Home modification information needs of peak consumer organisations in NSW

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Glossary

CDSA	Commonwealth State Disability services Act
CSDA	Commonwealth State Disability Agreement
DADHC	Department of Ageing, Disability and Home Care
DDA	Disability Discrimination Act
DSA	Disability Services Act
DSP	Disability Services Program
DVA	Department of Veterans Affairs
HACC	Home and Community Care Program
HIA	Housing Industry Association
HMM	Home Modification and Maintenance
NESB	Non English Speaking Background
NSW	New South Wales
OECD	Organisation for Economic Cooperation and Development
OT	Occupational therapist
OH&S	Occupational Health and Safety
RARA	Rural and Remote Areas Classification
RTO	Regional Technical Officer
SAP	Supported Accommodation Program
WWW	Worldwide web

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Introduction

This paper explores the home modification information needs of peak consumer organisations within New South Wales. It considers where the consumer peaks locate the information and how they disseminate the information to their consumers. Peak organisations, by definition, represent the views of their members. For the purposes of this paper, the term consumer refers to members of peak consumer organisations. Peak consumer organisations are a subset of peak organisations that focus on a specific consumer group. Therefore, the information needs of consumer peaks are assumed to reflect the information needs of their consumer groups.

The significance of these findings is accentuated by rising demand for information from consumer peaks about home modification intervention options, funding sources for home modifications, and the availability of services to deliver the modifications. Increasing demand for home modification information stems from population ageing and constraints on government expenditure. Consumer peaks often face high community expectations in the context of relatively low funding and changing laws and regulations.

All the peak consumer organisations interviewed are responsible for gathering and disseminating home modification information. Many also advocate for better home modification provision for the consumers that they represent and interact with within New South Wales. The emphasis on home modifications and division of roles within organisations varies between organisations depending on funding, focus and consumer demand.

Project Aims

This research directly addresses the information needs of Home Modification and Maintenance Consumer Peaks within NSW. For the purpose of this research 'information' was defined as "facts told or heard or discovered" (Hawkins, 1988) whilst "need" was interpreted as the discrepancy or gap between current practice and best practice (Witkin & Altschuld, 1995).

This paper overviews explorative research undertaken and presented in an honours thesis format (Cruickshank, 2003). The research explored the perspectives of NSW Consumer Peaks on their home modification information needs. Specifically, the research aimed to:

1. understand current Home Modification and Maintenance information needs from a Consumer Peaks' perspective

2. understand the dissemination of information sharing strategies already evident for Home Modification and Maintenance from a Consumer Peaks' perspective

3. systematically identify strengths, gaps or weakness with a view to building on strengths and minimising weaknesses

4. use findings to ensure that the HMinfo Clearinghouse strategies adopted and prioritised address the information needs identified by Consumer Peaks.

Background

Home modifications describe the changes made to the home environment to accommodate changing needs of older people and people with a disability. Home modifications aim to improve safety, independence, assist to reduce injury to consumers and their carers, and enable consumers to participate in society. Home modifications achieve these functions by reducing or removing barriers that consumer's experience whilst engaging with their home environment. Examples of home modifications include installation of ramps, lowering benches and removing scatter rugs (Mann, Ottenbacker, Fraas, Tomit, & Granger, 1999).

The increasing need for home modifications can be attributed to a number of factors including the increase in numbers of people with a disability, societal trends and Government Policy. The NSW Industry Group on People Ageing with Disability (2001) anticipates an 11.6% increase within NSW of the number of people with a profound or severe activity restriction or people reporting a disability. There is a trend towards Government's increasing reliance on carers to provide more support for consumers who remain in their own homes (NSW Industry Group on People Ageing With Disability, 2001). This trend increases the risk of injury to these carers. Implementing preventative home modification could assist to reduce this risk. As such, home modifications will become increasingly important.

The Ageing in Place policy encourages individuals to remain in their own homes minimising premature admission to residential care (Faulkner, 2000). This is achieved in part by bringing services into the consumers' homes. In New South Wales, consumers with disabilities or older people may be eligible for subsidised services through the Home and Community Care Program (HACC) (Department of Health, 2003). Services offered through the HACC program include Home Modification & Maintenance, nursing care, domestic assistance and social support (Ageing & Disability Department, 2003). These services assist consumers with increased needs to remain in their own homes.

There is an increasing body of evidence suggesting a growing demand for home modification services. Gitlin (Gitlin, 1995) suggests consumers prefer to utilise support services rather than implement home modifications. However, (Gosselin, Robitaille, Trickey, & Maltais, 1993) contradict this position, stating support services do not preclude consumers from implementing home modifications. That is consumers could select to implement home modifications in preference to or in addition to support services, consequently increasing the need for home modification information. The increasing demand for home modification services results in a greater consumer need for relevant information. Consumers may seek the information alone or through Peak Consumer Organisations. The corollary being Consumer Peaks have an increasing need for home modification information.

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Some research has focused on consumers' need for home modifications (Mann et al, 1999; Bayer & Harper, 2000; TasCOSS, 2002). Other work has categorised home modification interventions. These categories include fire safety, security, accident prevention and useability, construction related, and care-giver support (Steinfeld, 1993; Steinfeld & Shea, 1993). Picking & Pain (2003) noted that consumers prefer, if given sufficient information, to organise their own home modifications. (TasCOSS, 2002) studied the needs of HACC consumers in Tasmania, Australia and found that consumers require home modification information relevant to their local area. TasCOSS (2002) also found that consumers are unaware of the range of home modifications available to them. However, there appears to be a paucity of research that explores the specific home modification information consumers require or how consumers locate the required information.

(Bridge & Martindale, 2002) identified specific home modification information needs of the HACC funded Home Modification and Maintenance (HMM) Services in NSW. The specific topic areas of home modification and maintenance information needs identified include:

- spatial requirements
- carer requirements
- product requirements
- requirements for community inclusion
- requirements for meeting standards of care
- disability access components
- funding policy
- building and land regulations
- natural environment
- built environments
- other

As peak consumer organisations aim to represent the needs of their consumer groups, exploring the information needs of consumer peaks also provides information relating to consumer information needs. Peak organisations' services include information dissemination, advocacy, policy development, research, and representation of the views of their members (Charities Definition Inquiry, 2001). Peak consumer organisations, the focus of this study, are a subset of these organisations that specifically target consumers. Consumer Organisation Working Group (2002) state the advantages of peak consumer organisations are the agenda is set by consumers, they are consumer focused, and they provide an independent consumer voice. Consequently, as consumer peaks represent their consumer groups, it is assumed that the information needs of consumer peaks reflect the information needs of the consumers they represent.

In addition to the services offered by other peak organisations, the National Caucus of Disability Consumer Organisations, represents the disability sector to Governments (Commonwealth Department of Family and Community Services, 2002). Table 1 provides an outline of the consumers, national organisations and the state organisations represented in the National Caucus of Disability Consumer Organisations.

Table 1. Organisations forming the National Caucus of Disabiltiy Consumer Organisations

Consumer type	National Organisation	State Organisation
Carers	Carers Australia	Carers NSW
Intellectual impairments	National Council on Intellectual Disability	NSW Council on Intellectual Disability
Vision impairments	Blind Citizens Australia	Blind Citizens Australia – Sydney office
Physical impairments	Physical Disability Council of Australia	Physical Disability Council of NSW
Hearing impairments	Deafness forum	Deafness council
Women with disabilities	Women With Disabilities Australia	Women With Disabilities Australia – NSW representative
Head/brain injury	Head Injury Council of Australia	Brain Injury Association of NSW
Ethnic/Multicultural consumers with disabilities	National Ethnic Disability Alliance	Multicultural Disability Advocacy Association
People Living With HIV/AIDS	National Association of People Living with HIV/AIDS	People Living with HIV/AIDS (NSW) Inc.

A broad cross representation of consumers potentially seeking home modifications is provided by the Caucus with the addition of the Council of the Ageing. The level of specificity of the information needs varies between consumers, state organisations and national organisations as shown in Table 2. Consumers have specific home modification information needs to address the individual's specific requirements. National level organisations do not aim to address such specific consumer questions. State level organisations do not require the same level of specificity as consumers; however, they require sufficient information to assist consumers locate the information. Accordingly, state level organisations were interviewed in this study to indicate the home modification information needs of consumers.
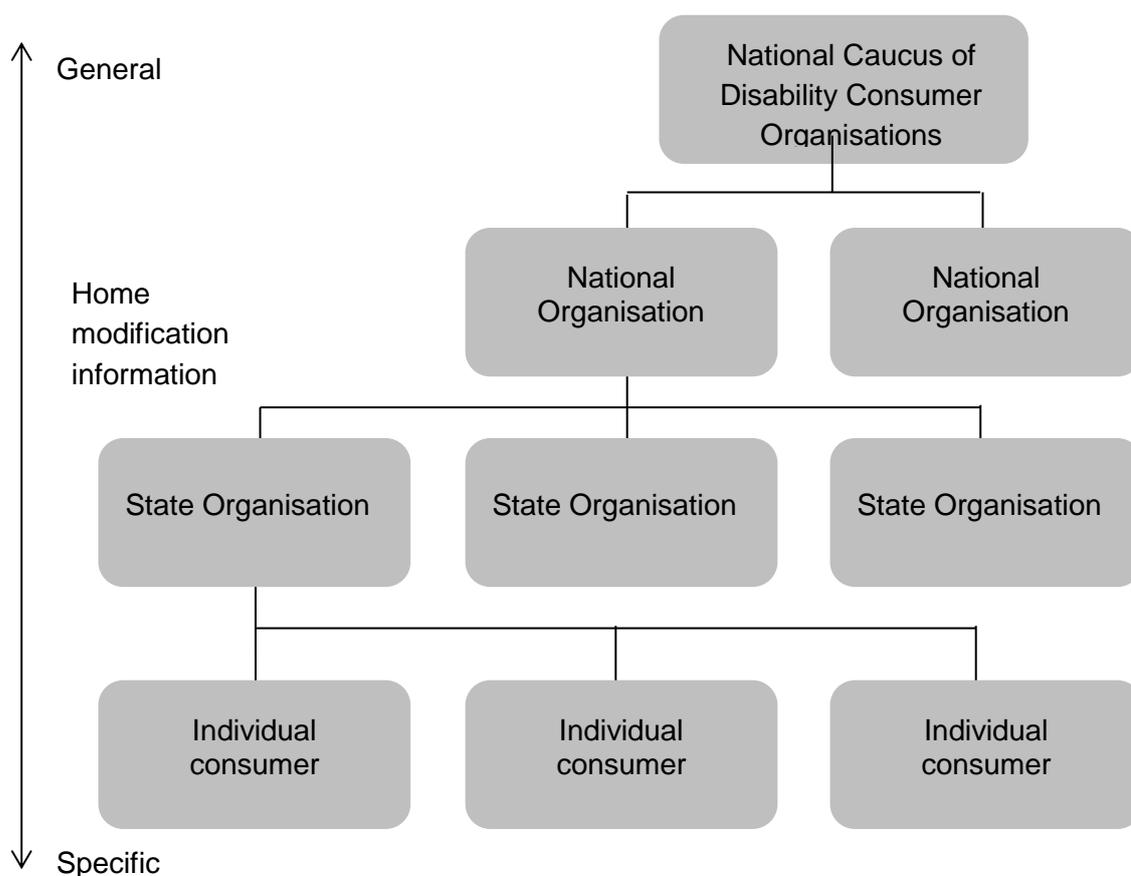
Figure 1. Organisational hierarchy and organisational relationship to home modification

The dissemination of accurate and useful home modification information by peak consumer organisations influences successful ageing in place. Addressing the information needs of consumer peaks is a critical element in this process. This thesis, aiming to determine the home modification information needs of consumer, related the information needs of peak consumer organisations to those of consumers. The assumption being that consumer peaks are a significant source for home modification information for consumers.

Methodology

This explorative qualitative research employed a three phase needs assessment framework as described by (Watkin & Altschuld, 1995). A needs assessment framework can be used to indicate the current and desired status of the topic of interest. Application of the three-phase needs assessment enabled exploration of the variance between current and desired home modification information needs.

During the first phase, exploration, the researcher engaged in two weeks participant observation with two peak consumer organisations. This phase enabled an initial exploration of home modification information needs and assisted in identifying potential informants. The participant observation also assisted in determining the appropriate

contact persons with consumer peaks. Using a stratified purposeful sampling method, potential consumer peaks were identified. The final sample represents a broad cross section of consumer groups. The informants represented each of the member consumer groups of the National Caucus of Disability Consumer Organisations and older people.

Phase two, data collection, involved interviewing each informant individually for approximately one hour. The telephone interviews were recorded and transcribed to enable content analysis.

The interviews were transcribed and returned to each informant for endorsement. Using thematic analysis they were coded and analysed. The final phase, utilisation, included all the informants receiving a copy of the final report thereby satisfying ethical obligations of ensuring participants benefit from the research process.

Sampling frame

The stratified purposeful sampling method enabled the selection of the most appropriate sample for the research. The National Caucus of Disability Consumer Organisations provided the framework for grouping consumer peaks as potential participants. The Caucus does not identify older people as a consumer type. As older people constitute a large proportion of home modification users, this group were also included in the sample. The final sampling frame is provided in Appendix A.

Inclusion criteria were developed to complete the sample frame. For inclusion, organisations were required to meet the definition of a peak consumer organisation as defined by Charities Definition Inquiry (2001) and operate at a state level. The organisation was required to have a disability or older person focus to ensure potential relevance of home modifications. The organisation services must include information dissemination to their consumers. This criterion increased the probability that the organisation's home modification information needs reflected those of their consumer groups. Finally, the organisation involved representation of the needs of consumers. There was one exclusion criterion. The organisation was required to represent the views of consumers in New South Wales. This criterion was applied for ease of access to the potential participants.

The first organisations listed for each consumer type in the frame were invited to participate in this research. If an organisation declined to participate, the next organisation in the frame was contacted. Two of the original organisations contacted declined to participate. Consequently, People with Disabilities and The Royal Blind Society were invited were contacted. The final ten participating organisations in this research are listed in Table 3.

Interview process

Potential informants expressing interest in participating received an information package. The package contained a letter of invitation, a consent form, a subject information sheet that explained the interview process. These documents are provided in the appendices as follows:

Appendix B: Invite to participate

Appendix C: Subject information sheet

Appendix D: Ethical consent form

Table 2. Organisations who participated in this research

Peak consumer organisations
Council On The Ageing (NSW)
Physical Disability Council of NSW
People Living With HIV/AIDS
New South Wales Council for Intellectual Disability
Carers NSW
Brain Injury Association of NSW
Deafness Council
People With Disabilities NSW
Royal Blind Society
Women With Disabilities Australia

Interview schedule

The data collection involved in-depth, semi-structured interviews. This technique was employed due to the paucity of research into home modification information research. There is insufficient data to develop and test a hypothesis. In addition, employing a similar methodology to the previous research into home modification information needs of HMM services (Bridge & Martindale (2002) enables a comparison of results between the two projects. To ensure consistency between the interviews, a semi-structured interview guide was developed, see appendix E. The guide included each of the home modification and maintenance information topic areas outlined by Bridge & Martindale (2002). These topic areas were defined and illustrated with examples as shown in Table 4. Informants were invited to comment of the need or role for the organisation to provide that specific information to their consumers.

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Table 3 List of topic areas, definitions and examples of topic areas.

Topic Area	Definition	Example
Spatial requirements	'relating to, involving, or having the nature of spatial data as pertaining to the needs of consumers with disabilities'	The size of walkers, wheelchairs,
Carer requirements	'Intended to signify an individual'.	Nurse, social workers, physician, family member, neighbour
Product requirements	'Refers to such things as building products, or products that are brought or sold commercially'.	Walls, floors, doors, vanities
Requirements for community inclusion	'Refers to the considering of needs of consumers with special requirements as a part of something larger'.	Ageing in place, social inclusion
Requirements for meeting standards of care	'Any established procedure or minimum that might be expected'.	Policies, Australian Standards, some organisations have members on councils or representatives on bodies.
Disability access components	'Products fabricated for people with a disability'.	Grab rails, hand held showers, nonslip tiles, lifts/hoists.
Funding policy	'All decision, policy and sums of money or resources set aside for a specific purpose'.	Legacy funding, DVA funding and HACC funding
Building and land regulations	'Relating to or concerning nature and the natural environment surrounding the home'.	Weather, floods, wind, sunlight, frost and snow
Built environment	'The state of human habitation or basic soundness of housing structure'.	Location of the house, suburb: maintenance of house & structure (i.e. mould & mildew, dry rot, brick vs. veneer house) Placing a grab rails into fibro wall.
Other	No definition of 'other' was provided	Rural and remote difference, OH&S equirements, modification follow up, maintenance and electronic data.

Participant endorsement is a process of providing participants with a copy of the information obtained to increase the validity of research results (Minichiello, Fulton, &

Sullivan, 1999). Informants were given an opportunity to alter, change or offer additional information on receipt of their interview transcripts. No changes to the results chapter were required, indicating the informants agreed with the information presented. All participants received a copy of the final research, fulfilling an ethical obligation to ensure that participants gain from the research process.

Theoretical Sensitivity

The interview guide underwent two reviews and one pilot to ensure its effectiveness. The first review occurred with an experienced professional working within the disability sector of the community. This review resulted in the inclusion of additional prompts and probes to elicit information on the topic areas. The first review also resulted in definitions within the guide to reduce the ambiguity of topic areas and general information.

The second review occurred with a researcher experienced in home modification research and consumer need. Revisions following this review primarily concerned the specificity of questions. As such, questions were modified to elicit more generalised responses from informants.

On completion of the amendments resulting from the reviews, a pilot was completed with an experienced professional working with older consumers in the community. The pilot demonstrated that no further alterations to the interview guide were necessary.

Thematic analysis

The thematic analysis involved extraction of material from the raw data that was relevant to the eleven topic areas. Following coding, the material was systematically analysised for similarities, differences and relationships between themes. The results were considered in relation to the consumer peaks need for specific home modification information, the medium that consumer peaks employ to locate the information, and the role and purpose of the consumer peaks in relation to home modifications.

Spatial requirements

Bridge and Martindale (2002) describe this area as relating the spatial demand including the ergonomic requirements of activities. Ergonomics consider the requirements of consumers and the tasks they perform within their environment (Woodson, Tillman, & Tillman, 1992), i.e. how the consumer's physical requirements affects an activity's performance in a specific environment. Current building stock often fails to meet the spatial demands of older people and people with a disability. The provision of accessible housing is relevant to consumer peaks. To provide accessible housing information based on the knowledge of spatial demands is critical. Most informants discussed the need for spatial requirement information. However, comments were divided between having and not having a need for this information. There was a slightly larger preference for organisations requiring this information. These informants stated that consumers, builders, architects and business owners

requested spatial requirement information. Of these stakeholders, consumers were perceived to have the highest demand.

The following statement illustrates this:

> *'Individuals who want to create or alter some space for some purpose … architects, designers, and local government planning officers'* ([1]).

A few informants commented that the organisations themselves required this information for systematic advocacy work and information dissemination. Very few informants specifically explored the needs their consumers have for spatial requirement information. One informant described the need to have an awareness of spatial information giving vertical clearances as an example as illustrated in the following excerpt:

> *'Looking at vertical clearances … so that they [consumers] are not bumping their heads into low doors or plants on the wall'* ([9]).

Some informants stated that consumers did not require spatial requirement information. Of the informants asserting that consumers did not need spatial requirement information, half stated other organisations address this role. For example:

> *'We don't specifically do that role; there are other specific disability organisations that have more specific information on that'* ([8]).

The other organisations referred to include home modification and maintenance services, Bobby Goldsmith Foundation, and the suppliers and providers of home modification products. That other organisations address this need implies that consumers do require this information.

Locating required information

In discussions relating to spatial requirement information, informants noted a range of possible sources. These sources included regulations, information services, Governments and disability organisations. Few informants noted the Australian Standards and the Building Codes of Australia as possible sources for spatial requirement information. Information services were also considered potential sources of spatial requirement information. The Australian Quadriplegic Association was commonly cited with a few informants noting IDEAs in Tumut and Disability Information and Referral Centre. Another informant noted the Independent Living Centre as being useful for specific information about wheel chairs as the following comment highlights:

> *'I was speaking to the Independent Living Centre and they talked me through how to calculate the dimensions of the wheel chair to do with the size of the person's body'* ([5]).

Several informants acknowledged Governments as potential sources for spatial requirement information. One informant stated they would source the State Government for this information, in particular the Department of Disability, Ageing and

Home Care. Another noted that the Development Control Plans from Local Government Authorities could also provide this information, evidenced by:

> '…the local authorities Development and Control Plan might have something to say [about spatial requirements]' ([1]).

Very few informants noted the use of electronic information sources to locate spatial requirement information. The Internet and electronic mail (e-mail) were the only electronic information sources utilised. One informant noted the use of professionals to obtain spatial requirement information. Specifically, they mentioned Occupational Therapists as the professional they would contact. One informant stated they would source the Master Builders Association and other bodies within the building industry, highlighted by:

> 'We would probably suggest that they contact the Master Builders Association or one of those big bodies in that area' ([6]).

These results indicate organisations employed a range of information mediums to locate the required information. However, little unanimity occurred between the mediums.

Carer requirement

Carers referred to any individual providing either formal or informal care. Formal care typically includes people such as physician, nurse, social worker or anyone who assist in the identification, prevention or treatment of an illness or disability. Informal care refers to someone who attends to the needs of a dependent adult or child such as parent, foster parent or guardian (Bridge & Martindale, 2002). The time spent providing care may vary form a few hours a week to full time care. Carer requirements are relevant to consumer peaks because of this impact on the consumer's quality of life. Consumers have a need for carer requirement information; hence, organisations are involved in this area.

Carers are exposed to health problems directly attributed to the caring role with some studies observing an increasing trend in these injuries. Evidence suggests that appropriate home modifications could reduce this risk of carer injury. Furthermore, changes in legislation such as the Disability Services Act and WorkCover are increasing the demand for carers. There are a large number of carers in Australia, equating to a carer in one in five households (Carers NSW, 2002). The combination of increasing demand for carers and the increasing rate of injury indicates information regarding carer requirements is critical. For consumer peaks, carer requirement information is necessary to advocate for the needs of their consumers by reducing the risk of their carers.

All informants explored the need consumers have for carer requirement information with a surprising number of informants detailing when their consumers require this information. Consumers require carer requirement information when they experience difficulty performing daily activities independently. These difficulties primarily related to

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the difficulty of engaging in their home environment or accessing services as the following demonstrates:

> '…they contact us because they can't get the service they require. They know about the service, they know its there, but they can't get the level of service that they need' ([8])

and,

> 'Some of them don't realise that there are problems until the problem arises and then they have to sort something out very quickly' ([1]).

Some informants spoke of the awareness their consumers have of what they are required to provide for carers entering their home, e.g. a safe work environment. While other informants stated their consumers would not know what to provide for carers. Informants who commented on this issue believed that consumers mostly became aware after they experience problems with service delivery. The following comment summarises this:

> 'Some of them [consumers] don't realise that there are problems until the problem arises and then they have to sort something out very quickly' ([1]).

Examples of these problems include ineligibility to access services or not receiving an appropriate level of service. One informant believed that members of their organisation would know what to provide but were unsure of the knowledge of people in the community, demonstrated by:

> 'The people who actually belong to [our organisation]… then I'd say yes. The…general people in the community with a disability, very difficult to say…' ([8]).

Informants explored occupational Health & Safety concerns relating to carers in detail. However, there was no consensus between responses. Responses ranged from comments relating to low consumer awareness, as discussed above, and the necessity for organisations to understand the impact of these issues on service provision. One informant summarised the reason for organisational involvement in this area and organisational response to this issue as:

> 'We would advise anybody that would ring us up on any issue, that they would need to carry out an Occupational Health and Safety audit on that home, because if it becomes a place of work immediately a person puts their foot into it, it's a place of work. And they should get hold of the Occupational Health and Safety standards that apply to that sector' ([6]).

An overwhelming number of informants expressed organisational involvement relating to consumer need. The few informants reporting a low need for carer information also reported that their consumers do not know what they are required to provide for carers.

Importantly, two opposing views regarding the magnitude of the need for carer requirement information were noted. One perspective stated a major need exists while the second perspective contradicts this statement arguing only a small need exists for this information.

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One explanation for this variation could be the type of consumers represented by the organisation.

Few informants discussed where consumers could locate carer requirement information. No consensus occurred between responses. Organisations such as Australian Quadriplegic Association, ParaQuad and Carers Association were primarily mentioned as a source for this information as highlighted by:

> 'We would tend to refer to much more specific organisations, we'd tell them about, the Carers Association and various other services that would be most likely to assist them in referring them onto much more specific services, and mainly by letting them know what else is available for them' ([3]).

Additionally, one informant noted that the Department of Disability Ageing and Home Care could potentially provide carer information.

Product requirement

This category referred to information regarding building products and products bought or sold commercially (Bridge & Martindale, 2002). The relevance of this category to consumer peaks relates to accessible housing and social inclusion. Manufacturers who consider consumer need in product design facilitate inclusive design features. That is the risk of stigma due to the home modification is reduced. Studies indicate that home modifications may not be implemented due the stigma they create (Gitlin, 1995; Mann, Hurren, Tomita, & Karuza, 1993; Steinfeld & Shea, 1993; Trickey, Maltais, Gosselin, & Robitaille, 1993). Peak consumer organisations advocate on behalf of consumers regarding these needs.

Most informants discussed a consumer need for product requirement information. Informants commented that consumer need for this information varied from a general understanding to specific requirements. One informant, describing the varying level of detail consumers require, stated:

> 'The more complex a set of questions become the more speedily we are going to say that we are not the agency you need to speak to, but here is the person or the organisation that you need to speak to' ([1]).

A few informants detailed and specific requirements of consumers. These requirements related to insulation, colour contrasts, signage, handrails and floor surfaces. Insulation primarily revolved around the reduction of excess environmental noise, whilst colour contrasting concerned the use of carpets and floor surfaces to indicate room changes. Signage related to the Building Code of Australia and its specifications. The informant raising this issue claimed that primarily it concerns sign writers and 'a couple of clients here and there'. The informant who discussed the need for handrails explicitly noted its necessity to aid and support consumers with mobility impairments and to function as a guide for consumers with vision impairment. The informant commenting on the need for information about floor surfaces noted its use as a visual guide and that slip resistance changes with different surfaces as demonstrated by:

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> *'We need to understand, some forms of concrete are slippery than other forms of surfaces, and so to put in that you need to be mindful of that, otherwise your going to have problems'* ([1])

and,

> *'Floor surfaces, so slip resistance and matt finishes vs. glossy finishes and using different surfaces of the building to indicate different areas of a building'* ([9])

Some informants commented that consumers were not interested in the process of locating products. One informant claimed consumers are only interested in the outcome, as highlighted by:

> *'Consumers and the family, they don't want to know where they can get the door (laughs). They just need someone to say the door will be provided (laughs)'* ([4]).

Another stated the need for this information had decreased, due to advances in medicine evidenced by:

> *'The level of need and the amount of calls we would get around these sorts of things would be ten fold less what they were five years ago. So, you know, they tend to be the rarity rather than the norm'* ([3]),

and,

> *'I don't know of any information needs in that area at all'* ([6]).

In exploring the organisations' need for product requirement information, most expressed a need for the information to enable information dissemination and systematic advocacy functions but noted that the need is small. A small number of informants suggested that knowing where to source the information was adequate. Where informants stated that the organisation did not require product information, limited funding and the detailed and technical nature of the information were cited. These informants claimed that product information was more appropriate for the Independent Living Centre and the Home Modification & Maintenance service providers to address. This is illustrated by:

> *'[Product requirement information] is an area that is relevant to the Independent Living Centre or [Home Modification & Maintenance] tradesmen who come in to do the home modifications'* ([4]).

Informants also commented on the need for information on warranties, training and useability information of these products. Most informants stated organisations did not require this type of information, again citing the technical nature of the information. Most informants discussing the consumer need for information about warranties, training and useability information of products noted little demand for this information. One informant believed this was the role for those providing products, demonstrating that there was some consumer need for this albeit not for the organisation. Another expressly commented on the need their consumers have for this information, stating that, 'there is definitely a need for that sort of information' ([9]).The differing perspectives

regarding the need for product requirement information by consumers could stem from consumer type and the subsequent ability to interact with the environment.

Consumers with a disability experiencing difficulties interacting with the environment might require more detailed and specific information regarding products.

Requirement for community inclusion

Essentially this category refers to the inclusion into society of consumers with special requirements (Bridge & Martindale, 2002). Reducing occupational health and safety risks and providing information to consumers in alternative formats, facilitates this inclusion. Advocating for the inclusion of consumers into society is a function of peak consumer organisations.

The large number of responses by informant relating to this area is an indication of organisations' great need for this information. Most informants discussed the organisation's role in promoting community inclusion. This is achieved, in part, by incorporating consumers into management positions of the organisation and by recommending service providers apply for funding to facilitate inclusive practices. The organisations' role in inclusion is illustrated by:

> *"I would think that is a juge area for us, to promote community inclusion. I mean the aim is to provide information, so that yeah, that would be a big thing for us'([4]).*

A number of informants state the task of promoting community inclusion was too large to sustain or cover thoroughly on current funding levels.

Few informants identified the specific functions the organisation performs to promote community inclusion. One informant identified barriers to their consumers' participation in the community; however, they do not assist consumers to remove the barriers. The organisations did ensure that their services were accessible to their consumers.

All informants discussed the political agenda of the organisation. They stated that the organisations were apolitical but had a political understanding.

> *'[We] try to be as aware as possible of the political context within which those decisions are being made'([1]).*

Informants raised both consumer and organisational awareness of relevant legislation such as the Disability Discrimination Act, Disability Services Act, the Age Discrimination Act, the Retirement Villages Act, and the Carer Responsibility Discrimination Legislation. Most informants who commented on legislation noted a need for the DDA. There was little unanimity for other legislation. The following highlights consumers' information need for a range of legislation:

> *'…in terms of carers who contact us they often want to know what their rights are and what the rights of those they are caring for are, in terms of services that they access and in terms of their rights within the community. So there's the Disability Services Act and the Disability Discrimination Act. There's also now Carers Responsibility Discrimination legislation, something that relates specifically to carers in the work place' ([5]).*

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Informants discussed consumer awareness of these legislation; however responses varied with little consensus between them. Some believed that the majority of consumers have awareness, whilst others believed fewer consumers were aware of relevant legislation. One informant specifically noted that younger consumers are generally more aware of relevant legislation than older consumers. Another informant stated that consumers are aware legislation exists although they do not know the specifics of the legislation, as illustrated in the following excerpt:

> 'I think they are aware they [legislation] exist, but I don't think they are aware of the details unless they happen to serve on committee or have a background professionally in he organisations that have that information, or read our policy publications' ([2]).

Essentially, the legislation facilitates organisations to engage in both systemic and individual advocacy functions. Systemic advocacy functions include comment on policy papers. Individual advocacy includes assisting consumers to lodge complaints with relevant authorities.

Within the context of awareness of legislation, most informants discussed consumers' need for information in alternative formats. These formats included large print, Braille, audio and electronically delivered formats. Most informants commented on the need for large print; however, the specific requirements of this format varied between informants. The large print comments included size 14 and bold font, size 16 to 18, and Sans Serif black font on a white background. One informant explained that consumers have difficulty reading Times New Roman font. The following comment highlights the specifications consumers require of large print formats.

> 'So on an individual basis they may get larger print, but as a standard its 16 to 18 point font and it's a font that's sans serif, so its something like Arial or Helvetica, rather than times new roman, which people with a low vision have trouble distinguishing the characters. And of course good contrasting print, so nice large black on white or pale coloured page or white print on a dark background' ([9]).

Very few commented on consumers' need for information in Braille. The few informants commenting on this noted that more recently consumers do not require this information as frequently, as the following highlights:

> 'Braille is unfortunately not as commonly used as it used to be, only about 10% of people who are blind use Braille' ([9]).

Similarly, some informants commented on the need for information in audio. The demand for this format does not appear to be significant, as the following comment demonstrates:

> 'Not a great extent. We should be producing more, but we don't really get that much call for that' ([6]).

Some informants commented on consumers' need for electronically delivered formats of information. Typically, consumers require Word documents and Rich Text Files (RTF), with a preference for the latter. This preference stems from the ability to use

RTF on older computers and a variety of software. The following comment summarises the use of this format:

> *'A growing area is the electronic format. So computer based documents, so whether it's a word document or a text only document – which is the preferred one so its only text, there's no formatting, or fancy formatting or tables or anything like that. So most people who have access to computer equipment, no matter how old it is can usually access a text document'* ([9]).

Informants did not comment on consumers' sources for requirements for community inclusion.

Requirements for meeting standards of care

This area refers to all policies and procedures ensuring a standard of care in the delivery of home modifications (Bridge & Martindale, 2002). Peak consumer organisations protect the interests of consumers through representation to the councils or committees that govern the policies and procedures. This facilitates the accessibility of the services with respect to the Disability Services Act.

Most informants discussed the need for this information, noting the importance of this need to both the organisation and their consumers. However, few informants explored this area in detail.

Some informants stated consumers only have a small need for this information, whilst one informant stated consumers are unaware of any such standards. The sub-theme, consumers not knowing their rights, was re-iterated by another informant. To highlight this they provided the following example relating to home modification:

> *'If a home modifications tradesmen did a lousy job, some of them wouldn't even speak up, because they feel they are lucky to get one. And they feel that if they complain … in future that [the complaint] would make it difficult to get services'* ([4]) and,

> *'Most of the community wouldn't even know their rights or wouldn't even think of asking for standards or quality assurance mechanisms'* ([4]).

Some informants explained the specific standards consumers require and the problems associated with some standards. Only a few informants outlined the specific standards consumers require. There was no agreement between responses; each informant listed different standards. These standards included the Disability Services Act (DSA), Disability Support Standards and the Australian Standards. I Informants noted that the DSA primarily concerns the service providers but with some relevance to consumers. One informant noted Government Departments are not going far enough to implement Australian Standards. The informant did not explore this area in detail, nor did they relate its impact to consumers. Another claimed the lack of clarity in the DSS definitions affects consumers, highlighted by:

> *'those standards [the Disability Support Standards] I feel need to be tightened when it comes to carers, I mean you could say appropriate care. But appropriate care, what is appropriate care?'* ([6]).

Some informants did not comment on a need for information regarding requirements for standards of care. This could indicate that they do not have a need for this information or a poor understanding. The following statement supports the notion that a poor understanding could be due to the technical nature of standard:

> 'Does that mean that I can I tell you if the Australian standards changed definition of what an accessible house is? No I've no idea; they change them all the time' ([1]).

Several informants claimed the technical nature of some standards might limit a consumer's ability to understand them. In addition, some informants highlighted the notion of the standards only being minimum requirements. They noted these standards are minimum requirements only and argued that efforts should be made to go beyond them. Exceeding standard requirements is not common practice. One informant stated that consumers require small, specialised service providers not larger, generic providers. The informant believed that larger service providers disregard the needs of consumers. The following highlights the perceived impact of large generic services on consumers:

> '…It's really more of a big business and you're paying big bloody dollars to the people at the top. The person at the bottom with the disability is still fighting for their needs' ([6]).

Although informants discussed the sources of requirement for community inclusion information, they did not explore these sources in detail. Essentially, informants concurred that three sources should be employed to gain this information. These sources included electronic, organisations and Governments. Only one informant explored electronic information in detail, noting the Internet and E-mail as useful sources. The following comment summarises some problems with the Internet:

> 'Again, e-mail, some web sites. However, most of the stuff that's on the web is very washed. The real sort of discussion takes place either face to face or email' ([7]).

A few informants noted using organisations to acquire this information, however they did not elaborate on which specific organisations are used. Most informants noted using Governments to find this information. The following quote highlights this, 'So it's from Government, committees and cognate organisations' ([2]).

Disability access components

This area includes products specifically fabricated for people with a disability such as ramps (Bridge & Martindale, 2002). These products are often termed assistive technology. Consumers frequently require home modifications to overcome the environmental barriers experienced in their own homes. Consumer peaks need to ensure these products are available to their consumers and therefore require the relevant information.

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Most informants acknowledged some need for disability access component information although perception of the extent of the need varied. Some considered this information need from a consumer perspective. Other informants discussed the role of other organisations addressing this information need.

Informants discussed the extent of consumers' need for this information in addition to the specific requirements of consumers. The specific requirements concerned flooring and reducing environmental noise. Flooring and environmental noise control are the most common information needs for consumers. Some informants noted the impact flooring has on consumers and related the flooring to the reduction of environmental noise. One informant noted that hard surfaces compound hearing difficulties for consumers with hearing impairment. The informant noted a need to have carpet and soft furniture to reduce environmental noise, demonstrated by:

> *'Yeah having carpet on the floor, and if possible having soft furniture rather than having hard surfaces because you get an echo off the hard surfaces' (7).*

Information relating to environmental noise reduction includes the implementation of double glaze windows and insulation. One informant specifically noted consumers require this information. The following summarises the needs explained by this information:

> *'Well reverberation and environmental noise are very difficult for hearing impaired people. So looking at ways to ameliorate the environment, looking at ways to get messages to hearing impaired people clearly and well through loop systems. Through better use of double glaze windows, insulation, that sort of thing' ([7]).*

One informant explored the specific period when their consumers require this information. They noted consumers typically require this information just after leaving hospital or during rehabilitation, not long after the diagnosis of their disability.

Organisational need for disability access component information varied between organisations. Most organisations required basic information regarding disability access component, sufficient to provide a broad understanding. This understanding enables the consumer peak to identify and refer consumers to relevant organisations and surfaces.

Most informants noted difficulties locating information relating to disability access components. Some informants noted specific sources for this information, but detailed exploration was limited. Organisations, professionals and electronic sources were the main sources identified. The following comment summarises the difficulties with locating this information:

> *'There is not real formal avenue that you know, that I can go there and get information about the particular device there' ([9]).*

One informant who noted that information services provide this information, specifically mentioned the Australian Quadriplegic Association Most informants referred to the Independent Living Centre (ILC) as a source. They specifically discussed the ILC web site of as a source, evidenced by:

> *'Knowing the Independent Living Centre has a database of products' ([5]).*

Most informants noted that consumers could contact peak consumer organisations who would then locate the appropriate information sources. The following highlights use of peak consumer organisations:

> *'I'll have a look on the [peak consumer organisations] database, and services that might be able to provide this information and just contact them [consumers]' (4).*

One informant noted that consumers could obtain this information from professionals, specifically Acoustic Engineers. Informants did not discuss using any other professionals.

Some informants discussed using electronic information mediums to locate this information. These informants noted that the Internet retains this information. They did not specifically mention web sites that provide this information, but rather:

> *'Well, you pick them [disability component information] up on the web site looking under searches for disability and seeing what it throws up' ([6]).*

The demand for this information relating to disability access components appears small. However, a need does exist, as highlighted by:

> *'About 2% of our calls relate to the issue "equipment" – that is, the person has a need for equipment or has some difficulties with their current equipment' ([5]).*

Funding policy

Funding policies concern any policy, money or resources set aside specifically for home modification purposes (Bridge & Martindale, 2002). This includes information relating to the management of contingency funds, funding guidelines or referral to organisations suitable for consumer application to finance the home modifications. Consumer peaks support their consumers to access home modification services according to need. However, the financial cost may affect the consumer's ability to implement the home modification. Information regarding funding options may facilitate opportunities for consumers to implement the home modifications.

All informants discussed the need for funding policy information including a few stating they did not require the information. The majority explored the need of both consumers and the organisations need. Those recognising an organisational need for the information stated the information would be useful for individual advocacy and in assisting other organisations to apply for additional funding. The individual advocacy role concerned consumer's ineligibility or exclusion from services:

> *'Again individual advocacy, the person has a problem and we find out that the reason they are not getting any HACC services, and then we let them know that's why you are not receiving the service. They [consumers] sometimes don't understand the reasons for why they aren't getting services'(8).*

A number of informants commented on consumer awareness of funding policies, specifically their awareness of HACC policies. Most informants commented that

consumers were not aware of funding options available to them although a few informants noted that most of their consumers were aware of their funding options. A few informants noted a slight need for the information. However, one informant discussed an increased need for this information attributed to social factors and increased living costs, as illustrated by the following excerpt.

> '[Consumers] have limited funds available, disability costs, you know the cost of living are quite high, to get the kind of support they need … any kind of funding packages out there are a help' ([5]).

The funding policies noted by informants included the Department of Veterans Affairs, Community Options Package, and Extended Aged Care at Home Packages. However, there was little unanimity between responses. This indicates the need for such funding policies is dependent on consumer type. The informant discussing Department of Veterans' Affairs funding policy believed these funding policies are 'antiquated' and require updating. The complexity of DVA's multiple schemes do not meet the needs of some consumers, in particular those who are blind or vision impaired. The following summarises the perceived limitations of DVA funding:

> 'DVA doesn't fund certain modifications like lighting for people who are vision impaired' ([9]).

Extended Aged Care at Home Packages, the Community Options Packages funding policies were not explored in detail. Some informants discussed their consumers' eligibility to HACC services. One informant noted that some HACC service providers do not receive adequate funding to ensure services meet the needs of their consumers. Others explored consumer knowledge of their eligibility to HACC services. Although many consumers are aware of the availability of HACC services, they still may not receive these services, demonstrated by the following:

> 'Most of them seem to [know about HACC services]. There are still large numbers of people of disabilities who still fail to get access to services despite the fact that they qualify' ([8]).

Overall, informants perceived a greater need for funding policy information relating to HACC services than other policies raised. One informant noted that the general public would not have an awareness of HACC demonstrated by:

> 'only recently up in Lismore where I was addressing a number of carers up there, and I was surprised that of the 20 odd families that were there, being represented there, there were 4 people who put up their hand who didn't know what HACC was' ([6]).

Few informants discussed how funding policy information was located. The following comment could indicate why they did not explore where they locate this information:

> 'There is no specific vehicle that accumulates that information [funding policy information]. It's more what you know and people share what knowledge they have' ([2]).

Some informants did note that Government agencies are a source for funding policy information. Typically, they referred to the Department of Ageing, Disability and Home Care, evidenced by:

> 'Quite often, particularly with DADHC, they will provide us with what's going on. We are in the loop there, where I get fast faxes or media releases of what is happening' ([6]).

Building and land regulation

Building and land regulation information refers to the principles, rules and laws that control construction practice and conduct (Bridge & Martindale, 2002). It generally relates to relevant codes governing building construction, e.g. the Building Code of Australia (BCA), Australian Standards and State Planning regulations. All legislation affecting consumers is within the consumer peaks domain of concern.

All informants spoke of the need for building and land regulation information. The majority commented on an organisational and consumer need for this information. Some specifically mentioned Australian Standards and the BCA. A small number of Informants discussed problems associated with the BCA. These informants state the BCA was not sufficiently stringent or enforceable. Comments regarding the level of understanding of the BCA varied.

Most informants commenting on the BCA noted a need to understand the 'basics' while other informants noted a need to understand the specifications. Some noted a need to understand that the codes do not apply to private dwellings, evidenced by the following quote:

> 'Knowing for instance that the Building Code of Australia has nothing what so ever to say about private dwelling' ([1]).

Although most informants perceived an organisational need for building and land regulation information, the need was small. A few informants claimed the organisation had an active role in this area while other informants noted the need for information when it was topical. When required, the organisations use this information to inform consumers, for systematic advocacy purposes, to lobby the Australian Building Codes Board and to advise the Building Codes Board.

A small number of informants specifically explored the need for information about Australian Standards. Primarily, these informants explored the problems with either Australian Standards or the difficulty obtaining current information. One informant noted that the mandatory Standards did not include visitability requirements and believed a regulatory change was required:

> 'I mean we don't have visitability in the Australian Standards…it's an area that we are looking for to see some regulatory change' ([8]).

A few informants stated there was no organisational need for building and land regulation information. Of these informants, most believed that other organisations covered this information as illustrated by the following statement.

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> *'I'm also aware that a number of organisations like People with disabilities, Australian Quadriplegic Association, who all have an active role in the implementation and changing of legislation'* ([10]).

Few informants discussed a consumer need for building and land regulation information. All these informants stated that consumers only require this information when problems arise, as the following excerpt summarises:

> *'But some consumers get involved only when they realise that what is going to be built doesn't suit their requirements. Some consumers know of the human right guidelines or the technical details concerned when building a building. Other people are not too concerned. Other people are far more informed and know all the details'* ([8]).

Informants discussed the information mediums they employ to locate building and land regulation information including consumer prior knowledge, legislation and other organisations. Specifically, some informants noted that consumers have this information. Essentially, consumers develop this knowledge through personal experience, seen by:

> *'In my personal experience, if I look at a bathroom, I can tell if it applies to the Australian Standards or not'* ([4]).

A few informants discussed locating building and land regulation information from legislation. They noted that Australian Standards and the BCA as appropriate sources. One explained that the BCA was particular useful for information about Braille signage and lighting requirements:

> *'I'm probably the only person in the organisation who sought the Building Codes specifications on Braille signage and lighting and that sort of thing and what it actually says about those aspects, and that's been it at this stage'* ([9]).

The majority of informants commenting on this topic area discussed locating this information through either Governments or Organisations. Informants mentioning Governments, specifically noting that the Human Rights and Equal Opportunity commission were useful in providing information on this area, highlighted by:

> *'Often we will be informed by the different government departments of the things they do. HREOC will always let us know if there are any changes involved'* ([8]).

One informant noted Local Government Authorities are useful for non-disability specific issues. Also, a few informants sourced industry bodies for this information. Specifically the Master Builders Association and the Royal Australian Institute of Architects were noted as useful for locating this information.

Natural environment

This area concerns nature and the natural environment surrounding the consumer's home (Bridge & Martindale, 2002). It concerns, terrain, weather and air quality. Peak consumer organisations need to understand how the natural environment affects their consumers' ability to participate in activities. The natural environment may pose

barriers preventing consumers form functioning independently. For instance, frost or snow may restrict community access for people with mobility impairment. Consumer peaks advocate for community participation for their members.

The majority of informants report consumers do not have a need for natural environment information, evidenced by:

> *'I assume we've always left that up to peoples commonsense'* (³)

and

> *'No, not directly to us. They [consumers] just don't come looking'* (²).

However, a few informants did note their consumers require this information, though no unanimity occurred between responses. The specific areas these informants reported include natural light, the impact of rain on ground surfaces, maintenance of the natural environment, and the wind. One informant discussed the needs of their consumers regarding natural lighting. Primarily they noted a need to understand lighting variance at different times of the day and between seasons.

They further noted that natural lighting affects the functional vision of their consumers. The following summarises these need for natural light:

> *'We need information about aspects of sunlight, daylight or natural light. That it is so variable: that it's seasonal [and] varies from the time of day to whether conditions to all sorts of things. That impacts on the visibility of someone who has poor vision'* (⁹).

One informant commented on the affect of wind hearing, balance and orientation. That is, wind reduced consumers' ability to use environmental cues effectively as illustrated in the following excerpt.

> *'[Wind] affects people's orientation when they are out in the environment. A very windy day can be very distracting and can cause, or lessen you r ability to pick up other aspects of the environment, whether it's, you know, your balance is affected or you hearing* (⁹).

Another informant briefly discussed the need to have some understanding of the impact of rain on ground surfaces. They stated that it was important to understand that some forms of concrete are more slippery than others. Furthermore, information on the most appropriate surfaces for ramps is important to reduce the risk of litigation, evidenced by:

> *'You know, you put in a nice new wooden ramp and you think that looks in keeping with the building and then discover that the first time it rains that nobody can get up it, 1 or 2 people fall down and one of those two people sues you arse off'* (¹).

One informant noted consumers require information about maintaining the natural environment.

Specifically, consumers required information about assistance available for mowing lawns, gardening and for removing branches as the following quote highlights:

> *'The main thing that comes up is people's decreasing ability to maintain their own yard – lawn mowing, gardening, removal of branches etc' ([5]).*

A small number of informants believed that the house included the surrounding natural environment. Hence, more attention should be given to outside the home. One informant stated that there was a need to understand that some forms of plant material impact on consumers' functional ability.

> *'There's a week that grows around Wagga, that has really long talons on it that punctures your [wheelchair] tyres, and if [the local] council doesn't keep the weed control down, then there's real problems ([1]).*

Because informants were not able to easily identify consumers' needs regarding natural environment information, it is not surprising that they could not state where they find this information. However, some informants postulated consumers could find this information on the Internet, and through Information services or other peak consumer organisations. The information services included Australian Quadriplegic Association, IDEAS, and Disability Information and Referral Centre, as the following summarises:

> *'[They would go] back to an information service. Which would again be AQA, IDEAS, DIRC. Those tend to be the three of them' ([8]).*

Built environment

This topic area concerned the state of human habitation and the basic soundness of the housing structure (Bridge & Martindale, 2002). Consumer's housing conditions affect their health and well-being (Wilkinson, 1999). Hermanson & Citaro (1999) identified consumers' perception of indicators of poor housing. The indicators included exposed wiring, cold housing, signs of vermin, cracks in walls, and incomplete plumbing. As housing conditions influence consumers' health and well-being, information relating to the built environment is relevant to consumer peaks.

Informants provided a large range of response for this category with little agreement between them. Informants highlighted several issues for consumers, maintenance of housing, cambered roads, reducing environmental noise and reverberation. House maintenance was an issue noted by a few informants, specifically preventative housing maintenance. However, they believed this role should be filled by building authorities.

> *'That's their [the building authorities] role – to make sure that the buildings are given appropriate treatments to minimise that [preventing mould, mildew and dry rot]' ([6]).*

Other informants noted a need for the Department of Housing to maintain their housing stock better. This was due to a need for maintenance to specific dwellings or because consumers were placed into inappropriate housing conditions, evidenced by:

> *'I mean a lot of people in Department of Housing contact us saying they are in inappropriate housing' ([5]).*

Organisations represented consumers to the Department of Housing to address the issue of inappropriate housing.

Some informants noted a need for information relating to environmental noise and reverberation reduction. This issue primarily concerned consumers with hearing impairment as the following comment demonstrates:

> 'Only what can be done to ameliorate environmental noise and reverberation … because most people who are hearing impaired … are mainly retired or on a pension and already in a house that can't be changed or it would be too expensive to change' ([7]).

Some informants commented on built environment issues beyond the house e.g. cambered roads and lack of paved paths of travel. These issues were often specific to the consumer group the organisation represented. It was also noted that some issues were more relevant to rural New South Wales as illustrated by:

> 'If you're living in country NSW the notion of pavement may not apply in the same way, and that, even somewhere as Dubbo, it's not a small town by any stretch of the imagination, but once you're off the main drags, quite a lot of the time people just don't know of pavements. I mean they just have nice grassy ground. It looks pretty but it may not work for most people' ([7]).

Another issue noted by a small number of informants related to consumer housing purchase. This area was not explored in detail. One informant noted consumers should conduct b ilding and housing inspections before purchase. Essentially, the informant believed this role was for consumers to follow up with the building authorities although the consumers may require information regarding which inspections were relevant. Other informants noted their organisation provided information on housing structure to consumers. For example, issues associated with grabrail installation on fibro walls.

Some informants stated the organisation did not require information on the built environment although consumers required this information. However, the informants believed the building industry and building authorities were responsible for this area, as the following indicates

> 'No again that [built environment information] wouldn't be an area that is our responsibility. I think that it is a very professionalised areas. Yeah, we'ld go to a builder' ([4]),

and,

> 'We don't have a role in that, yeah and that's more of a specific information service who would have roles in that' ([8]).

Informants noted consumers use a range of information mediums to locate built environment information. These include organisations, Governments, professionals and electronic mediums such as the Internet. The majority of informants commenting on this area note that organisations are a useful source of information. A few particularly note that information services and the Independent Living Centre are useful, as seen by:

> *'We'll probably ring the Independent Living Centre… that would be the main source of information about that I think'* ([9]).

Smaller numbers of informants noted using electronic mediums, Governments and professionals to find built environment information. One informant specifically noted that the Internet provides this information, while another stated the Department of Housing is a particular source within Governments. One informant noted they obtained built environment information from professionals, in particular builders, as the following comment highlights:

> *'Again that [built environment information] would not be an area that is our responsibility. I think that it is a very professionalised area. Yeah, we would go to a builder'* ([4]).

Other

Informants noted additional information needs they considered important but not covered within the previous topic areas. These two categories included rural and metropolitan living and the Home Modification & Maintenance Services.

Some informants noted the differences between rural and metropolitan living and the associated issues for consumers. These issues included the difference between the quality of information in these two areas. These informants claimed that consumers residing in metropolitan areas have access to better quality information than consumers living in rural areas of New South Wales.

The informants noted that consumers from these two areas have similar needs but different experiences. This is illustrated by:

> *'There is a great difference in the quality and the accessibility of information depending on where you live. Coffs Harbour, Lismore, Port Macquarie are generally pretty complete in their information but the further west you go … I don't know'* ([2]), and

> *'You'd have to say that the nature of everything that happens in NSW, the primary support will always come from the Sydney CBD area. That doesn't say that there's not the needs out there in the wider area – there are. But, our history shows that the support is really in and around Sydney'* ([6]).

The majority of informants also discussed consumers' information needs related to the Home Modification & Maintenance Service of New South Wales. Essentially, the informants noted differences between individual services and a need for the services to increase their awareness of persons with disabilities. Informants noted the differences between individual service providers such as their differing rules, evidenced by:

> *'Something which does come up a bit is the differences between different branches of a services, so home maintenance & modification in one area will have different ideas about how to operate than in another area'* ([5]).

Furthermore, one informant noted that some HMM services willingly provide information on request, however others do not. The informant believes this creates

frustration for consumers. Some comments related to the need for HMM services to refrain from making assumptions when conducting assessments in the person's home, that consumers issues should be addressed on an individual basis, and not to make assumptions based on a persons disability. The following comment summarises this:

> *'Often [HMM] service providers make assumptions about what a person doesn't need. Often they make the assessment in their [consumers] own home and they make assumptions that I'm going to tell you that "you need a grab rail here – not over there". Everyone is different and the body works different ways and the same disability affects different people in different ways'* ([4]).

Summary of findings

This research indicates that peak consumer organisations need home modification information relating to each of the topic areas, except for natural environment. Only a small number of consumer peaks required natural environment information. The critical element of each topic area is summarised below:

- Consumers, builders, architects and business owners need spatial requirement information. Most peak consumer organisations need spatial requirement information although some organisations already address this need.

- OH&S concerns of carers impact on service delivery to consumers. Consumers need this information when they fail to receive the appropriate services.

- Organisations need product requirement information, but do not need warranties, training or useability information about products. Consumers require information on handrails, signage, and insulation.

- Community inclusion information is essential to peak consumer organisations to support research, policy, systematic advocacy and to reduce barriers in consumers' experience. Some legislation facilitates organisations in performing these functions.

- Some peak consumer organisations require standards of care information. Primarily these organisations require information on Australian Standards, disability Support Standards and the Disability Services Act.

- Consumers require information on floor surfaces, signage and reducing environmental noise. A few organisations do not require this information as they refer consumers to other organisations.

- Peak consumer organisations require funding policy information for individual advocacy of consumers. Information regarding the BCA, Australian Standards and visitable housing is important to peak consumer organisations and consumers.

- Most peak consumer organisations do not require natural environment information.

- Peak consumer organisations have diverse needs regarding built environment information. Some organisations do not require this information as it is the responsibility of the building industry.

- Peak consumer organisations require information on the Home Modification & Maintenance Services of NSW and note differences between rural and metropolitan living.

In general, the information needs reflect the consumer groups' disability or situation and consequently reflects the consumer peak's information need. People working within the home modification field should be aware of differing needs and provide the relevant information accordingly.

The specific information required determines where consumer peaks locate information. Informants found information from a range of sources including:

- Electronically delivered material such as the internet

- Organisational resources, including networks

- Peak consumer organisations use Government, BCA, DDA and HMM services

- Other organisations such as Australian Quadriplegic Association and Paraquad

- Professional or specialists such as acoustic engineers, occupational therapists and manufacturers.

Peak consumer organisations have a significant role in relation to home modification because their charter is to represent and advocate for their consumer groups. Consumer peaks could share useful information with consumers, occupational therapists, policy makers and construction industry via a web-based facility such as the HMInfo project. A web-based facility could be an efficient and effective mode for locating home modification information.

This explorative research highlights the home modification information that consumer peaks believe is important. Further research could explore the particular areas identified within this paper that consumers indicated as important. Specifically, future research should focus on the components of information that consumers require. Overall, this research highlights the specific home modification information that consumers need and outlines how consumers currently locate this information.

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Appendix A: Sampling frame

	Consumer Type									
	Carers	**Intellectual impairment**	**Visual impairment**	**Physical impairment**	**Hearing impairment**	**Female**	**Head injury**	**Ethnic/ multicultural**	**HIV/AIDS Aged**	**Aged**
Organisation	Carers NSW	NSW council for Intellectual Disability	Blind Citizens Australia	Physical Disability Council of NSW	Deafness Council	Women with Disabilities Australia	Brain Injury Association of NSW	Multicultural Disability Advocacy Association	People living with HIV/AIDS NSW	Council on The Ageing NSW
	Carers' Taskforce Australia, Inc.	The Endeavour Foundation	Royal Blind society	Disability Council of NSW	ACROD (services)	Australian Women's Health Network	Head Injury Council of Australia	National Ethnic Disability Alliance	Aids Council of NSW	National Seniors Association
	Headway Victoria	Development al Disability Council of WA	ACROD (Services)	Disability support Pensioners Australia	Australian Deaf-Blind council	Country Women's Association of Australia	Headway Victoria	Ethnic Communities Council of NSW	Australina Federation of AIDS Organisations	Aged & Community Services Australia
	Parent Carer Resource Centre	S.T.A.R Inc.	Australian Deaf-Blind society	People with Disabilities	Deaf Society of NSW	Older women's Network	The Brain Foundation	The Migration Heritage Centre	Australian Red Blood Cross (AIDS campaign)	Australian Association of Gerontology
	QLD Carers Council Inc	DEAL Communication Centre	Christian Blind Missions International	DEAC Inc.	Royal Institute for Deaf & Blind Children	The group for Australian Women with Disabilities	Alcohol Related Brain Injury – Acquired Brain Injury Service (ARBIAS)	Centre for Ethnicity and Health	AIDS Trust of Australia	Australian Pensioners' & Superannuation Federation
	Benevolent Society of NSW	Down Syndrome Assoc. NSW	Glaucoma Australia Inc.	Australian Quadriplegic Association	Australian Association of the Deaf	Women's Centre for Health Matters	Brain Injury Rehabilitation & Development Service	Ethnic News digest	Country AIDS Network	ARPA Over 50s Association

Appendix B: Invitation to participate

Dear _____

The Ageing, Disability and Home Care Department of NSW and the University of Sydney would like to invite you to a discuss your information needs and priorities as a part of the preliminary work being undertaken to establish a Home Modification Information Clearing House.

Older people and people with disabilities and their carers are living in homes that are inappropriate for their needs. Not only is this a large problem today, it is also a problem that is increasing as the number of older households and households of people with mobility restrictions increase in NSW.

The collation of interview findings from a range of service providers, industry and consumer advocates will be used to inform the design and contents of an information clearing house. This collaborative, action based approach is, we believe, the best means to ensure that stakeholders' needs are appropriately identified and prioritised.

As a key stakeholder, you may wish to contribute. Consequently, we want to explore your perspectives on a number of issues concerning Home Modification and Maintenance information needs, policies and services. We can do this in person and anticipate that the interview will take no more than 60 minutes of your time. Following notification of your interest in this project, we will contact you to confirm your preferences, so that a visit or telephone interview can be arranged at a time most convenient to you. With your written consent, we will audiotape the interview so that you can later verify the key themes and priorities that emerge.

If you are interested in contributing to this important project, we would ask that you complete the attached forms, and reply in writing to Mr. Adam Cruickshank at the address given below. If you have any queries regarding the project, please do not hesitate to contact Mr. Adam Cruickshank or Ms Catherine Bridge (the Chief Project Investigators).

We look forward to your response and contribution to this exciting project.

Yours faithfully,

Adam Cruickshank
Co-Investigator.

For further information about the HMM information Clearinghouse project please contact Adam Cruickshank or Catherine Bridge (Chief Investigator) on (02) 9351 9376.
Email: HMinfo@fhs.usyd.edu.au
Faculty of Health Sciences:

The University of Sydney
Cumberland Campus
PO Box 170, Lidcombe, NSW, 1825

Any person with concerns or complaints about the conduct of a research study should contact the Manager for Ethics Administration on (02) 9351 4811

Appendix C: Subject information sheet

Semi-structured Interview Questions No specific questions will be used, instead you are invited to give your perspectives on key topics including the impact and significance of long to medium term service trends on:

Home Modification & Maintenance information availability within NSW

We are particularly interested in which of the following areas you believe is most significant and your rationale for thinking this. Please consider this in the context of current information availability across NSW, particularly considering geographical variance across urban, metropolitan, rural and remote regions of NSW.

For instance, how might you find out about or consider the following areas in terms of both assessment and intervention:

- Spatial requirements (i.e. walkers, wheelchairs, scooters, ambulance trolleys, canes, traymobiles etc.)

- Carer requirements (i.e. carer accommodations, occupational health and safety regulations etc.)

- Product requirements (i.e. policy and procedure manuals, independent living centre equipment data base, building supply catalogues etc)

- Requirements for community inclusion (translation into accessible formats, strategies and process etc.)

- Requirements for meeting standards of care (policy and procedure manuals, how to guidelines etc.)

- Disability access components (ramps, lifts, doors, floor treatments, sanitary facilities, thermostatic mixer valves etc.)

- Funding policy (assistance for purchasing or loan of equipment etc.)

- Building and Land Regulation (access standards, human rights and equal opportunity guidelines, building approval guidelines etc.)

- Natural environment (terrain, altitude, weather and air quality, light, sound etc) Built environment (structural stability, age, health etc.)

- Other

The data gathered from the 'stakeholder' interviews will provide a basis to consider the implications of web site design initiatives being undertaken as part of the establishment of a Home Modification and Maintenance Clearing House at the University of Sydney.

Appendix D: Ethical consent

CONSENT FORM

Please take as much time as you wish to consider participating in this study before you sign.

Feel free to contact the project investigator (details below) to ask any questions on aspects of this study that are not clear.

In no way should you feel obliged to participate in this study.

I _____ have read and understood the

Name (please print) 'Subject Information Statement' and letter inviting me to participate in the above research project, and have chosen to participate in the study. I am aware of what is involved in the study and understand that I may withdraw at anytime.

I agree/disagree to the interview being audiotaped (Please indicate your preference by crossing out the response that is not applicable).

I also understand that for the purposes of this study my identity will remain confidential.

My signature indicates that I have received a copy and agreed to this consent form.

_____   ___/___/____

(Signature of participant)   (Date)

_____   ___/___/____

(Signature of witness)   (Date)

This study is being conducted to meet the requirements of the degree Bachelor of Applied Science (Occupational Therapy) Hons under the supervision of Catherine Bridge ((02) 9351 9376) of the School of Occupation & Leisure Sciences.

For further information about the HMM information Clearinghouse project please contact Adam Cruickshank or Catherine Bridge (Chief Investigator) on (02) 9351 9376.
Email: HMinfo@fhs.usyd.edu.au
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Appendix E: Semi-structured interview guide

The following is the semi-structured interview guide employed for this research. Where the following appears: xxxxxxxxx, researchers inserted the name of the organisation. Guides or reminders appear through this interview guide. These guides are in Italics and only prompted the research of what to say.

➢ denote statements by the researcher to informants.

Q denotes questions asked by the researcher.

P denotes either prompt or probe for the researcher.

Introduction:

(Establish rapport)

➢ I would like to start by thanking you for responding so quickly to the letter to participate in this research. I'm sure your views and insights will assist me in better understanding your organisations home modification information needs.

Q: Did you receive the subject information sheet and the ethical consent forms I posted?

Q: Do you have any questions about the topic areas before we start?

Q: Does the xxxxxxxxx have its own web site?

Q: Does xxxxxxxxx use the Internet to find information? Is this the main method?

Q: What sort of information do you look to the Internet for?

Q: What would be the main sources of information xxxxxxxxx uses?

Q: How would you describe the mission/purpose of the organisation (xxxxxxxxx)? How does home modification information fit into this?

Q: Is xxxxxxxxx primarily a metropolitan organisation?

Q: Does the organisation include rural and remote members?

Q: What is the main method for your consumers to access information?

➢ I'm going to just talk you through (or prompt you), through the various topic areas. It is all in the context, if you like, of the sorts of information that would be helpful to you as a peak consumer organisation.

Topic Areas:

Spatial Requirements:

Definition: 'of, relating to, involving, or having the nature of spatial data as pertaining to the needs of consumers with disabilities'.

Examples: Anthropometrical data = human dimensions (height, reach, arm length), equipment & aids (wheel chairs, walkers, walking sticks) fitting into home environment.

Q: Is there a need (or a role) for xxxxxxxxx in providing or seeking spatial information to your consumers?

Q: How do you as an organisation find out information about spatial requirements?

P: Where do you find this information?

Carer Requirements:

Definition: Intended to signify an individual. Example: nurse, social worker, physician, family member, neighbour.

Q: Is there a role for xxxxxxxxx in providing or seeking information about carer requirements?

P: How does xxxxxxxxx find out information about carer requirements?

P: How do you provide information on carers to your members?

P: Are you aware of the types of things you may need to provide for a carer?

Examples: clean working areas, overnight carer = sleeping facilities.

Product Requirements:

Definition: Refers to such things as building products, or products that are brought and sold commercially.

Example: Walls, floors, doors, vanity.

Q: Is there a need (or a role) for xxxxxxxxx in providing product information to your consumers?

P: What are the sorts of product information your consumers typically seek (Nonslip tiles)?

P: How do you find out about these products?

P: How does xxxxxxxxx locate information about new products? – What sort of ways does xxxxxxxxx use to communicate this information to their members?

P: What about the warranties, training and the usability information of products.

P: What sort of demand might there be for these in terms of alternative formats?

Requirements for community inclusion:

Definition: Refers to the considering of needs of the consumers with special requirements as a part of something larger.

Example: Ageing in Place, Social Inclusion.

Q: In general, is there a need (or a role) for xxxxxxxxx to provide information, enabling your members to access services and information?

P: Are there any reports or documents produced or endorsed by xxxxxxxxx about community inclusion/ageing in place etc?

(NSW Industry Group on People Ageing With Disability)

P: Does xxxxxxxxx as an organisation need to know about such things as the DDA?

P: How are these sorts of information communicated to your members?

Q: How does xxxxxxxxx promote community inclusion?

P: Are resources produced by xxxxxxxxx in alternative formats?

P: Are you able to describe some of these alternative formats?

Requirements for meeting standards of care: Definition: Any established procedure (or minimum that might be expected).

Examples: Policy, Australian standards. Some organisations have members on councils or representative bodies.

Q: In general, is there a need (or a role) for xxxxxxxxx in advocating or providing information concerning quality or appropriate standards of care?

P: Does xxxxxxxxx recommend, support or endorse any guidelines, reports or policies about standards of care? **P:** Are you able to briefly describe these?

P: Does xxxxxxxxx have any representatives on committees, boards etc whom govern these standards eg. Australian Standards?

Q: How does xxxxxxxxx find out about relevant standards of care? (Eg. email, Government reports etc).

Disability access components:

Definition: Products fabricated for people with a disability.

Examples: Grab rails, Hand Held Showers, non-slip tiles, lift/hoist.

Q: Is there a need (or a role) for xxxxxxxxx in providing or seeking disability access component information?

Q: How do you as an organisation find out information about disability access components?

P: Where do you find this information?

P: How then is this information, generally portrayed to your members?

Funding policy:

Definition: All decisions, policy and sums of money or other resources set aside for a specific purpose (home modifications).

Examples: Legacy funding, DVA funding and HACC funding.

Q: Is there a need (or a role) for xxxxxxxxx in providing funding policy information?

Q: How does xxxxxxxxx (as an organisation) find out information about funding policies? OR

P: How does xxxxxxxxx locate information about sources of funding available?

P: Where do you typically find this information?

P: What sort of things or how does xxxxxxxxx inform their members of these things/findings? (Eg. newsletter, e-mail list).

Building and Land Regulations:

Definition: Any Code, sets of code governing action or procedure.

Example: Australian Standards, Planning Approvals, building applications, state planning regulations, the Building Code of Australia, human rights guidelines.

Q: Is there a need (or a role) for xxxxxxxxx in providing or seeking building and land regulation information?

Q: How does xxxxxxxxx as an organisation find out information about building and land regulations?

P: Where do you find this information?

Natural environment:

Definition: Relating to or concerning nature and the natural environment surrounding the home.

Example: Weather, Floods, Wind, sunlight, frost, snow.

Q: Is there a need (or a role) for xxxxxxxxx in providing or seeking natural environment information to your consumers?

Q: How does xxxxxxxxx (as an organisation) find out information about the natural environment?

P: Where does xxxxxxxxx locate this information?

Built environment:

Definition: The state of the human habitation or basic soundness of housing structure.
Examples: Location of the house, suburb, maintenance of house & structure (ie. Mould & mildew, dry rot, brick vs. veneer house). Placing a grab rail into a fibro wall.

Q: Is there a need (or a role) for xxxxxxxxx in providing built environment information to your consumers

Q: How does xxxxxxxxx (as an organisation) find out information about the built environment?

P: Where does xxxxxxxxx locate this information?

Other:

Definition:

Example: Rural and remote difference, OH&S requirements, Modification follow up and maintenance and electronic data.

Q: Is there anything else that you would like to say about information or information needs of:

    - Peak consumer organisations, or

    - Their consumers?

Q: Is there anything else that you would like to say that would be helpful for the future provision of information to:

    - Consumer organisations, or

    - Consumers?

Conclusion:

Q: I guess that the main things that you have said are… (list)…
(Checking validity of what the participant is saying).

Q: Your Organisation seems to be accessing most of the information through the following sources: (list). (Checking validity of what the participant is saying).

Q: Your consumers seem to only access…(list)…for information and seem to use …(list)… very little. Would you say that this is accurate? (Checking validity of what the participant is saying).

➢ Thank you very much for your time, it has been really helpful – your comments will go a long way in understanding the information needs of peak organisations and their consumers.

> ➤ I appreciate the time that you have taken to explain all this – I know how busy you must be. If there is anything that you would like to be included that you think of later – please feel free to e-mail or phone me with these.

> ➤ I will be in contact with you about the checking that the transcript and results are accurate.