to match with questionnaire:

Date:

Q1 As you age, what are your main concerns about the person with the disability that you care for? (Prompts: accommodation; support; transport; independence; finance; activities; friends/advocates)

Q2 (For those who are currently caring for a person with a disability at home)(for those who used to do this but the person is now in supported/other accommodation – rephrase question)

What are the everyday challenges for you as a carer

Q3 What services do you currently access for yourself?

Q4 What services do you currently access for the person with a disability that you care for?

Q5 Considering your circumstances, are there services that you wish you could access? (prompt for what those services are; barriers to access eg don't exist; costs)

Q6. If there was just one service that you could have that you don't have currently, what would it be?

Q7 What is it that keeps you going at the times when life is very difficult?

Q8. What are the costs of caring? (prompt: financial, emotional)

Q9 In your view who should be providing services for people with a disability?

Q10 In a small rural community it is more difficult to provide the range of services that would be available in the city. What ideas do you have about how more services could be provided for people with a disability, in the Warwick district?

Q11 Who should fund services for people with a disability?

Q12 Do you have any questions or final comments?

Thankyou for your time and assistance. Would you like a summary of the report Y/N

Interview guide – person with a disability

Date: ID to match with questionnaire:

Q1 As you age, what are your main concerns about your future for? (Prompts: accommodation; support; transport; independence; finance; activities; friends/advocates)

Q2 What are the everyday challenges for you?

Q3 What services do you currently access?

Q4 Considering your circumstances, are there services that you wish you could access? (prompt for what those services are; barriers to access eg don't exist; costs)

Q5. If there was just one service that you could have that you don't have currently, what would it be?

Q6 What is it that keeps you going at the times when life is very difficult?

Q7 In your view who should be providing services for people with a disability?

Q8 In a small rural community it is more difficult to provide the range of services that would be available in the city. What ideas do you have about how more services could be provided for people with a disability, in the Warwick district?

Q9 Who should fund services for people with a disability?

Q10 Do you have any questions or final comments?

Thank you for your time and assistance.

Would you like a summary of the report Y/N

Interview guide – Key informant

Q1 What services are CURRENTLY AVAILABLE to PEOPLE WITH A DISABILITY in the Warwick district? (Prompt for this provider and other providers, respite, residential, day services, transport, social, aged care, high needs, in home, recreational, independent living)

Q2 What services are you aware of that are CURRENTLY AVAILABLE to specifically support CARERS in their role? (Prompt for this provider and other providers, social, psychological, educational, information, financial; also services that a Carer could access that are NOT specifically designed for Carers)

Q3 What do you think are the GAPS IN SERVICES for PEOPLE WITH A DISABILITY in the Warwick district? (Prompt for respite, residential, day services, transport, social, aged care, high needs, in home, recreational, independent living skills, independent living)

Q4 What do you think are the GAPS IN SERVICES FOR CARERS in the Warwick district? (Prompt for social, psychological, educational, information, financial)

Q5 What IMPACT do you think these service gaps have on people with a disability and/or their carers? (Prompt for social, emotional, financial, psychological, family, long term/short term, travel, multiple/related, sets of ...)

Q6 What do you think are BARRIERS TO SERVICE DELIVERY/PROVISION for these people?

a) Locally?

b) State-wide?

(Prompt for funding, staffing, buildings, willingness of Carers or PWD to access services, scale - number of people with a disability / no. People with specific types of disability, priority given to people who are part of a minority group)

Q7 Would there be BARRIERS TO CARERS AND/OR PWD COMPLETING the questionnaires in this project? y/n If yes, what would these be?

Q8 Do you have any questions or final comments?

Thankyou for your time and assistance. Would you like a summary of the report Y/N

Appendix 8: Results

Support needed for self-care

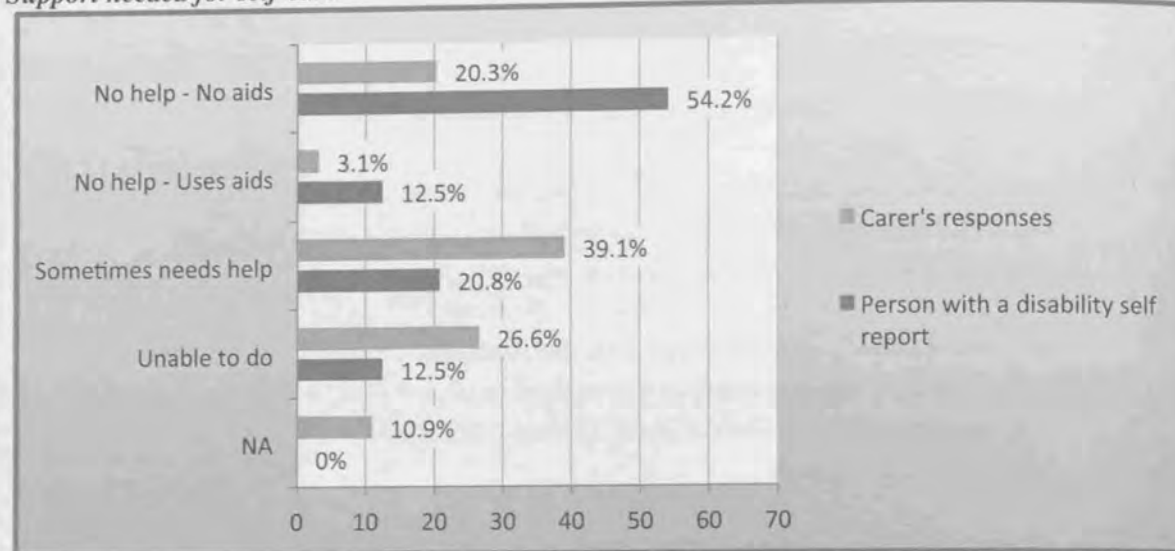


Figure 3: Support needed for self-care – carer's responses and Person with a disability self report.

Support needed for mobility

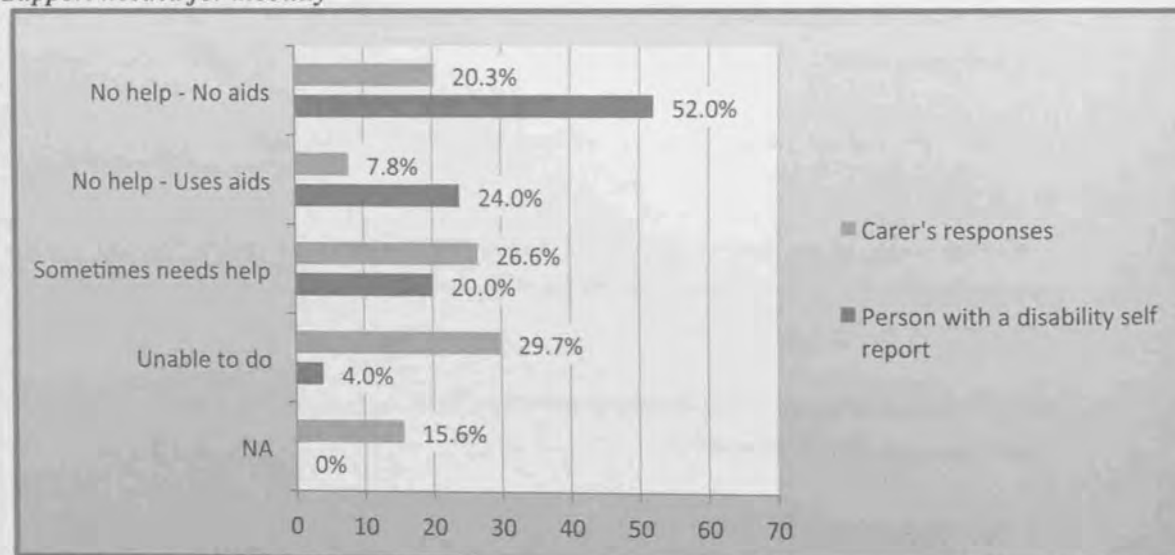


Figure 4: Support needed for mobility – Carer's responses and Person with a disability self report.

Support needed for communication

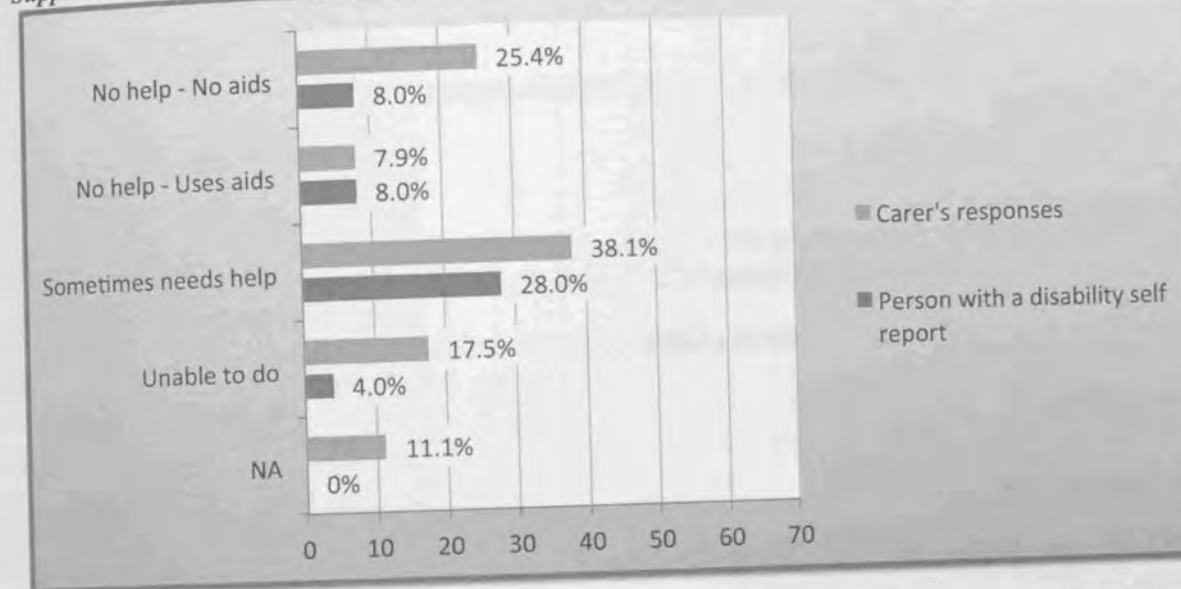


Figure 5: Support needed for communication – Carer's responses and Person with a disability self report.

Support needed - interpersonal

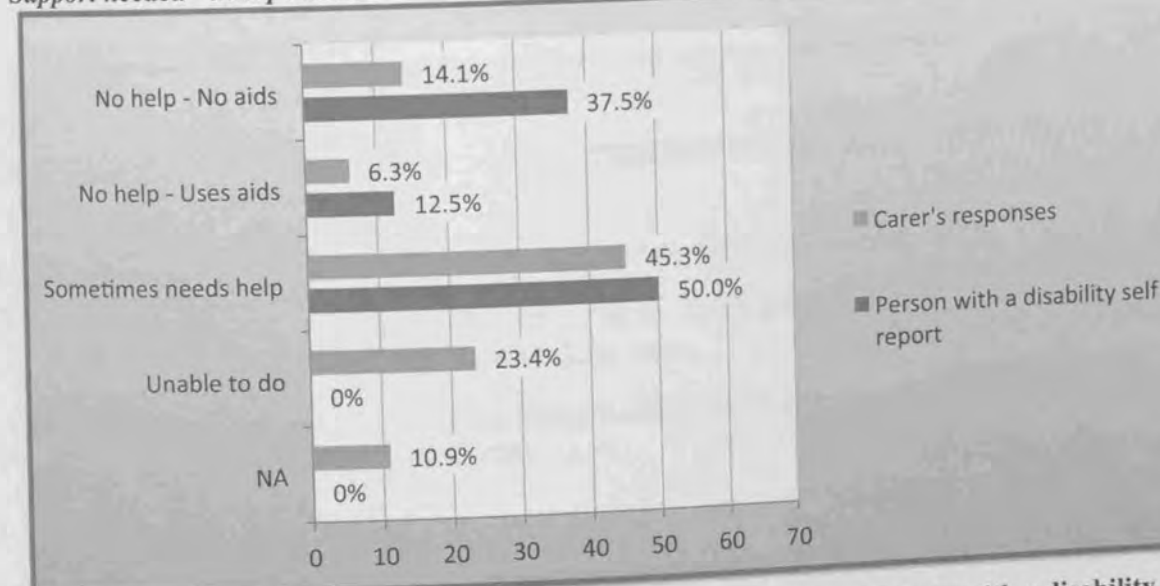


Figure 6: Support needed for interpersonal – Carer's responses and Person with a disability self report.

Support needed – learning, applying knowledge, general tasks – both

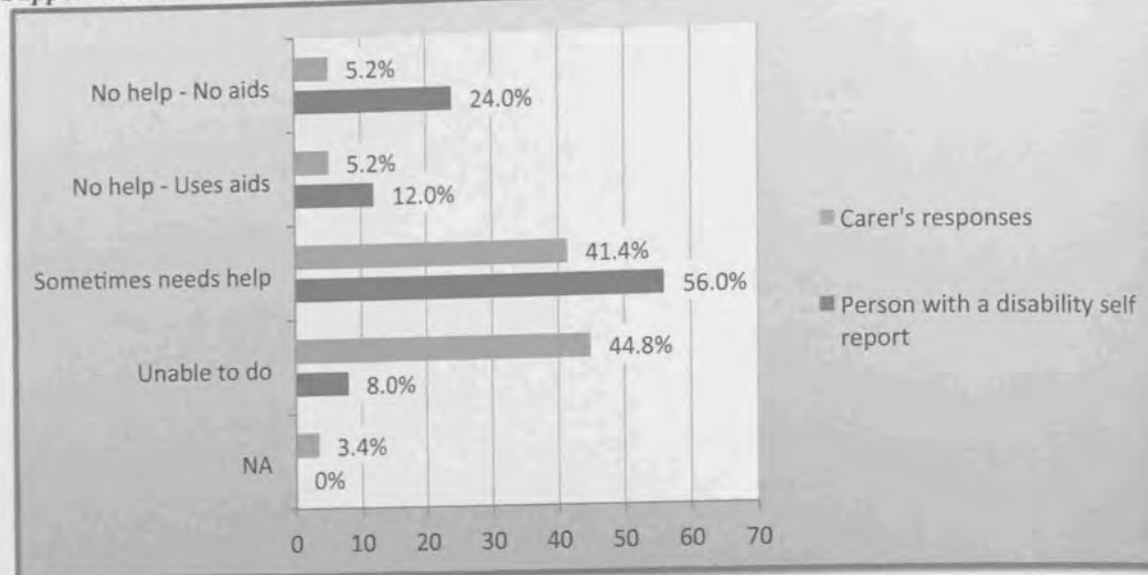


Figure 7: Support needed for learning, applying knowledge, general tasks – Carer's responses and Person with a disability self report.

Support needed for education - both

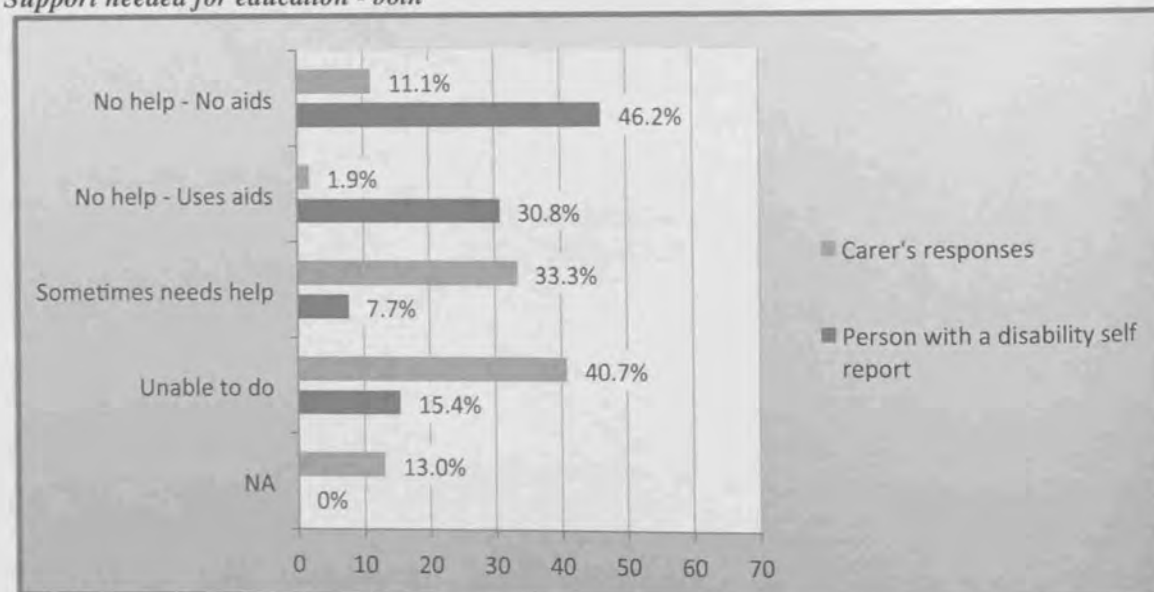


Figure 8: Support needed for education – Carer's responses and Person with a disability self report.

Support needed for community and economic life

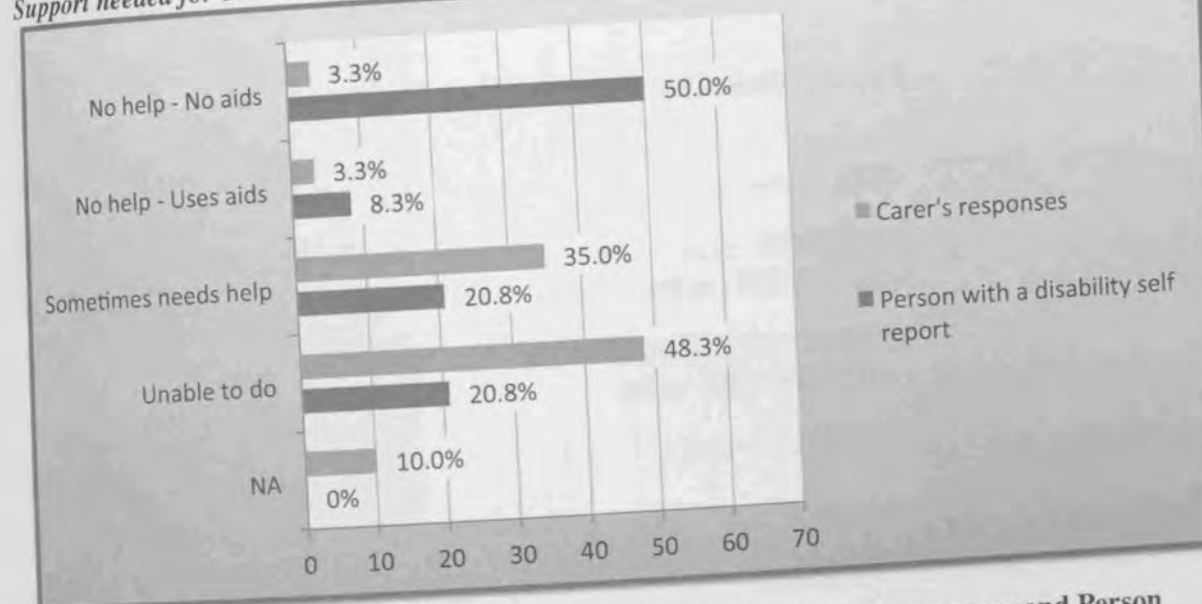


Figure 9: Support needed for community and economic life – Carer's responses and Person with a disability self report.

Support needed for Domestic life

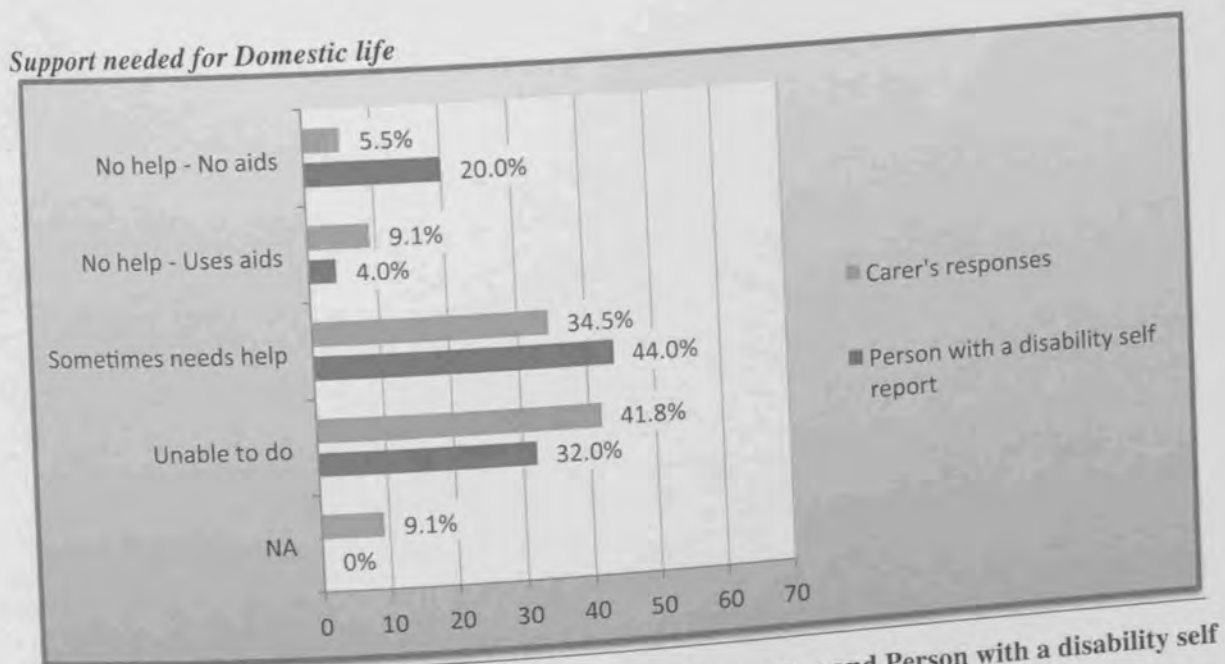


Figure 10: Support needed for domestic life – Carer's responses and Person with a disability self report.

Support needed for Working

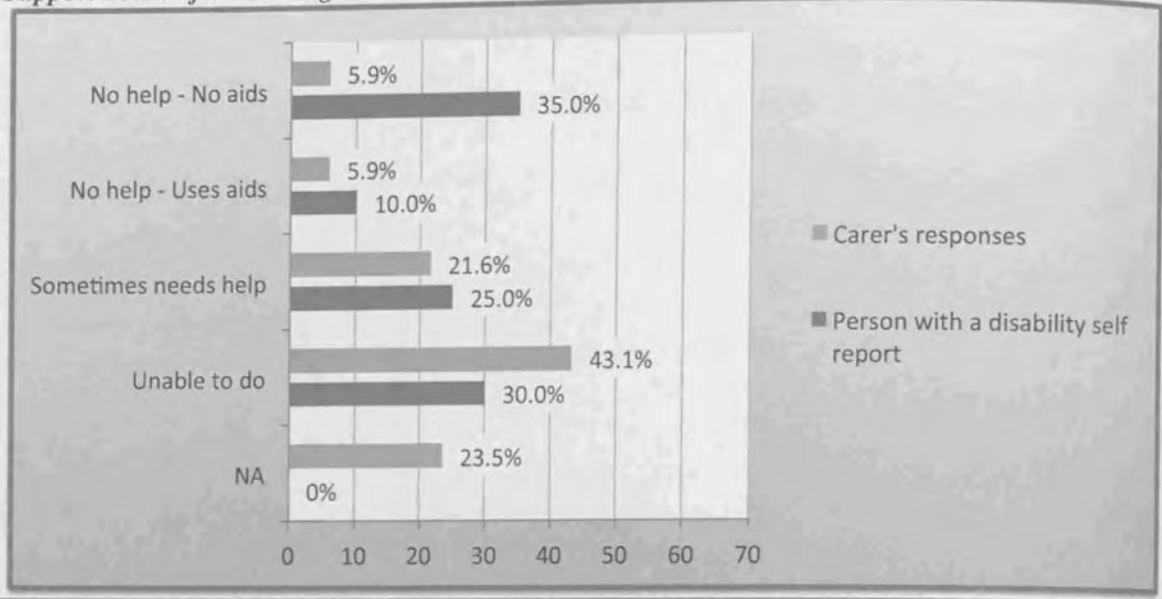


Figure 11: Support needed for working – Carer’s responses and Person with a disability self report.

