Inclusion by design: A vision for choice, control and agency in Home Modifications

Modifying the Home – BUILDING INCLUSION PRACTICE

Home Modifications Australia National Conference
National Convention Centre, Canberra 28–29 April 2016
Will you include or exclude me in your design?

Why people experience the same place differently
Around 15% of the world's population, or estimated 1 billion people, live with disabilities. They are the world's largest minority.
Aging Populations

Source: Australian Bureau of Statistics 2004
http://www.travability.travel/papers/occasional_4.html
Accessibility has improved, and standards and legal instruments now mandate minimums for once-excluded communities, but poor and disadvantaged people remain in poorer quality environments.
Home Modification that is not aspirational
Design disconnect

Zeisel’s user-needs gap model

“The governing principle behind good approaches to risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same.”

(Independence, choice and risk: a guide to best practice in supported decision making – DH, May 2007.)
The Importance of the Person

- Starting point – the organisation or the individual?
- Traditional focus – needs, deficits and entitlements
- Future focus – abilities, assets, responsibilities and rights
- Choice and control
Housing is a life raft: Shelter is a primary need

Security

Esteem

Creativity

Acceptance

Beauty

Self-expression

Self-actualisation

Image source: http://mortgageorb.com/online/issues/SVM1404/images/PB_1_fmt.jpeg
Policy Level

- Eligibility for services and insurance reimbursement

Community Level: Neighborhood

- Availability of home health care providers

Family Level: Social Resources

- Potential disruption of family relations, needs of other family members

Individual Level: Cultural Expectation

- Home care challenge: decision required on level of disruption of home routines and environment acceptable to meet challenge

Linkage between providers: quality of home technology and service providers

- Neighborhood resources to support medical technology in homes: safety, reliable services; physical environment of home

- Family consensus, supportive division of labor; appropriate information gathering

- Expansive definition of "home," strong filial obligation; traditions of home care

Reputation of providers: confidence in providers; waiting time

- Consistent relationship with service providers

Willingness to include home health care status as "family," reasonable division of labor with home care providers; modification of home

Choice to adapt home for high-tech medical care

http://www.nap.edu/read/12927/chapter/14#249
# Dual Role of Home Modifications

## Societal Role
- Increasing proportion of accessible housing
- Reducing collective care burden
- Offsetting institutional care

## Individual
- Increasing utility and health related quality of life by:
  - improving safety/confidence
  - improving mobility
  - improving independence
  - increasing community participation
7 barriers to home modification:

- Financial problems
- Lack of social support
- Tenure
- Denial
- Concerns about desirability or aesthetics
- Concerns about stigma
- Lack of knowledge

Graphics source: http://www.homemods.info
5 C’s

Change in Quality of Life following home modification

AQoL scores by Age Bracket

- Australian Population Norm*
- Mean HACC Client Utility Score AFTER Home Modifications
- Mean HACC Client Utility Score BEFORE Home Modifications


Source: Carnemolla, 2015
Themes identified as home modification effects in NSW Study

Sample of 157 HACC Home Modification recipients

Source: Carnemolla, 2015
Results of Systematic Review of Home Modification Impacts

Source: Carnemolla & Bridge, 2014
"A home modification project that is undertaken by a person with a disability themselves or with the assistance of family members or friends" (Bleasdale, McNamara, Zmudzki & Bridge, 2014)

92% of respondents (33) agreed with the definition. Some additional qualifiers to the proposed definition were suggested, including:

- “work done or designed by the end user not a professional” (C13), “necessary work to make safe ability for an elderly person” (C31), and simply “do it yourself work” (C12).

The three respondents that disagreed with the proposed definition suggested:

- “…under instruction of PWD” (C15) and (C20); and
- “… People may design a DIY modification and have it carried out by tradespeople, handymen, etc.” (C21)
Framing the issues in DIY home modifications

- Economic analysis - increasing segment of DIY market
- Results of consumer and industry surveys and interviews: Main findings
- Introduction to discussion method and key discussion questions
Home modification providers

<table>
<thead>
<tr>
<th>NDIS / HACC / DVA</th>
<th>Retailers</th>
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<tbody>
<tr>
<td>No DIY</td>
<td>DIY?</td>
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DIY product costs by category

<table>
<thead>
<tr>
<th>Home mod group (1 – 3)</th>
<th>Product cost</th>
<th>Informal care</th>
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</thead>
<tbody>
<tr>
<td>Grab rails</td>
<td></td>
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<tr>
<td>Ramps</td>
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<tr>
<td>Hand showers</td>
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<tr>
<td>Level access shower</td>
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<tr>
<td>Stair/step railing</td>
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DIY Project Deliverable

- Informed product choice
  - Most suitable product
  - Alternative options?
  - Cost (over life of modification)
  - Safest
  - Other product advice

DIY Home Modification decision

Motives / incentives
Planning and design
Levels of assistance / DIY Experience
Government / agencies
Individuals

Outcomes
- Better informed choice
- Increased number of DIY Home modifications
- Increased safety (Reduced risk of falls)
- Avoided or Delayed transition to residential aged care accommodation
- Increased quality of life

Cost Effectiveness Modelling
Cost effectiveness evaluation
Cost effectiveness scenarios

DIY Survey

Retail sales data

UNSW Australia
Types of DIY home modifications that were undertaken by respondents

- Grabrail/s
- Hand-held shower/s
- Level access shower recess
- Ramp/s
- Hand railing/s for stairs or steps
- Other

Number of respondents

Types of DIY home modifications
Overview of Preliminary Qualitative Findings

Key stakeholder interviewees (n = 12)

Why do people choose to do DIY home modifications?

- Aesthetics
- Availability/Ease
- Confidence
- Control
- Cost
- Expertise
- Independence
- Knowledge
- Time
- Trust
- Sustainability

Source: Chris Nicholls, SCIA, 2009
Choice and control, confidence in personal ability

◆ DIY “gave my dad a feeling of control and satisfaction” (C16)
◆ “Choice of products used and control of how/where installation took place” (C32)
◆ “We had total control of the project with the builder of our choice. Works completed to a high standard to complement the home” (C28)
◆ “It was good to be confident of the quality of the work as we had experienced poor quality home modifications done "professionally" … previously” (C26)
Time constraints and control over project

◆ “Could do it in my own time and make it specific to personal needs” (C14)
◆ “Control over the timeframe, builder, materials and design.” (C6)
◆ “Able to do it quickly at lower cost than engaging trades persons” (C34)
◆ “Was good to have my family assist with the planning. To have it done by the organisation that arranged the OT would have been too expensive” (C27)
◆ “Designing to suit your own need and budget.” (C21)
◆ “Cost saving, home owner had more control, faster” (C22)
Economic

- Retail data indicates DIY home modification market similar scale in costs to NSW operated HACC home modification programs.
- Established trend in growth across product groups from 2011 – 2013
- Cost effective given moderate reductions in risk of falling potentially offset significant healthcare costs and early transition to residential aged care.
- Cost effectiveness driven by relative costs and benefits over the program timeframe
Total DIY Sales by Product Group
2011 to 2013

Year

2011 2012 2013

Millions $}

Ramp
other
Handrail
Grabrail
Hand-held shower

UNSW Australia
Cost effectiveness

- Primary cost of modifications not funded by government programs, yet results deliver substantial societal benefit and possible offsets to government funded services.
- Base case 10% reduction in falls shows average estimated reduction in cost of $2,508 and estimated increase 0.03 quality of life years.
- Modelling shows annual cost offset to health and aged care services is estimated at $3.75 million for NSW.
- Retail data indicate potentially 3-4 times this quantity of modifications indicating a net saving above 10 million and potentially as high as 15 million per annum.
- At the base rate scenario, a DIY home modification government investment of up to $2000 would remain cost effective.
DIY home modification cost effectiveness

DIY Home Modification
Cost Effectiveness Scenarios
Over estimated 10 year timeframe

Estimated cost of falls over 10 years

$0
$10,000
$20,000
$30,000
$40,000
$50,000
$60,000
$70,000

Base fall rate 25.6%
1%
2%
5%
Basecase 10%
20%
30%
40%
50%

Estimated quality adjusted life years

8.70
8.75
8.80
8.85
8.90
8.95

Percentage reduction in fall rate for 65 to 75 age group

Cost
Effectiveness

UNSW Australia
What kind of advice?

Advising on products, possible approaches and solutions, and standards were mentioned as the types of advice given:

- Safety aspects, expected difficulties, AS1428 hand outs
- We have customers ask for advice on regular basis about shower rails and outdoor/indoor ramps
- I talk to shoppers who are wanting to know how to do these and be able to do it them self.
- Have advised about hand rails for stairs/steps. Non slip tread for ext stairs.
- How to use a product
- Right equipment to use
- Possible solutions that our equipment can provide
- Going through products with them/refer them to a professional eg. Electrician
What is good about doing home mods DIY

There were multiple reasons mentioned but general themes were:

- Saves money
- Saves time in planning, arranging and installation.
- Have the work done to a standard that people want
- More control over the process.
- Designed to specifications and needs
- Option if not eligible for funding
- Aesthetics: house appears “normal” rather than “hospital” style
- Pride and satisfaction in doing the work
- Sense of ownership
- More choice
What is bad about doing home mods DIY?

Multiple reasons were given but some general themes were:

- Lack of financial assistance
- Temporary inconvenience
- Difficulty in communicating to others what was needed and why it would need to be done in a way that is different to standard practice for non-disabled
- Finding tradesmen who were able to adapt their practice from standard procedures to modifications that suit the consumer’s needs
- Finding appropriate products
- Time and anxiety
Evidence-based design

Global Impact

Total Website Registrations: 1671
Total Content Downloads: 59230
Total Content Reads: 873887
Newsletters: 27
Newsletter Downloads: 3169
Number of registered individual OTs (listserv): 603

A Wide Range of Sector Support Activities

Key Publications Most Frequently Downloaded

299,233
Home Modifications options

1. VERTICAL LIFT
2. RAMP
3. LANDSCAPE MODIFICATION
Designed to raise living standards
The ‘Whole of Life: Whole of Use’ competition was initiated by the National Affordable Housing Consortium (NAHC) last year and involved teams from four universities. The UNSW team won the low and medium density housing categories.