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Caring for the Carer: Home design and modification for carers of young people with disability

**PEER
REVIEWED**

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Glossary

ABS	Australian Bureau of Statistics
ACCNA	Australian Community Care Needs Assessment
ADHC	Ageing, Disability and Home Care (an agency of FACS)
AIHW	Australian Institute of Health and Welfare
CENA	Carer Eligibility Needs Assessment
FACS	NSW Department of Family and Community Services
HMinfo	Home Modification Information Clearinghouse
SDAC	Survey of Disability, Ageing and Carers

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Introduction

This HMinfo Occasional Research Paper focuses on carers, that is those who deliver informal (unpaid) care to young people with disability, and particularly those carers who share their home with the person they are caring for, as well as the housing design considerations that may support carers in their caring role. In this report, paid carers are referred to as support workers, and their role is clearly differentiated from that of carers, who are unpaid. It should also be noted that many people with disability are themselves the carer for a partner or family member (Bridge, Parsons, Quine, & Kendig, 2002). Both carers, who are usually family members or partners, and support workers, who are paid to provide care to a person with disability, need supportive and safe environments in which to care for people with disability. The definition of a carer is:

“A person of any age who provides any informal assistance, in terms of help or supervision, to persons with disabilities or long-term conditions, or older persons (i.e. aged 60 years and over). This assistance has to be ongoing, or likely to be ongoing, for at least six months.” (ABS 2012a).

This research adopts a definition of disability that understands it as the product of interaction between an individual and their environment. Whether or not a particular physical condition is experienced as disabling depends on the natural and built environment, social, political and cultural structures, and interpersonal processes of the individual concerned (Brandt & Pope, 1997). In addition, Eley et al highlight that both people with intellectual disability and their carers are ageing, and the concurrent ageing of these groups poses specific challenges in providing suitable housing (2009).

For the purpose of this research, the concept of ‘care’ is defined as the provision of assistance to a person with disability or chronic health condition or frail older person, to ensure their health, safety and wellbeing. Care is generally triaged into:

- formal care delivered by waged staff or trained volunteers
- informal care delivered by unpaid carers, usually family members; or
- self-care, a newly evolving conceptual category (Aronson & Neysmlth, 1997) that will be referenced in this report insofar as it impacts on the degree of care provided by carers. The ABS describes self-care as the capacity to undertake tasks associated with: showering or bathing; dressing; eating; toileting; and bladder or bowel control (ABS 2012a).

This HMinfo Occasional Research Paper will focus on the unpaid (informal) carers of young people with disability (<65 years) only, and from the following perspectives:

1. What tensions, if any, may exist between a carer’s needs and the needs of the person with disability in home design?
2. What design features of the physical home environment would enable carers to

care in the home in more comfortable and sustainable ways?

3. What assessment criteria should home design and modification professionals consider when assessing for home modifications or adaptations which will support a whole-of-household approach to assessment and incorporate the needs and preferences of all members of a household, including carers?

The paper explores whether there are any benefits that home modification interventions in particular can offer to carers of young people with disability, and what carer-centred considerations home modification professionals should be mindful of when designing and implementing their interventions.

Background

This section outlines the role and characteristics of home modifications and of carers. It also considers the circumstances in which carers provide care and their housing situation as well as the composition of their households and how home modifications intersect with these matters.

There is increasing recognition that the design of buildings such as offices or homes can be enabling or disabling for those who work or live in them (Innes, Kelly, & Dincarslan, 2011). Little is known about the home design needs of those who care for people with disability within the home environment. Limited research has been conducted into how care in the home affects the physical and social environments of those who live there (Williams, 2002). Literature on housing and disability tends to concentrate on issues to do with physical disability and on the needs of the person with disability, rather than the needs of the carer and other household members (Oldman & Beresford, 2000).

Carers and Home Modifications

Carers of young people with disability provide the bulk of care to them, usually in their home of the carer. In many cases they are also the home owner or tenant. Therefore, carers work in, and usually live in, the home which may not be designed to support them in their caregiving role. To assist them in their role, carers may require modifications to their home to make them safe to work in and enabling for the person with disability to reduce workload on the carer.

Home modifications are changes made to the home environment to help people to be more independent and safe in their own home and reduce any risk of injury to their carers and careworkers. Modifications to the home include changes to the structure of the dwelling e.g. widening doors, adding ramps, providing better accessibility etc. and the installation of assistive devices inside or outside the dwelling e.g. grabrails, handrails, lifts etc. Home modifications assist people with disability and older people to be more

independent and may reduce the need for ongoing assistance (Home Modification Information Clearinghouse (HMInfo), 2014).

The relationship between caregiving and home modifications means that the attributes of carers require some consideration. Carers are drawn from all groups in society, from children to frail older people. The majority of primary carers in Australia are between 30–64 years of age with more than a quarter of primary carers being aged 65 years or more, and over 60% of primary carers are women. A primary carer is a “*person who provides the most informal assistance, in terms of help or supervision, to a person with one or more disabilities*” (ABS 2012a). For young people with disability, the most frequent relationship to the carer is as their child, and the carer is usually their mother (ABS 2012a). Caring for a young person with disability is often a lifetime’s work, continuing into the old age of the carer; thus a quarter of older carers with primary carer responsibilities care for a child with disability (Nepal, Brown, Ranmuthugala, & Percival, 2008).

Carers provide most long-term personal care in the community, with waged care supplementing the informal network as disability levels increase (Agree, 1999). The ABS estimates that 1 in 10 people are carers (ABS 2012a). Carers provide up to 80% of support to older people in Australia, enabling them, particularly older people, to stay at home longer and defer entering residential care (Dow, Meyer, Moore, & Hill, 2013). No comparable data is available for young people with disability. In Australia, the cost of replacing the care provided by all carers for the year 2010 was conservatively estimated at \$40 billion to replace the hours of unpaid care provided by carers (Access Economics, 2010). Providing care for a lifetime in an unsuitable home environment may create significant risk of injury and stress to carers. Therefore the housing circumstances of carers are of great importance in supporting them delivering care.

Carers’ Housing and Home Modifications

Young people with disability typically live in the family home for much longer periods of time than their non-disabled peers due to the lack of suitable housing and support services for them to live independently (Productivity Commission, 2011). Consequently, for much of their life, young people with disability are actually living in their carer’s home, not their own. At this time, it is quite likely that the carer, if they are a home owner, will have a mortgage with limited equity in their home. This means that it is often the carer’s home which is the subject of home modification interventions.

With respect to housing tenure, 66.9% of carers live in their own home with or without a mortgage, while the rest live in various forms of rental, including social and private housing options (ABS 2012a). Generally, the older the carer, the more likely they are to live in their own home. Home ownership gives carers greater control over whether, when and how they modify their homes, although they may still lack the resources to undertake the modifications.

The SDAC does not distinguish between carer home owners living in standard Torrens Title dwellings and those living in Strata Title dwellings (ABS 2012a). Home owners who live in strata title dwellings must seek the permission of the Owners Corporation to undertake home modifications within their lot (apartment) if they impact on common property e.g. drilling into a wall to attach a grabrail, and to ask the Owners Corporation to undertake modifications to the common property such as disability access to the building (HMinfo 2014).

Providing care can lead to economic disadvantage and increased risks of carers themselves acquiring disabilities (Bridge et al., 2002). Carers are more likely to be unemployed or on low incomes than the general population because of the difficulties encountered in balancing paid work with caring responsibilities (Carers Victoria, 2012). Overall, carers tend to be clustered in the lower income groups, with 38.5% being in the two lowest quintiles (ABS 2012a). This could impact on a carer's capacity to pay for or contribute to home modifications, and may make them more likely to need subsidised home modification services.

For a carer, when it comes to arranging for home modifications, issues of home ownership and equity, security of tenure in rental properties, Strata Title complexities and raising the funds to pay for home modifications, can cause considerable stress and may impact significantly on their wellbeing and their capacity to care for the person with disability.

Carers and their households

A household is defined as a *“group of two or more related or unrelated people who usually reside in the same dwelling and who make common provision for food and other essentials for living; or a person living in a dwelling who makes provision for his or her own food and other essentials for living without combining with any other person”* (ABS 2012a). Carers of young people with disability tend to live in households that comprise themselves, the person they care for (the care recipient) and often other members of the household, such as the carer's spouse or other children of the carer (ABS 2012a). There is no typical household composition or size for people with disability.

Household size affects home modifications for carers in three ways. First, the greater the number of members in the household, the more likely one of the members will become a carer (Mentzakis, McNamee, & Ryan, 2008). Second, the larger the household size, the more likely the carer to suffer psychological distress (Goldstein, Atkins, Landau, Brown, & Leigh, 2006). Last, the ability to have sufficient economic resources to initiate or contribute to home modifications can be affected negatively by household size in combination with adults who are unemployed or underemployed.

In summary, we can see the impact of household size on the question of care and home modifications could be significant in terms of crowding, resulting in lack of available space for storage, accessible route of travel and adaptability. Further, modifications for carers in

larger households may be both more necessary in terms of reducing psychological distress, yet less obtainable because of reduced financial resources.

Home Modification and Housing Support

From 1985 to 2012, the federal and state governments of Australia worked together to implement the joint Home and Community Care (HACC) Program, which provided basic services to young people with disability and their carers as well as to frail, older people and their carers. These basic services included home modification and home maintenance services. Since 2012, those services from the former joint HACC Program for young people (aged <65 years) and their carers fall under the jurisdiction of the various State and Territory governments.

With respect to the housing needs of young people with disability, Tually et al (2011) have identified that: “*Governments can improve social inclusion for persons with a disability by ... Ensuring housing is appropriate to the needs of the person with a disability and their household through modifications and providing on-going maintenance*”. There has been no research to date which analysed the value of the housing support, including any modifications, which is provided by their carers to young people with disability. This is surprising given that most young people with disability live in their carer’s home for a major part, if not all, of their lives. In fact, Qu et al (2012) noted that: “*People with a disability face enormous difficulties with leaving the parental home and finding alternative accommodation, which leads many to remain in the parental home well into middle age.*” (p. 2). The need for research into this issue does not just apply to young people with disability who live in their carer’s home. It also applies to those who return.

Adults who acquire disability often find themselves returning to the parental home for lack of other options as illustrated in the case cited in *Disability Care and Support* (Productivity Commission, 2011, p. 142). Therefore, home modification for young people with disability often mean modification to the carer’s home, as in that example. It is unlikely that the public/community housing sector can meet these housing needs for young people with disability due to the long term and continuing disinvestment in this sector by all levels of government and the limited proportion of liveable i.e. meeting one of the levels of the Livable Housing Design Guidelines (Livable Housing Australia, 2012), or adaptable housing within that sector (Community Housing Federation of Australia, 2014).

The lack of suitable housing for people with disability was also identified as a barrier to effective planning by ageing parent carers for the future needs of their adult children with disability (Qu et al., 2012). In a study conducted by Petriwyski et al (2012), participants identified the lack of appropriate and desirable [government] housing as a limiting factor in their planning for the future, as was the difficulty of finding accommodation of suitable design or which could be modified. The authors expanded on these issues in their research and reported families considering a wide range of options:

“Both the parents and their [child] leave the current home, e.g. to alternative homes, nursing home or retirement village; Both the parents and the [child] stay in the family home, or set up a granny flat; Child stay and parents move, either to a new home to downsize or to a retirement village or aged care facility; [Child] moves from the family home, e.g. to a unit or apartment nearby to the home, a shared living situation with peers, or a specially developed living option such as a farm development; Some parents were also looking at multiple options to move into in a staged approach.”(p.2)

Overall the lack of suitable housing, either built or modified, has emerged as a significant barrier to the provision of support to young people with disability and to providing support for their carers by under-delivering in:

- Building or modifying the home so that person with disability can be more independent and self-caring, including being safer or unsupervised in their home environment and thus reducing demands on their carer;
- Providing a safe working environment for the carer with some space in which to rest from their caring role and space to meet the needs of other members of the household; and
- Facilitating the person with disability moving to their own home through the provision of universally designed built/modified homes and thus reducing day to day care demands and pressures on the carer.

The NDIS is premised on young people with disability being assisted to live as independently ‘at home’ wherever possible. Despite its commitment to *“engage people with disability, their families and carers in the design and delivery of services”* (Council of Australian Governments, 2012), the NDIS does not recognise that most young people with disability live in their carer’s home for a major part, if not all, of their lives. So, although the NDIS will provide necessary care and support for a person with disability to live ‘at home’, it specifically excludes the provision of housing per se, and does not expand on to what extent home modifications will be subsidised and how any investment in home modifications will be balanced against the ongoing costs of care. Therefore, the only method of addressing the design and adaption needs of carers of young people with disability is likely to be through judicious and timely home modifications to the carers’ homes.

Aims and Methods

This section sets out the aims, research questions and methodology of this research. The focus is on a literature review to identify that which is known about the topic, while recognising that little research has been published to date that specifically addresses how home modifications and effective home design can support carers in their caring role.

Aims

The aims of this narrative literature review were to: identify to what extent the needs of carers have been considered in research about home design, home adaptation and home modifications; and to identify particular features of the home environment that can be modified to benefit carers, for the consideration of carers themselves and the home design professionals who design or implement home modifications such as Occupational Therapists, designers, architects and builders.

Research Questions

The key research questions that this literature review sought to answer are:

1. What tensions, if any, may exist between a carer's needs and the needs of the person with disability in home design?
2. What design features of the physical home environment would enable carers to care in the home in more comfortable and sustainable ways?
3. What assessment criteria should home design and modification professionals consider when assessing for home modifications or adaptations which will support a whole-of-household approach to assessment and incorporate the needs and preferences of all members of a household, including carers?

Methods

This is an Occasional Paper rather than an Evidence Based Practice Review because it uses a thematic/exploratory literature review methodology rather than a systematic review methodology. The literature review is exploratory in nature due to the limited body of research on this specific topic. It seeks to identify broad themes and issues around the home environment and carer needs for further investigation, and to make a list of general recommendations for home design professionals to consider when implementing home modification interventions. The literature is presented in a thematic structure common to standard narrative literature reviews. This structure was chosen to accommodate the thematic, cross-disciplinary search methodology that drew on materials published within diverse research databases in health, care and built environment disciplines.

This study comprises two research activities:

1. Literature Review: A meta-analysis of a diverse range of publications, policy documents, and legislation relating to disability, impairment, carers and housing modifications.
2. Analysis – Reference guide: The reviewed literature was analysed and this analysis is presented for a cross-disciplinary audience of architects,

designers, occupational therapists and carers.

Scope of Work

The research was confined to the carers of young people with disability (<65 years) as these carers are likely to be providing care in their own home, rather than the home of the person with disability, and therefore in a position to make decisions about which modifications will be done and how they will be funded (ABS 2012a). In addition, the carers of young people with disability are often carers for a lifetime and will be caring for the young person with disability through all their life stages, from infancy to middle age or more (ABS 2012a) (Petriwyski et al., 2012).

The home modification needs of carers of older people with disability (>65 years) are more complex, as the home in which care is delivered is likely to be the home of the older person themselves and care is likely to be needed for a relatively shorter period of time, rather than whole of life (ABS 2012a). In addition, the resources of the older person can be used to assist with the financing of the home modifications, including access to home equity products where possible (Bridge, Adams, Phibbs, Mathews, & Kendig, 2010). Therefore, this topic will be considered in a separate research paper.

Literature Review

The UNSW library 'Search first' function, databases such as ASSIA (Applied Social Sciences Index and Abstracts), Medline, ARCH (Australian Architecture Database), and CINAHL (Cumulative Index to Nursing and Allied Health Literature), Google Scholar, and Trove were searched using the following keywords: carers/caregivers; disability/disabled/impairment; and home/home environment/housing/home modifications. The Home Modification Information Clearinghouse Library was also included in the search and key public databases such as the ABS, AIHW and the Productivity Commission. From this original keyword search frame, a range of peer reviewed articles, reports and books, as well as grey literature, such as manuals and magazine articles, were reviewed for this report. Additional literature was identified through the reference lists of key sources and feedback from reviewers.

A traditional systematic review strategy was impracticable to implement because of the limited nature of the evidence currently available. Using the traditional systematic categories of nationality, research rigour etc. would not have captured the key themes nor identified new insights. Therefore, the narrative presentation approach was determined to be the best fit for this research to explore a topic with such limited published research (Hammersley, 2001). A meta-analysis of the selected literature was undertaken to identify alternative/new approaches to home modifications to support carers of young people with disability, as well as wider implications for care provision in the home and current home modification service provision.

There is an established body of research into the home design needs of people with disability and older people, and a growing body of research into the service and support needs of both people with disability and their carers. However, little research has been conducted into the home design or home modification needs of the people who care for a person with disability, particularly carers. For example, much research has been conducted into what features of the home environment may pose risks of accident and injury to people with disability, but very little is known about the effect on carers of caring for injured people in terms of the carer's wellbeing (McAllister, Derrett, Audas, & Paul, 2012). In the falls-prevention literature, the focus is most often on the person who is falling, but falls also have a considerable impact on both carers and support workers who must compensate for the care recipient's lowered levels of mobility and change their caring routines accordingly (Dow et al., 2013).

Studies on carer/support worker injury due to caring activities tend to be nursing-practice orientated, geared towards professional, formal carers within nursing home settings (Nelson & Baptiste, 2004; Nelson et al., 2006), rather than addressing carers who care in domestic residential settings. Literature from nursing and allied health disciplines also tends to focus on behavioural interventions, rather than interventions of the built environment features or the home environment. When these studies do focus on carers, they concentrate on carer competence in behavioural characteristics and recommend training in patient handling techniques (Brown & Mulley, 1997).

This literature review has thus focused on the more limited body of research into built environment interventions, such as home adaptations and home modifications that will assist and support carers in their caregiving role. It firstly surveys the broader issues relating to the home environment and the need to support carers within the home, and then discusses the key design and modification features identified in the literature as beneficial for carers. Finally, it discusses the ways that these features can be taken into account by home design professionals who are involved in the building of a new home or modification to an existing home, through 'whole of household approaches' that consider the needs of all household members rather than just the individual with a disability.

Assessing the home environment

Disability services for young people with disability and their carers are administered by various state and territory governments with a gradual transition to the National Disability Insurance Scheme (NDIS) happening through to 2019. The NDIS is the outcome of the Productivity Commission's report *Disability Care and Support* (Productivity Commission, 2011). In this report, the Commission noted that "*support provided by families would be considered in assessments, and where appropriate, carers also assessed and given additional supports*" and the need to "*consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')*" as part of the assessment of a person with disability and their support needs.

Assessment of carer needs are highly desirable in preventing crises further down the track (Nankervis, Schofield, Herrman, & Bloch, 1997). Aggar (2012) concludes a study into the service needs of carers by recommending that structured, individual and regular carer assessments are conducted that address carers' individual needs as well as the caregiving situation in general. Currently, in Australia, carers are not consistently individually assessed in all disability support programs, but assessments would have the potential to support and improve carer wellbeing and health and facilitate the provision of timely and appropriate support services (Aggar, 2012). However, broader community support programs such as the former Home and Community care (HACC) Program and its successors have always included carers in their target group and provided for the concurrent assessment of a carer with the care recipient as well as providing complementary services where indicated (Commonwealth of Australia, 2012).

In their Final Report on the development of Version 1 of the Australian Carer Eligibility and Needs Assessment (CENA) instrument, Ramsay et al (2007) identified the need for assessment of the home environment for service specific requirements, such as home modifications, and the potential for carer training and support to assist carers with lifting, mobility etc. However, neither the CENA nor the ACCNA, of which it is a part, has an environmental assessment component for the home.

This means that no evidence-based and validated assessment process or tools are yet available for assessing the environment of the person with disability and its impact on them and their carer, particularly with respect to whether the home environment is enabling or disabling, and how it could be made more enabling through home modifications. This is despite the Productivity Commission's Recommendation 7.8 that *"The NDIS should establish a coherent package of tools (a 'toolbox'), which assessors would employ across a range of disabilities and support needs (including ... home modifications)"* (Productivity Commission, 2011). The Productivity Commission also identified that when home modifications are needed, they are not always provided in a timely manner: *"I spent over 12 months as an inpatient ... because government funding would not help with a bathroom so I could go home to my mum. ... One area of government then spent over \$300 000 keeping me in ... and would not give us \$15 000 tops to help renovate a bathroom so I could go home. (trans., p. 318)"* (Productivity Commission, 2011, p. 142). The importance of home modifications in enabling young people with disability to live in their own or their carer's home continues to be identified as significant and is emerging as an issue for the roll out of the NDIS.

The NDIS can fund home modifications to the home of a person with disability who is an NDIS participant, but not the purchase or rental of suitable housing (National Disability Insurance Agency, 2014). In fact, a Community Housing Federation of Australia forum on this issue noted that *"no matter how well funding from the NDIA is leveraged the demand for housing from people with disability will almost certainly exceed supply for many years to come"* (Community Housing Federation of Australia, 2014). Therefore, it is anticipated that the roll out of the NDIS will continue to put pressure on the demand for suitable

accommodation for people with disability and on the need for the modification of existing dwellings to meet their needs.

Carers and the home environment

This section reviews the background literature on carers and the home environment, examining the links between carer stress and strain, the housing circumstances of carers, and the potential benefits of home modifications for carers. There is much consensus in the literature reviewed for this section that an unsuitable or unsupportive housing situation is a major contributor to carer stress and strain; also that home design and home modifications which take carer needs into account as an important consideration can alleviate or eliminate this source of stress, with a variety of other health benefits. In this research, the home environment is understood as a domestic dwelling space, privately or publicly funded, which is not an institutional setting such as a disability group home.

Carers may care for a person with disability for a few hours a week, or on a permanent ongoing basis all day and every day (NSW Health, 2013). Some carers care for more than one person with disability, often across different generations. Other than being mostly female and less likely to be in employment, especially full time employment, carers mirror the diversity of the general Australian population (ABS 2012a). Over 11% of carers are children or young people (aged < 24 years). This is important in a home modification context as these young carers are unlikely to have access to resources to undertake home modifications on their own and more likely to be living in the care recipient's home, rather than their own (ABS 2012b).

Additionally, 11.2% of indigenous people are carers, and at younger ages than the general population (ABS 2012b). Indigenous people also have more difficult housing circumstances such as crowding, which impact on carers, and have a lower rate of access to home modification services, primarily because they are much less likely to be home owners and much more likely to be living in public or community housing, including Aboriginal community housing (ABS 2012b). The complex issues around the housing situation for indigenous people with disability and their carers have been recently reviewed (Walls, Millikan, Bridge, & Davy, 2013).

The relationship of carers to the care recipient varies significantly with the age of the carer. Young people with disability typically have a parent carer, usually their mother as *"caring is considered as women's responsibility, and ... all of the mothers ... in this study had the main responsibility for caring for the child with the disability."* (Traustadottir, 1991). However, older people tend to have spouse or adult child carers, typically their wife or daughter (ABS 2012a). For example, Huber et al found that:

- Partners and Children most common informal carers
- Women predominant as carers (both formal and informal), never below 70%
- Men take care of partner above all other relatives and usually take on caring

tasks at a later stage. (Huber, Rodrigues, Hoffmann, & Marin, 2009)

Therefore, the attributes and circumstances of carers, such as whether they are caring for one or more persons, the ages and abilities of each care recipient as well as the carer, and the relationship of the carer to the care recipient(s) all need to be taken account when assessing for home modifications.

Carer stress and strain

There is growing evidence that carers are under considerable stress and strain due to long term care responsibilities at home and unmet support needs. Factors leading to this stress include a lack of formal care and housing options for people with disability, demand for services such as respite care greatly exceeding supply, and ageing of the carer and of the person with disability (Aoun, Kristjanson, & Oldham, 2006; Ranmuthugala, 2009; Watson & Mears, 1996).

Well-being studies in many countries have found that carers experience higher levels of stress and poorer physical and mental health than others in the general population (Dow et al., 2013; McConkey, 2005). In Australia, carers have the lowest level of subjective wellbeing scored by any group (Cummins et al., 2007), and are more likely to experience financial stress (Ranmuthugala, 2009). In the New Zealand context, McAllister et al used two well-being tools, the Bakas Caregiving Outcomes Scale (BCOS), and Personal Well-being Index (PWI) to measure the wellbeing of carers. They found that female carers and those with poor pre-caring health, had significantly lower well-being, particularly carer health and social participation (McAllister et al., 2012).-Many carers also report 'burnout', a feeling of physical, mental or emotional exhaustion.

Providing care can also lead to economic disadvantage and increased risks of carers themselves acquiring disabilities (Bridge et al., 2002) (Watson & Mears, 1996). Carers are more likely to be unemployed or on low incomes than the general population because of the difficulties encountered in balancing paid work with caring responsibilities (Carers Victoria, 2012). Family members may be required to change their employment situation to become a 'carer' (McAllister et al., 2012).

When asked what would prevent them from continuing to provide care in the home in an Australian survey conducted by Aoun et al. (2006), the majority of carers mentioned health issues, including mental health issues, stress, depression, ageing, injury of the carer or being incapacitated from ill health or old age. The next area of concern included financial issues such as giving up employment to be a carer, reduced employment, cost of services, financial commitments, having to continue to work to provide for the family, or having to return to work for financial reasons. It is clear that being a carer impacts on every part of a carer's life, including whether they can arrange or benefit from home modifications or suitable and enabling housing.

Carers and housing

The literature on carer stress and strain suggests that while supportive housing may be crucially important, it is not the only solution for supporting carers and care recipients. That being said, unsuitable and poorly designed home environments are closely linked to poor physical and mental health outcomes, not only for the person with disability living in the home but also for the whole household (Oldman & Beresford, 2000).

Community care policies increase demand for living environments that promote independence and physical functioning for the person with disability and make caring activities easier for carers (Van Hoof & Kort, 2009). The home environment needs to be able to support remaining ability, rather than operate to diminish it, and to support the development and maintenance of relationships between family and household members, including carers (Innes et al, 2011). The home environment should promote safety for the person with disability, and make caring tasks safer and easier for the carer, achieving a balance between safety, security and independence for all members of the household (Rossiter, 1994).

Access to secure, affordable and suitable housing for people with disability is also a major concern for carers and often a source of great anxiety for caring families (Carers Victoria, 2012). The lack of suitable, available, supported accommodation for adults with a disability, particularly intellectual disability, means that many ageing parents currently caring in the home have no choice but to continue in this caring role (Eley et al., 2009).

A major Australian Housing and Urban Research Institute (AHURI) study into the housing situations of people with disability and carers found that the housing outcomes of carers are strongly influenced by their caring role and responsibilities (Beer & Faulkner, 2008). For example, a reduced capacity to engage in paid employment is one impact of substantial care responsibilities which shapes the housing careers of carers. For parents of a child or adult with disability, one parent is often unable to engage in paid work due to their care responsibilities – thereby reducing household income – and lower household income reduces the level of choice within the housing market (Beer & Faulkner, 2008).

Carers may also face higher housing costs and greater transport costs as a consequence of disability. This study also found that carers tend to have a very strong preference for home ownership because this is perceived as providing greater security of tenure for the person with disability and autonomy for making home modifications if necessary (Beer & Faulkner, 2008). But carers who do own their own homes usually do so at the expense of holding other assets such as superannuation, and those purchasing homes are more likely to be in mortgage stress than other home owners (Beer & Faulkner, 2008).

Unsuitable housing impacts on carers in many ways. It impacts on their physical health, for example through common injuries such as back injuries sustained when lifting, and interrupted sleep (Beresford & Rhodes, 2008). However, appropriate and secure housing is also important to carers because of what it represents for overall security for the whole

household, including the carer and the person with disability. For instance, one carer in Oldman and Beresford's study on housing for children with disability and their families stated, "If you've got your home right you can cope. This house is like a cocoon, it doesn't matter what's coming to us now" (Beresford & Oldman, 1998, p. 1). Carers appear to derive a sense of comfort and security from having a home that is designed to support them in their caring role.

Heywood (2005) highlights that unsuitable and inappropriate home environments can also cause strain in family relationships, often because of the difficulty involved in things like lifting, carrying and running up and down stairs, "The mother of a 7-year old with cerebral palsy said that before the adaptations, when the child was confined upstairs whilst everything she needed to do was downstairs, she 'used to get to screaming point'" (Heywood, 2005, p. 543). The ongoing impact of trying to provide care in an unsupportive or even disabling environment would accumulate over the years and affect carers' capacity to continue caring.

The manual, *At home with dementia: A manual for people with dementia and their carers* (referred to hereafter as 'At home with dementia') (FACS-ADHC 2011), explores a number of ways in which the home environment can be made more supportive of care activities for people with dementia, including young people with early onset dementia. It makes a number of general recommendations around how the home environment can support carers by:

- Making personal care as easy and comfortable as possible for the carer;
- Reducing any problems from carer difficulty in operating fixtures, modifications etc. in the bathroom.
- Consider whether there is enough space in the bathroom, as modifications of the toilet or shower may be needed because the rooms are too confined or awkward, requiring the carer to stoop, twist or reach;
- Maximising the carer's sleep; and
- Ensuring that lifting and transfers are easier and safer for the carer or community service provider.

The practical steps outlined in 'At Home with Dementia' are applicable to carers generally, including those of young people with disability, and identify a number of areas where home modifications can make a difference such as making transfers, personal care, bathing and toileting safer and easier for the carer.

Home modifications and carers

Physical environment interventions which assist people with disability and their carers to live safely and as independently as possible in their home comprise: rearranging the environment; additions and alterations [home modifications] and relocation (Barnes,

1991). Additions and alterations may take the form of home modifications, such as ramps, and/or aids and appliances, such as moveable hoists. Generally the trade-off is around sustainability. All aids and appliances require maintenance and replacement and may not be suitable for long term use with many, such as shower chairs, requiring regular replacement. Home modifications on the other hand are specifically designed for longer term use, although they may require some maintenance.

Thus, home modification is an important contributor to people with disability being able to remain in their own home and community, and is also essential for carer safety and comfort. As Yong et al (Jung & Bridge, 2009) noted: “*unlike group facilities where multiple care givers are available, at home the loss of a care-giver through injury is a critical incident*” (p.21). A critical incident in this context may result in a carer who is unable to continue in the caring role and this precipitate institutionalisation.

Prevention of institutionalisation through home adaptations potentially support carers as much as the care recipients (Barlow & Venables, 2004). Modifications can make the home environment more enabling for the person with disability, for instance by installing ramps for a mobility impaired person, which then also supports the carer in assisting the care recipient’s mobility, or providing grabrails to facilitate self-care during bathing (Carnemolla & Bridge, 2011). Further, because of the high physical strain and risk to health that caring in the home can pose to carers, home-based informal care may be unsustainable without home modifications that support both the person with disability and the carer (Bridge, Phibbs, Kendig, Mathews, & Cooper, 2008; Heywood, 2005).

Home modifications are not just about support for a care recipient’s physical care requirements. As noted in *At home with dementia* there is also the need to consider any “*risk [to the carer/support workers] of assault or considerable stress from the person with dementia because of challenging behaviours*”. Challenging behaviours arise from many other causes of disability and usually have a major impact on carers. In fact, modifying the home environment to support carers and support workers may be one of the most effective ways to ensure that a person with disability can continue to live at home (FACS-ADHC 2011).

The body of literature on the benefits of home modifications and adaptations for people with disability tends to deal implicitly rather than explicitly with carer needs. Home modifications can promote mobility, social participation, quality of life and self-care for many people with disability (Bridge & Gopalan, 2005; Jones, deJonge, & Phillips, 2008; Kendig & Bridge, 2007). Therefore, home modifications for people with disabilities and functional impairments also assist carers by facilitating independence and self-care, reducing the need for assistance from carers, and reducing their care-load and risk of injury.

Studies that provide empirical evidence into how home modifications reduce care load are limited. A typical example is a study by Mortenson et al. (2012) who undertook a systematic review of the literature around carers and assistive technology, which they

used to include both home modifications and aids and appliances. They found that while it is *assumed* in the literature that assistive technologies will lessen the degree of care that carers need to provide to their family member with a disability, there was a lack of strong empirical evidence to support this hypothesis (Mortenson et al., 2012). However, while Mortenson et al measured the outcomes of people using powered and manual wheelchairs and their impact on the users and their caregivers, they did not measure the impact of modifying the home to enable the use of the wheelchairs, so have attributed the benefit as arising from provision of the wheelchair, not the pre-requisite home modifications.

One of the studies that looked specifically at the impact of home modifications on enhanced independence of the person with disability and consequent support for the carer was done by Østensjø et al (Østensjø, Carlberg, & Vøllestad, 2005). They found that home modifications had moderate to very large effects on the [care recipient's] mobility, 25% on self-care skills, and 20% on social function. Furthermore, 65% reported that the modifications lightened the caregiving for mobility, 75% for self-care and 25% for social function. The authors concluded that functional independence and care demands often benefited from different types of modifications. Current research being undertaken may provide new insights into how home modifications impact carers and their caring role in an Australian context (Carnemolla, 2014).

Other studies that examine the link between home modifications, increased care recipient independence and reduced carer workload include Liu and Lapane (2009), who found that in many circumstances home modifications can reduce or eliminate the need for care assistance in the home, and Allen, Resnik, and Roy (2006) who found a strong correlation between home modifications to improve wheelchair accessibility and decreased hours of informal care.

A study into the 'substitutability' of home modifications and waged care by Carnemolla and Bridge (2011) found that home modifications have the capacity to minimise individual care needs by enabling individuals to perform tasks independently in their own homes. An example of a home modification that facilitates self-care practices (and reduces the need for personal care assistance) could include the installation of grabrails alongside a toilet which enable independent, safe transfers from sit-to-stand, and without which a person may require assistance every time they visited the toilet in order to transfer safely (Carnemolla & Bridge, 2011).

However, sometimes the housing needs of a person with disability and the housing needs of carers and other household members may be in tension (FACS-ADHC 2011). One carer in a study conducted by Beresford and Oldman stated, "*We need two houses. One for him and one for us*" (Beresford & Oldman, 1998, p. 2). One couple interviewed in a study conducted by Astley, Atkinson, Eakin, and Nord (2008) were not able to keep their bath (which was an important source of rest and relaxation for the wife/carers), as well have the specially modified shower needed by the husband, due to space constraints.

Carers also reported liking modifications that were easily reversible, such as bath benches that could be removed when no longer needed (Messecar, Archbold, Stewart, & Kirschling, 2002). In the study by Astley et al. (2008), carers also reported paying extra for personal furnishing touches such as additional tiling and other decoration, and the authors of the study state that the extra costs, which all [participants] had incurred, indicated that the appearance of the adaptation is very important to many home modification clients and their carers.

Particular care must be taken to integrate the priorities of the person with disability and the priorities of the carer and other family members as much as possible. Therefore, Occupational Therapists and other professionals who are evaluating or assessing the suitability of a home and the need for home modifications should ensure that the modification:

- Enhances the independence and self-care of the person with disability (the care recipient)
- Reduces the risk of injury to carers, especially in providing personal care; and
- Takes account of the carer's needs and preferences for space, privacy etc. as well as those of the person with disability.

Overall, there needs to be assessment of the intersecting requirements of the carer and the care recipient to ensure that home modifications are recognised as an integral part of enhancing self-care for the care recipient, as well as providing support for carers and making the delivery of care easier and safer.

Home design considerations for carers

This section presents some key home design features and considerations that could be useful to professionals when designing supportive home environments for carers. It looks at home safety and Work Health and Safety (WHS) considerations for carers, the need for adequate space in the home, including a space for carers to retreat to, and the ways that home modifications can support carers in performing specific care activities.

Home safety and carer needs

When care is provided in the home, certain breakdowns of the traditional divide between public and private space occur. The home is now not just a domestic space, but also a site of work for the carer, and when formal services are also provided in the home, this heightens the incursion of the 'public' sector into what is usually seen as a private space (Power, 2010). Milligan (2000 p55) argues more strongly that community care policies have resulted in an 'institutionalisation' of the caregiver's private space. In a section on "Health and safety for carers and community service providers" in 'At home with dementia' (FACS-ADHC 2011), it is emphasised that the home of the person with disability is also the workplace of paid care workers, and therefore it is necessary to consider the care

workers' safety needs as highly important, even if they may be in conflict with the needs and preferences of the person. Similar consideration needs to be given to the work safety needs of carers.

Home modifications can make the home a safer place for both carers and care recipients, by supporting and supplementing care activities (Axtell & Yasuda, 1993; Cantu, 2003; Trickey, Maltais, Gosselin, & Robitaille, 1994). The majority of private dwellings in Australia have stairs or other inaccessible features that make people with disability more dependent on informal care, and place people with disability and their carers at risk of accidents (Bridge et al., 2002). Even in single-storey homes, design features such as steps or other inaccessible building elements affect mortality and morbidity and place people with disability and their carers at risk of injury (Bridge et al., 2008; Iwarsson & Isacson, 1993). Home modifications can improve the safety of the home (Ambrose, 2001; Van Haastregt, Diederiks, Van Rossum, DeWitte, & Crebolder, 2000), for example by reducing the risk of falls (Chang et al., 2004), reducing the risk of the carer having an accident, and reducing carer stress and strain if the person with disability falls or is harmed in the home.

Improving the safety of the dwelling for the person with disability who lives there can also benefit carers. Informal caregivers are often poorly trained and equipped for moving and lifting care recipients with a disability. In a study conducted by Brown and Mulley (1997), 31 out of 46 caregivers had injured themselves during lifting and handling their disabled relative, and these injuries included back pain, muscular aches and pains, a twisted knee, and possible hernias, all of which constrained their quality and life and their ability to continue caring. Increased fear of falls [of the care recipient] meant that carers restricted social and work opportunities and arrangements to go out because of concern about leaving the care recipient alone. Carers also required extra time to assist the care recipient and were often unable to complete chores or get a restful night's sleep (Dow et al., 2013). To enable carers to continue providing optimal care at home, the authors suggested their physical health [of the carers] should be assessed and they should be trained in safe lifting and handling techniques (Brown & Mulley, 1997).

Using aids and appliances in a home that is not adequately adapted for these devices is also unsafe for both carers and people with disability. A study by (Roberts, Young, Andrew, McAlpine, & Hogg, 2012) found that 39 per cent of carers in their survey reported not having suitable home adaptations for wheelchair use, and steps, tight corners and limited space were the most frequently cited problems. Carers who regularly push wheelchairs usually support people with a high degree of physical dependency, often over many years, and while they themselves are ageing (Office for Public Management, 2006). Though paid carers are protected by employment regulations on moving and handling, unpaid carers are not, and usually do not receive relevant training, either in moving and handling or in wheelchair management.

Maintaining some control over the home environment enables carers to provide personal care more safely and easily and restrict potentially dangerous behaviours may use a

number of simple modification strategies. Examples including hand showers, fixed seating and grabrails; installing monitoring equipment; or ensuring electrical and water safety etc. (FACS-ADHC 2011). A study into modifications of the home made by caregivers for people with dementia (Calkins & Namazi, 1991) found that these adaptations promoted the safety, independence and comfort of the person with dementia, and made caregiving easier (Dow et al., 2013).

Space in the home

A key finding from this literature review was that carers often report needing or wanting a space of their own to retreat to when they are not caring. Exclusive areas or inaccessible areas are reported to be an advantage to carers in some situations. For example, Mayes (1997) reports that parents of children with disability sometimes valued inaccessible aspects of their home. For example, a mother of a disabled child in Mayes' study indicated that an inaccessible second storey provided her with a personal space for much needed 'time out'. Carers have been found to report mental health problems related to lacking the space in their home to take time out from the demands of caring, particularly when the care recipient has challenging behaviours (Council for Disabled Children, 2008).

These findings contrast with findings from research into home design for people with disability, which generally recommend that the whole house be as accessible as possible to those with impairments. The exception to this is some research on home modification and older people with dementia which does note the need for closed-off spaces to protect carer privacy and valuable objects, for example, 'at Home with Dementia' (FACS-ADHC 2011) and Van Hoof and Kort (2009). Van Hoof and Kort (2009) emphasize that carers have a need for privacy, and to facilitate this, there should be some part/s of the home that are less open and less accessible. They recommend that in the bedroom, there be a special compartmentalised section for the carer to withdraw to in order to carry out activities privately, or a room for the carer's use that can be locked. This room, a 'quiet room' (Gitlin, 2007), could be set up with comfortable furniture for the carer to retreat to for rest. 'At home with dementia' (FACS-ADHC 2011) also emphasises that it is important for carers to establish their own area to retreat to, such as a locked bedroom or sitting room.

Other issues regarding space also emerged as important in the literature, particularly for home design and modification in households that have multiple members. Implementing home modifications whilst preserving enough space in the home for other members of the household is a key challenge, as is ensuring that home adaptations use the space that is available in the most effective and efficient ways. Carers can feel constrained by lack of space and imprisoned in the home if there is not adequate space for the whole family (Oldman & Beresford, 2000). Over half of the families of 3,000 children with disabilities that were surveyed in one UK study reported a lack of family space (Beresford & Oldman, 2002).

A review of the literature on housing and children with disability found that some of the most common problems reported by families were lack of family space, defined as "space

to play, space apart from other family members” (Beresford & Rhodes, 2008, p. 6), lack of space for storing and using therapeutic equipment such as standing frames, and lack of space to meet carers’ needs while lifting, toileting and bathing. The authors emphasised that while accessibility is certainly a key issue and the one that tends to be focused on the most by policymakers, the key problems found in this research centred on space (Beresford & Rhodes, 2008).

Overcrowding and associated lack of space for different family members to have time out from each other can be a significant source of stress. When required to share a room, siblings of a child with disability can experience disturbed sleep, and particularly if the child with disability displays challenging behaviours, they may need private space for ‘time-out’ and space to store valued possessions, which cannot be accessed by their disabled sibling (Beresford & Rhodes, 2008; Oldman & Beresford, 1998).

A reduction in usable space can also be a major challenge for families after home modifications have been implemented, such as when living rooms are adapted into bedrooms or lifts installed, without extensions also being provided. One family in a study by Heywood (2005) felt that home modifications had been implemented solely for their son, and that the rest of the family members “*were left to use residual space*” (Heywood, 2005, p. 544). Another example drawn from this study describes a man who needed a shower installed and had to struggle with local health services to ensure that the bath was not removed during the modification process, as it was important to his wife (Heywood, 2005).

There is no doubt that home modifications for young people with disability impact on carers and other household members. However, for the space needs of carers and other household members to be considered, there would need to be significant changes to the way home modification needs are assessed and addressed in Australia.

Assisting care activities

Modifying the physical environment by implementing home modifications is a key way of supporting carers in care activities (Barnes, 1991). Caregivers in one study reported the following specific care tasks most difficult, in order: 1) toileting, 2) helping in and out of bed, 3) washing and bathing, assisting walking, and helping up from a fall, 4) helping on stairs, dressing (Brown & Mulley, 1997). Forty-eight per cent of respondents in one major survey (Heywood, 2005) mentioned reduced mental stress and physical strain on carers as an outcome following home adaptation. Carers often implement minor adaptations to their home environments themselves in order to make completing care tasks easier. Messecar et al (2002) looked at the home design strategies that carers implemented on their own without professional assistance, and found that a number of these supported carer well-being as well as the health and safety of an older person with disability, for example:

1. Arranging separate living spaces for the older person and the carer/s
2. Altering set up of supplies and objects for ease of access or to keep out of sight
3. Setting home up to minimize housekeeping
4. The use of assistive devices for personal care activities, and assistive clothing that is easy to put on and remove
5. Obtaining special supplies or equipment to make caregiving in the home easier.

In order for home modifications to be really effective, home environment assessments are essential to determine the relevant environment and any necessary training of the users (Agree & Freedman, 2000). Assessors may need to discuss with carers how care activities and processes will change before and after home modifications. One study found that some people with disability and their carers had, over time, developed particular care routines when using the bathroom, which they chose to continue even after the home modification was completed. They were unable to foresee how the modification would offer opportunities for changes in care practices (Astley et al., 2008).

Therefore it would appear that the key requirements for carers with respect to home modifications design will be:

- a holistic home environment assessment which takes into account the carers' needs and preferences, as well as those of the person with disability;
- consideration of the space and privacy requirements of the carer, including circulation space, storage, and room for non-care activities; and
- the judicious use of aids and appliances to complement home modification supports for carers.

Providing home modifications to the carers of young people with disability that support care activities has the potential to maintain the caring arrangement and reduce risk to the carer. Therefore, effective assessment and investment in home modifications, which assist in sustaining the caring relationship, make good sense.

Whole of household approaches

The housing career and living conditions of the whole household are affected by the inclusion of a person with disability, not only those of the person with disability themselves (Beer & Faulkner, 2008). For this reason, much of the literature reviewed for this report emphasised a *whole of household approach* to designing and modifying the home environment to meet the needs of the person with disability and family members and carers. (2006) call for a whole of family approach to service delivery, stating that “*every member of the family is affected by the caregiving experience and, while community*

programs focus on the wellbeing of the consumer, they do not generally support and meet the needs of the family” (p8). A whole of household approach means that all family members are considered and informed when modifying any aspect of the home, in order to meet the needs of all occupants. That is, home modifications affect not just the person with disability and their carer, but also the whole household.

Whole of household approaches were advocated at all stages of designing and modifying the home, from consultation and assessment, to the implementation of specific home adaptations and follow-up of their effectiveness. The carer’s needs and the needs of the household as a whole must be considered in the planning stages of home design and home modification, as the person with disability may not be the primary user of all home facilities (Oram, 2005). Home modifications that do not take into account the needs of all household members, and also importantly, how to facilitate the relationships between them, may do more harm than good. Oldman and Beresford (2000) state that too often, the housing needs of households with a person with disability are defined too narrowly in terms of wheelchair access, etc., whereas their needs are in reality much wider and should include those of carers and other family members. They offer an example of when occupational therapists and housing officers planned the installation of a through floor lift in one home, but did not consider the way in which the adaptation might restrict the lives of the child with disability and the parents even further by limiting space in the home, which would also have a detrimental effect on the family’s health (Oldman & Beresford, 2000, p. 438). The importance of sufficient space in the home for families and a space to retreat to for carers was documented in the previous section.

Home modifications designed to support the daily activities of the person with disability may impact adversely on other household members when home design professionals do not adopt a whole of household approach. For example, Oram (2005) cites examples where lowering a toilet for a child with a disability can make the toilet impractical for adults and may also present a drowning risk for younger siblings, or where introducing a shower chair may promote independence in showering, but at the same time create a trip hazard for household members if it does not have a storage place. It is also important to measure household members of the person with disability to highlight possible conflicting requirements in home design (Snell, 1983). If the home environment does not facilitate independence or accommodate the use of specialised equipment required for prevention of injury to carers, the demands upon other household members only increase (Oram, 2005).

Studies have suggested that more positive outcomes will be achieved for both the carer and the person with disability if housing and health professionals are able to effectively collaborate with carers. While professionals recognise the importance of family-centeredness as individuals, support service structures do not facilitate family involvement consistently (Carpenter, 2000). Consultation regarding the needs and wishes of carers is encouraged by policy, but generally only occurs at the care recipient’s insistence or the care provider’s discretion, and carer availability and burden are not systematically explored (Nankervis et al., 1997). This is clearly shown in the limitations of the Carer

Eligibility and Needs Assessment (CENA) (Ramsay et al., 2007) and home modification guidelines (FACS-ADHC 2012).

Carers often face significant barriers to accessing information about what support services exist and how to access them. Services can be fragmented across different departmental jurisdictions, and carers face many difficulties in accessing information about the services, resources and sources of support available for the person they are caring for and themselves, negotiating many gatekeepers, eligibility requirements, changing legislation, and so forth (Power, 2010). As a consequence of these barriers, “constant battling with health boards and practitioners” becomes “a fundamental aspect of life” (Power, 2010, p. 169) for many carers.

One study into communication between health and occupational therapy professionals and clients with disability and family members while implementing home modifications stated: “*the clients’ level of participation in the design was relatively small. An occupational therapist said that they try to integrate the client’s, carer’s and family member’s wishes but they are often inhibited by lack of space, or by challenges of the individual disabilities*” (Astley et al., 2008, p. 9). Collaboration is more likely to be effective when both professionals and carers value each other’s contribution to the care of the care recipient, and collaboration will be stifled when the carer’s needs and experiences of stress are not acknowledged (Wynaden et al., 2006).

Parents report difficulties with delivery of home modifications services when assessments do not take into account the needs of other family members and when disagreements occur (due to funding constraints) about the best solution (Beresford & Rhodes, 2008). Family-centred models of service delivery need to focus on the needs of the whole family rather than just on the needs of the person with disability, respect family diversity, emphasize flexible and responsible services, and respect choice and decision-making within the family (Carpenter, 2000).

A number of studies recommended comprehensive need-assessments for carers as well as people with disability, which should include assessment for home design and modification services. In their work on the development of the CENA tool, Ramsay et al (2007) noted that “*there may need to be an assessment of the home environment for service specific requirements, such as home modifications, and/or there may need to be an assessment of the potential for carer training and support to help in caring tasks such as lifting ...*” (p.65). However, to date no evidence-based home environment assessment tool has been researched, tested or implemented. Nor is there evidence of consistent consideration of the needs and preferences of carers when assessing for home modifications. Therefore, there is a need to modify assessment practices for home modifications to incorporate whole-of-household approaches. These would include:

- wholistic assessment which includes the needs and preferences of other members of the household, especially carers, not just the person with disability;

- consideration of the space and living requirements of other members of the household, not just support for care activities;
- ensuring sufficient circulation space for other members of the household, not just the person with disability and their mobility aids and equipment; and
- providing for the privacy needs of other members of the household, especially carers.

All of this needs to be done with balance and an understanding of any compromises required if the suggested home modifications are to support the person with disability by increasing their independence, support the carer by facilitating care activities and provide all members of the household with sufficient space and privacy.

Conclusion

Conventionally, accessible home design and home modifications are aimed primarily at supporting the independence and the functional ability of the person with disability, and many of the strategies utilised in home adaptation assist carers in performing care tasks as well. However, this report, through a review of the literature on home design for carers, makes a case for home design professionals to specifically consider the needs and priorities of carers when designing supportive home interventions. While the primary aim may be to support the person with disability, home design and modification also needs to meet the needs of all household members, particularly carers. Home modification that appropriately takes into account the needs of carers will not only enhance their health and well-being, but often that of the person they are caring for and the rest of the family or household as well. The modifications could also facilitate future planning for people with disability whose carers are also ageing.

This report has explored many of the key issues that must be taken into consideration when designing home environments and home modification strategies for carers of people with disability. Due to the wide variation in individual abilities and situations, both of carers and care recipients, this literature review could not seek to be a comprehensive overview of all issues of relevance to home design for carers of people with disability, but rather is conceived as a launch pad for further consideration and research.

A key role for home modifications is in assisting in the completion of self-care tasks such as going to the toilet, getting in and out of bed, and washing and bathing. Adapting the home to support the whole household's health and wellbeing and provide better, more efficient care should be seen as central goals of home modifications (Messeccar et al., 2002). Another finding has been to strongly consider the need for space/s in the home for carers to retreat to for 'time-out' for themselves. For example, it may be assumed that the whole house should be made accessible, but for privacy and security reasons many carers may want a space in the home that is inaccessible. The carer needs a place to retreat to for personal time and to store personal belongings. It may be that partitioning or

screening could provide a room upstairs or downstairs that might provide suitable respite and 'panic room' facility if required. Many carers may also prefer a separate en-suite or a bathroom that is their own to relax in, and have concerns about how their bathroom environment will look and feel after home modifications have been implemented.

Inadequate space, unsafe home environments, and unsuitable or insecure housing conditions are all issues that increase the considerable burden and stress already placed on carers. The literature review found that home design and modification considerations for carers should include:

1. Ensuring that consultation about home design or adaptation includes the perspectives and views of carers and other members of the household, as well as those of the person with disability.
2. How the design or adaptation of the home will assist carers in specific care activities relevant to the care needs of the person with disability who is living in the home.
3. How home design or adaptation can best utilise the space inside the home by providing:
 - a. the carer with a private space to retreat to, and
 - b. space for care activities and for activities of other members of the household.

For the issues raised in this report to be addressed fully, the whole of household approach reviewed in the last section of the literature review that was called for by many commentators must be adopted first. One of the major findings from the literature has been for home design professionals to take a 'whole of household' approach to assessment and to modifying the home, in order to take into account the built environment needs and perspectives of all family members and particularly carers. This is more likely to ensure the continued use and effectiveness of home modifications, as all stakeholders are happy with the changes to their home. This approach also resonates with Australian state and federal policy around support for carers and their role in supporting people with disability, and the increased choice and flexibility that will be offered to people with disability and their carers under the National Disability Insurance Scheme (NDIS).

However, there are not yet the evidence-based assessment tools and processes to assess consistently and robustly the home environment of a person with disability and their carer' nor is there a tool which respects the needs and preferences of other members of the household. Without such a tool, the ability to identify where home modifications can support carers, not just the person with disability, and to achieve more than access will be undermined. Therefore, the most critical need identified in this research is for a robust, evidence based environmental assessment tool, which considers the needs of all members of the household, especially the person with disability and his/her carer(s). Home design and modification professionals should be supported to put these policy emphases into practice through consultation with all members of the household and by considering the needs of carers as well as those of the person with disability.

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Appendix 1: Home Modifications Checklist for Carers of Young People with Disability

Home Modifications	Home Modification Outcome		
Home Modification Design Requirement	Carer	Person with Disability	Others in Household
Circulation			
<input type="checkbox"/> Therapy areas for person with a disability are located on the same level as the kitchen and main recreational areas, in multi-level dwellings	- Reduced injury risk - Reduced care burden	- Reduced injury risk - Social participation - Continuity of care	
<input type="checkbox"/> Bedroom areas for person with a disability are located on the same level as the kitchen and main recreational areas, in multi-level dwellings where the person with disability does not need regular and frequent care during the night	- Reduced injury risk - Reduced care burden	- Reduced injury risk - Social participation - Continuity of care	
<input type="checkbox"/> There is adequate space for the path of travel on stairs, ramps, hallways and other circulation areas, for a person with a disability to use mobility equipment	- Reduced injury risk - Reduced care burden	- Increased self-care - Reduced injury risk - Continuity of care	- Reduced injury risk
<input type="checkbox"/> There is adequate space for the path of travel on stairs, ramps, hallways and other circulation areas, for a carer to assist a person with a disability move throughout the home	- Reduced injury risk	- Reduced injury risk - Continuity of care	- Reduced injury risk
<input type="checkbox"/> Stair lifts or vertical lifts installed to access a multi-level home retain circulation space on the stairs and on the path of travel	- Reduced injury risk	- Continuity of care	- Reduced injury risk

Home Modifications		Home Modification Outcome		
Home Modification Design Requirement	Carer	Person with Disability	Others in Household	
Bedrooms				
<input type="checkbox"/> Household members have a bedroom space provided separate to the bedroom space used by a person with disability	<ul style="list-style-type: none"> - Undisturbed sleep - Reduced care burden - Private space - Space for non-care activities 	<ul style="list-style-type: none"> - Private space - Continuity of care 	<ul style="list-style-type: none"> - Undisturbed sleep - Private space 	
<input type="checkbox"/> There is adequate space in the bedroom space for a person with disability to use mobility equipment and assistive technology	<ul style="list-style-type: none"> - Reduced injury risk - Reduced care burden 	<ul style="list-style-type: none"> - Increased self-care - Continuity of care 		
<input type="checkbox"/> There is adequate space in the bedroom space for a person with a disability for the carer to assist with personal care activities, such as dressing	<ul style="list-style-type: none"> - Reduced injury risk - Reduced care burden 	<ul style="list-style-type: none"> - Continuity of care 		
<input type="checkbox"/> There is adequate storage in the bedroom of a person with a disability for assistive technology to be stored away when not being used	<ul style="list-style-type: none"> - Space for non-care activities 	<ul style="list-style-type: none"> - Space for non-care activities - Private space - Safety when alone 	<ul style="list-style-type: none"> - Space for non-care activities 	
<input type="checkbox"/> Storage space in bedrooms provides easy access to contents and/or keeps contents secured and out of sight	<ul style="list-style-type: none"> - Private space - Secure space - Reduced care burden 	<ul style="list-style-type: none"> - Increased self-care - Safety when alone - Private space 	<ul style="list-style-type: none"> - Private space - Secure space 	

Home Modifications		Home Modification Outcome		
Home Modification Design Requirement	Carer	Person with Disability	Others in Household	
Bathrooms				
<input type="checkbox"/> There are bathroom facilities provided for a carer and others in the household, separate to the bathroom facilities where care is provided	- Private space - Space for non-care activities	- Private space	- Private space - Space for non-care activities	
<input type="checkbox"/> There is adequate space in the bathroom for the person with disability to use home modifications e.g. grabrails and/or assistive technology e.g. shower chair, for personal care activities, such as toileting, washing and bathing	- Reduced injury risk - Reduced care burden	- Increased self-care - Continuity of care		
<input type="checkbox"/> There is adequate space in the bathroom for the carer to assist a person with a disability with personal care activities, such as toileting, washing, and bathing	- Reduced injury risk - Reduced care burden	- Continuity of care		
<input type="checkbox"/> Changes to the shower or bath area to provide additional space for the 'wet area' maintains electrical safety in the bathroom	- Reduced injury risk	- Reduced injury risk - Continuity of care	- Reduced injury risk	
<input type="checkbox"/> Changes to increase access to bathroom fixtures, such the bath, shower or toilet, for a person with a disability do not impede usability or safety of other bathroom users	- Reduced injury risk	- Reduced injury risk - Continuity of care	- Reduced injury risk	
<input type="checkbox"/> Bathroom layout, design of plumbing fixtures and selection of surface finishes minimise cleaning requirements	- Reduced injury risk - Minimise housekeeping - Continuity of care	- Continuity of care	- Minimise housekeeping - Social participation	
<input type="checkbox"/> There is adequate storage in the bathroom of a person with a disability for assistive technology to be stored away when not being used	- Space for non-care activities - Reduced injury risk	- Space for non-care activities - Reduced injury risk	- Reduced injury risk - Space for non-care activities	

Home Modifications		Home Modification Outcome		
Home Modification Design Requirement	Carer	Person with Disability	Others in Household	
<input type="checkbox"/> Storage space in the bathroom can provide either easy access to contents or keep contents secured and out of sight	- Secure space - Private space	- Safety when alone - Private space	- Secure space - Private space	
Kitchens and Laundries				
<input type="checkbox"/> Changes to increase access to kitchen fixtures, such the sink or stove, for person with a disability, do not impede usability or safety for other kitchen users	- Reduced injury risk	- Reduced injury risk - Continuity of care	- Reduced injury risk	
<input type="checkbox"/> Changes to the kitchen or laundry maintain electrical and gas safety for all users	- Reduced injury risk	- Reduced injury risk - Continuity of care	- Reduced injury risk	
<input type="checkbox"/> Kitchen layout, design of plumbing fixtures and selection of surface finishes minimise cleaning requirements	- Reduced injury risk - Minimise housekeeping - Continuity of care	- Continuity of care	- Minimise housekeeping - Social participation	
<input type="checkbox"/> Changes to increase access for person with a disability to laundry fixtures, such the washing machine or dryer, do not impede usability or safety for other kitchen users	- Reduced injury risk	- Reduced injury risk - Continuity of care	- Reduced injury risk	
<input type="checkbox"/> Laundry layout, design and location of fixtures and selection of surface finishes minimise cleaning requirements	- Reduced injury risk - Minimise housekeeping - Continuity of care	- Continuity of care	- Minimise housekeeping - Social participation	
<input type="checkbox"/> Cleaning products are safely stored and inaccessible to the person with disability if they present a risk	- Reduced injury risk - Continuity of care	- Reduced injury risk - Continuity of care	- Reduced injury risk	

Home Modifications		Home Modification Outcome		
Home Modification Design Requirement	Carer	Person with Disability	Others in Household	
Recreational Areas				
<input type="checkbox"/> Household members each have private recreational space to retreat to	- Private space	- Private space	- Private space	
<input type="checkbox"/> Household members have secure storage space in recreational areas for storing valuable/personal items	- Secure space	- Safety when alone - Secure space	- Secure space	
<input type="checkbox"/> Recreational space converted to bedroom, therapy, or other private space for a person with disability is replaced with adequate recreational space in another area of the home	- Space for non-care activities	- Space for non-care activities	- Space for non-care activities	
<input type="checkbox"/> Electric or gas controls, devices and appliances that can be accessed by the person with disability, have a means of being made inactive if they are not safe for the person to use	- Reduced care burden	- Safety when alone - Increased self-care		
<input type="checkbox"/> If limited space prevents a sole-purpose therapy room, a recreational area used for therapy has therapeutic equipment and storage space designed so the area can be cleared for recreation	- Space for non-care activities	- Space for non-care activities	- Space for non-care activities	
<input type="checkbox"/> Where the person with disability has challenging, violent behaviours, a secure place is provided for the carer and other household members to retreat to	- Secure space - Reduced injury risk - Continuity of care	- Continuity of care	- Secure space - Reduced injury risk	
Assistive Equipment				
<input type="checkbox"/> Mobility and other assistive equipment is provided where needed and carers and other users instructed in its use and maintenance	- Reduced injury risk - Reduced care burden	- Increased self-care - Safety when alone - Reduced injury risk - Continuity of care	- Reduced injury risk	