Transdisciplinary Perspectives on Home, Health & Disability along the Process of Ageing

Susanne Iwarsson
PhD, DHC, professor

Department of Health Sciences & Centre for Ageing and Supportive Environments
Lund University, Sweden
Vision

Supportive Environments for Ageing

creating societal change enhancing healthy ageing
in Sweden - and Europe
Interdisciplinary Research

- (Environmental) Gerontology
- Health Sciences (OT, PT, nursing, public health)
- Clinical Sciences (geriatrics, neurology, rehabilitation medicine)
- Social and Behavioral Sciences (psychology, sociology, social work)
- Engineering (public transport, design science, computer science)
Interdisciplinarity:
• The blending and integration of different academic disciplines (Thompson Klein, 2010)

Transdisciplinarity:
• A fusion of academic interdisciplinary knowledge with the knowledge of lay-people
• Creating a new hybrid extending beyond what would otherwise be possible
  (Lawrence, 2004)
Senior citizen (NGO outside Sweden): “For the researchers, user involvement, knowledge translation and research impact are intellectual issues, but for older people these are emotional experiences.”

Senior citizens: “Scientific jargon is a problem, both spoken and written. There is a risk putting older people off.”

Politician: “I think that the statement that users must be able to represent more than themselves is unrealistic. Can that really be expected from, for example, frail older people?”
Transdisciplinary Research Requires Adaptive Capacity...
...of older adults
...of professionals, public agencies, industry, politicians, media
...of researchers
...of society overall
Research Themes 2007-2016

Healthy Ageing, specifically:

• Ageing & Housing
• Ageing & Public Environments
• Ageing & Disability
Ecological Model of Ageing and the Docility Hypothesis

Lawton & Nahemow, 1973
Still, After All These Years…

Many stellar studies on ageing and health, in Sweden and worldwide, but person-environment-balanced datasets are scarce:

• Few longitudinal studies
• Paucity of research with larger samples
• Paucity of cross-national research
• Limitied comparability
• Lack of systematically accumulated knowledge
The ENABLE-AGE Project
Enabling Autonomy, Participation, and Well-Being in Old Age:
The Home Environment as a Determinant for Healthy Ageing
Main Aim

To examine, from a European perspective, the home environment as a determinant for "Healthy Ageing"

Recommendations for evidence-based housing solutions across Europe

- In very old age
- In private households
- Living alone

"Healthy Ageing" (autonomy, well-being, participation)

Home Environment (objective, perceived)

Risks and potentials
Mixed-methods Approach

- ENABLE-AGE Survey Study, N= 1,918
- ENABLE-AGE In-depth Study, N= 189
- ENABLE-AGE Update Review, five countries
- 1,600 variables (survey database)
- Interview audio tapes/transcripts in six languages
- Uniquely detailed in data on environmental aspects
Home, Health and Disability along the Process of Ageing

Very old people (ENABLE-AGE):

- Six-year follow-up in Sweden, Germany
- Nine-year follow-up in Sweden, Germany, Latvia (N=56-71)
- Continuous follow-up of mortality (now 15 years) in Sweden
Additional Substudies

- **People aged 67-70 years**, N=371 (in collaboration with SNAC-GÅS)
- **People ageing with Parkinson’s disease**, N=255, 3-year follow-up 2016 (in collaboration with CLASP), N=155
- **People ageing with spinal cord injury**, N=123

60+ original publications
Nine completed PhD theses; five ongoing
Aspects of Housing

**Objective** (professionally assessed/observed)
- Housing standard
- Physical environmental barriers
- Accessibility

**Perceived** (subjective, self-rated)
- Housing Satisfaction
- Usability in My Home, UIMH
- Meaning of Home, MOH
- Housing Control, HCQ
P-E Fit (accessibility)

Relation of the person’s functional capacity and the demands from the environment

Comprises
a) a personal component
b) an environmental component
- based on national standards & guidelines for housing design

Objective, professional on-site assessment (interview, observation)
Housing Enabler Methodology

- **Research-based instrument for assessing and analysing accessibility problems in housing**
  - Rests on 20+ years of research and application (Iwarsson & Slaug)
  - Established in close cooperation with actors in the health care and housing provision sectors
  - Based on national standards and guidelines
  - Several national version, e.g., U.S. (Lien et al.)
Some Results…

- Very old people with good housing accessibility and usability at home have a better sense of well-being and less depressive symptoms.
- Good housing accessibility is associated with more independence in daily life.
- Among people aged 67-70, perceived aspects of home are related to symptoms, depression, and psychological well-being.
Housing Accessibility Problems

- Functional limitations X environmental barriers generate the problems
- Use of a rollator and balance problems contribute the most to accessibility problems
- Lack of handrails at entrances are related to mortality
- Ageing with Parkinson’s, environmental barriers at entrances and outdoors generate more problems than for people in general
Why Do Older People Move?

• "Younger old" move to something - "older old" move from something

• Living in a one-family house, percieving oneself as functionally independent but in need of cleaning services = move to another ordinary dwelling

• Having cognitive limitations, being in need of help for cooking and living in a dwelling with accessibility problems = move to assisted living facility
Over time, very old people manage increased frailty by means of intertwined processes concerning changes in everyday life:

- **The turning-points**
- **The struggle**
- **The negotiations**

These processes take place

- in the context of
  - “the homelike functional home”
- with an “awareness of frailty”
  - state of mind
Conclusions (examples)

Home, health and disability along the process of ageing studies require attention to objective as well as perceived aspects of housing.

Accessibility (P-E fit) is related to aspects of health, while environmental barriers (as such) are not.

Objective and perceived aspects of housing interact in complex ways and are related to health, with similarities and differences across sub-groups of the ageing population.

Results are surprisingly consistent across different national contexts.
Scientific and Popular Knowledge Synthesis

Iwarsson et al., Journal of Housing for the Elderly, 2016
Making use of existing databases, the objectives were:

- To examine environmental barriers and accessibility problems in different types of buildings and building periods
- To display the severity of housing accessibility problems for senior citizens with different functional limitation profiles

We always publish original papers as well, see Granbom et al., 2016; Pettersson et al., 2017
Functional Profiles

1. Limitations in mobility only
2. Limitations in mobility + upper extremity limitations
3. Limitations in mobility + upper extremity limitations + dependence on mobility devices
4. Limitations in mobility + upper extremity limitations + dependence on mobility devices + visual impairment

Ageing, injuries, diseases...increasing complexity as years go by...
Accessibility Problems According to Functional Profile, Type of Dwelling and Building Period

Dwellings built before, during and after the 1960-1970-ies program of massive multi-dwelling block construction in Sweden
Message to Policymakers

• Despite high housing standard in Sweden there are substantial accessibility problems for senior citizens with functional limitations
• Tendency of fewer environmental barriers in newer dwellings – but progress is slow
• Knowledge from individual housing adaptations useful for public health efforts targeting housing
• Research with potential to inform political decisions and housing provision practices

Large-scale and systematic efforts are required to improve housing accessibility for senior citizens!
User Empowerment Studies Ongoing...

innovAge
SOCIAL INNOVATIONS PROMOTING ACTIVE AND HEALTHY AGEING
UserAge Program

A 6-year inter- and transdisciplinary research program

• Four universities
• International collaboration
• Coordinated by CASE
Ultimate Goals

- Maximize the impact of user participation
- Enhance the execution of high quality research
- Increase the knowledge about what difference user participation can make
- Evaluate the extent to which research about and with user participation makes an impact on practices and outcomes

<table>
<thead>
<tr>
<th>Levels of participation</th>
<th>Characteristics</th>
<th>The users will</th>
<th>Examples of methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>One-way communication Q &amp; Answers</td>
<td>Know</td>
<td>Newspaper Web, Public meeting</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Printed matter</td>
</tr>
<tr>
<td>Consultation</td>
<td>Seek input Often at one point</td>
<td>Express their opinion</td>
<td>Survey, Focus group, Walk-along</td>
</tr>
<tr>
<td>Dialogue</td>
<td>Exchange of ideas Often several occasions</td>
<td>Reason</td>
<td>Research circle, Dialogue seminar</td>
</tr>
<tr>
<td>Cooperation</td>
<td>Activities are planned and implemented</td>
<td>Implement</td>
<td>Work group, Future workshop</td>
</tr>
<tr>
<td>Codecision</td>
<td>Joint decision making</td>
<td>Decide</td>
<td>Counsel</td>
</tr>
</tbody>
</table>

Based on: Lindholm & Moritz (2007)
Thanks to...

- European Commission
- Forte
- Lund University
- Ribbingska Foundation in Lund
- Swedish Research Council
- Swedish Institute
- King Gustaf V & Queen Victoria’s Freemanson’s Foundation
- ScanBalt Bridge Award
- Norrbacka-Eugenia Foundation

...and many co-workers