

NORDIC INNOVATION

*Independent living of the frail  
elderly and disabled*

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*Background material for the  
competition - toolbox and a  
framework for innovators*



## **Aim - solving the multiplicity of different everyday needs regarding independent living of the frail elderly and disabled**

- Organizing of the independent living for the frail elderly and disabled is a complicated challenge that all Nordic capitals are currently facing. The challenge is constantly growing and becoming more complex.
- Finding solutions for different aspects of the challenge is crucial for the future of Nordic welfare societies.
- Nordic Innovation and the Nordic capitals recognize the need to engage actors from all fronts of society in solving this challenge and they are organizing a challenge prize competition for gathering the most innovative ideas across the Nordics.
- This package serves as a framework and an inspirational tool box for the competition - to help participants grasp the multiple challenges on the grassroot level and to create solutions for relevant everyday needs.

# METHODS FOR UNDERSTANDING THE NEEDS OF THE FRAIL ELDERLY AND DISABLED

## Damvad's report



### Mapping the common findings

Policy consultancy Damvad built a report on the issue from the municipalities strategic point of view. As a part of our work we identified the key commonalities of their findings and our findings from the user point of view.

## Desktop research



### Framing the empirical research

We went through multiple existing reports and prominent academical literature on issues regarding ageing and living with disabilities in the Nordic countries and around the world.

## Ethnographic interviews



### Building deep contextual understanding

We conducted ethnographic interviews in people's homes and their other everyday environments to understand their needs, challenges and aspirations in the real context.

## Group discussions



### Understanding the discourse of the experiences

We moderated group discussions for the frail elderly, disabled and care workers in all Nordic capitals. This served in understanding how people share and formulate the challenges together.

## Expert interviews



### Engaging the expert point of views

We conducted expert interviews with professors, activists and representatives of organisations among the field of ageing and different kinds of disabilities.

# USERS OF SERVICES AND PEOPLE WHO PROVIDE CARE TO SUPPORT INDEPENDENT LIVING



## 25 ETHNOGRAPHIC INTERVIEWS

Copenhagen	Helsinki	Oslo	Reykjavik	Stockholm
Rigmor	Sylvi	Erna	Jóhanna	Ruth
Bjarne	Aili	Ulf	Þórður	Eeva
Johanne	Ritva	Sverre	Sigfús	Gunn
Oliver	Ritva	Rigmor	Hallgrímur	Sigge
	Liisa	Björg	Rúnar	Victor
	Anni			

## FIVE EXPERT INTERVIEWS

**Freyja Haraldsdóttir**, human rights activist who has been active in the development of the personal assistance system for disabled people in Iceland.

**Margrét Margeirsdóttir**, Social worker and entrepreneur who has been a leading influence on social and welfare issues in Iceland.

**Tuomas Tuure**, Kynnys ry. Organization for the basic and human rights of people with different kind of disabilities.

**Petri Helander**, Lyhty ry. Organization that arranges housing, workshops, events and other activities for the people with intellectual disabilities.

**Antti Karisto**, Professor of Social Gerontology from the University of Helsinki. Has run social scientific studies on many aspects of old age.

# METHODS FOR PACKAGING THE NEEDS OF THE FRAIL ELDERLY AND DISABLED

## Analysis sessions



### Recognizing patterns in the data

Gathering the vast amount of data and mapping it out in the analysis serves as a way of finding commonalities between particular interviews and seeing common phenomenon behind the individual experiences.

## General framework



### Combining information to frame ideas

Challenges shared between the very heterogenous groups of frail elderly and disabled in Nordic capitals serve in building a framework for understanding what independent living is about. Connecting similar key findings from the Damvad report of the municipalities viewpoint and user challenges gives a checklist of shared key challenges to dig deeper into.

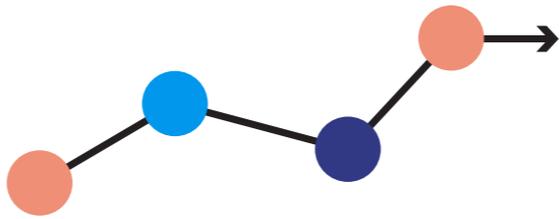
## Thematic profiles



### Stories that crystallise the needs in inspiring ways

Ideal types based on the analysis describe a specific theme through a fictional person. Narratives help innovators change perspective and look at things from the viewpoint of the elderly, disabled and care workers.

## Design drivers



### Drivers that give direction on how to provide value for the people

Drivers give general guidelines on how to go about solving the needs of each profile. They serve a checklist on what to keep in mind.

## Documentary clips



### Video brings the stories behind the profiles alive

Videos support the profiles by giving a glimpse to the data in the form of stories people have told in the interviews.

*General framework:*  
*How to interpret the results*



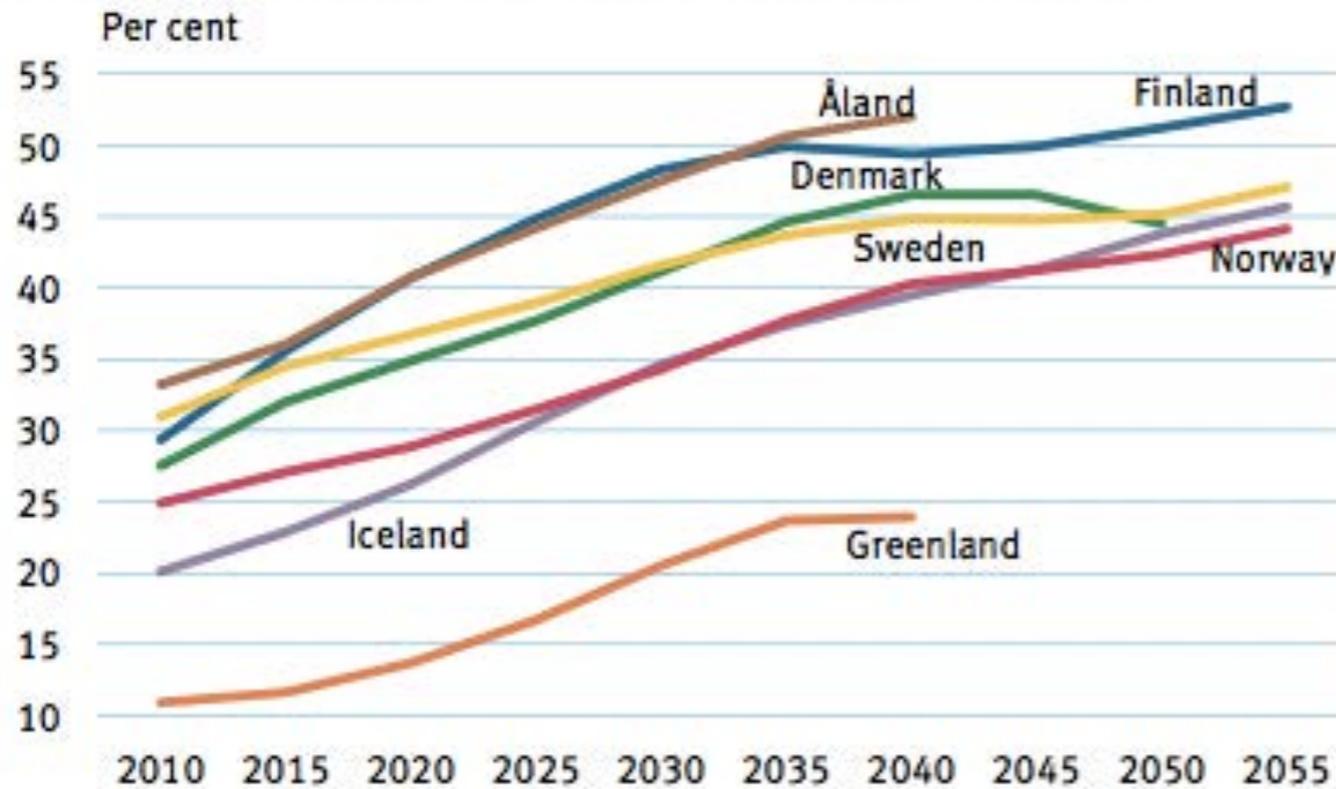
*Amount and variety of the need  
for care are on the rise*



# The overall need for care of the elderly and disabled is drastically rising in the Nordic countries

65+ year olds as per cent of population aged 20–64 Figure 3.1

Åldersgruppen 65+ år i procent av åldersgruppen 20–64 år



The population is ageing fast and life expectancies are getting longer.

Western lifestyle diseases are getting more common.

Issues with memory and cognition become a part of the everyday life for many.

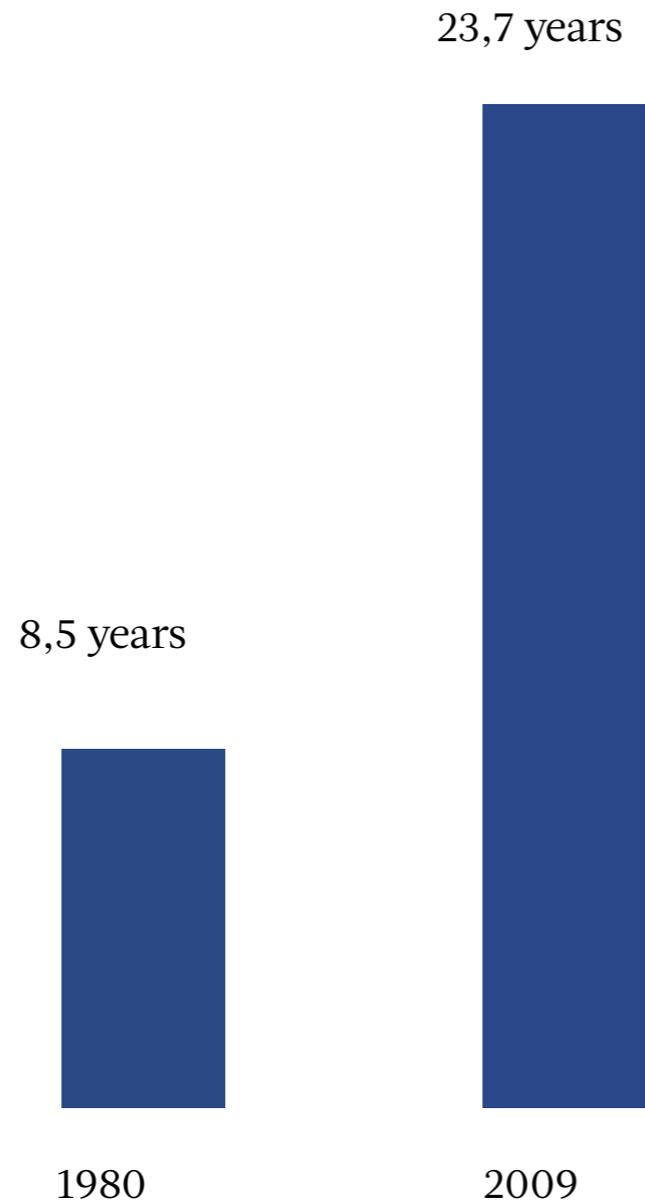
Source: National statistical institutes and Eurostat.

Note: EU27: The 27 member states of the European Union as per 1 January 2013. Not:

EU27: De 27 medlemsstaterna av Europeiska unionen per 1 januari 2013.

From: Nordic Statistical Yearbook 2013

# Variety of the different needs regarding the care of the elderly and disabled is also rising at the same time



**The elderly become a more diverse group with a wider age spread.**

**Variety of disabled people have a spread of different needs regarding care to support independency.**

**Medical science develops new diagnostics and new forms of care.**

**Years Finnish women spend on retirement on average.**  
Similar change concerns both genders in all Nordic countries.  
Source: ETK, Finnish Centre for Pensions.



# The variety of different life situations with different kinds of needs is easily overlooked

## Different kinds of disabilities cause concrete challenges in different ways

*"Disabled people have very different needs. Accessibility means different things for someone who is blind and for someone who uses an electric wheelchair."*

-Tuomas Tuure, Kynnys Ry.



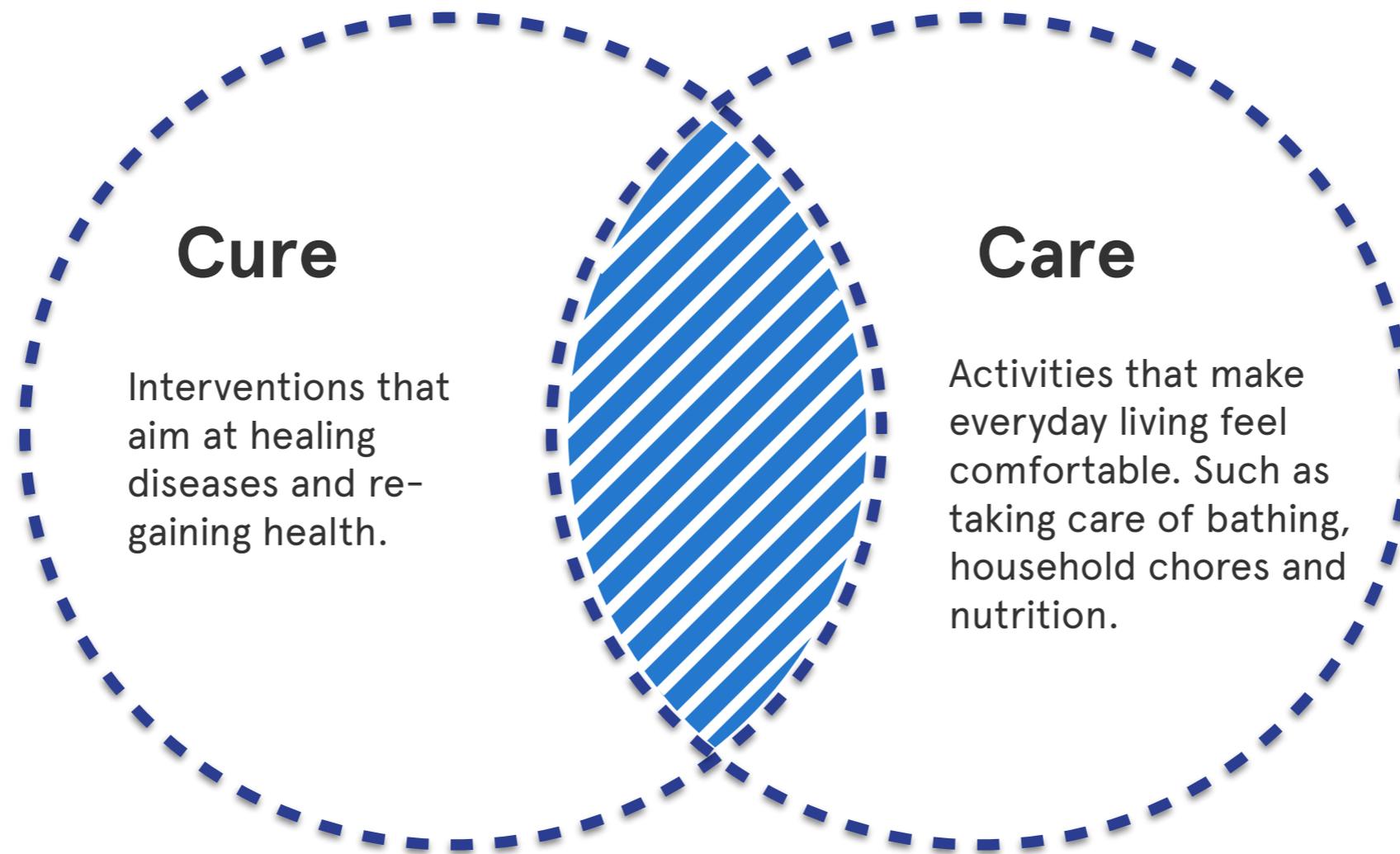
## We often forget the wide scope of different life situations within the life stage of elderly

*"The idea of the independency of the frail elderly is very important. The discussion is often only about the active 3rd agers or the ones who are very sick and old, living in institutions."*

-Antti Karisto, professor of Social Gerontology



# Care consists of a variety of different practices by different actors - it's not just about healthcare



Based on Mol 2009

*Independence consists of many different aspects - it's more than having your own home*



# Independency is not just about having your own home

## Living independently means that your life is not institutionalized

People are afraid of having to move into institutions because institutions *diminish our freedom*. They may also hurt our identities by making us obey habits set by the rules of the institutions. This losing of freedom is not restricted to physical places. It's an experience of being under the mercy of the bureaucracy.

## It means you have capabilities to live in a meaningful way

Having a space that you feel is your own is a part of independency, but it's equally important that you have capabilities to make use of that space and also be able to leave that space. *Meaningful living includes activities one can enjoy and social connections one can keep up*. These are the important capabilities that should be supported to enhance the independency. *Independency without any meaningful social activities is just loneliness*.

# When independency works you become a *subject* instead of being an object of care

## **It means that you have control over your own life**

In order to feel that the way you spend your time is meaningful, it is necessary that you have some form of control over it. *In ideal cases the care, services and aid tools people receive actually support them in keeping up and gaining control over their own lives, homes and activities.* Having control is also a way to take care of your own everyday life as much as possible.

*"It's a mindset, a strong experience. You can actually become institutionalised in your own home if you don't have any control and some people you don't know just come to your home in hours you can't decide and just do things to you."*

–Runar, Reykjavik

Doing gardening work or keeping your home clean and tidy is a form of control over one's own life.

## People who need care wish to live as independently as possible

### Elderly people wish to live in their own homes as long as possible

Practically all elderly wish that they could live in the familiar environment they have themselves created over time. Home is a place where you know how things work and can easily navigate. It is a place where you feel you belong.

*“They are pushing me to leave, but this is the place where I will stay for the rest of my life.”*

-Elderly respondent, whose pension benefits are cut since she owns an expensive apartment even though she doesn't have much money.

### Disabled people who live in service apartments or institutions wish to gain freedom by leaving

People who have challenges regarding mobility mention that it is really important to find ways to get outside of home. It is a way to remain active and also to challenge the environment to become more accessible.

*“Sometimes I just leave without asking. If I know I wouldn't get a permission it is better to just go. I may get lost and people may become worried, but I still do it to feel the freedom.”*

-Respondent living in service housing, who is supposed to have someone with her when she goes out.

# Meaningful independent life has routines and rhythm

## Framework of routines gives structure in life

People who are satisfied with their lives visit places and meet people within some recurring timetable. These can be hobbies, volunteer work or any other planned routines.

## Structured routines allow you to have uplifting experiences

Having a set of daily and weekly routines also allows you to plan and experience uplifting moments in life. These can be simple such as a festive lunch once a month in the local service centre or a trip to the theatre.

2014  
Plano

# Good tools and services empower people to do things by themselves, but help is also needed

**Empowerment is considered a good goal**

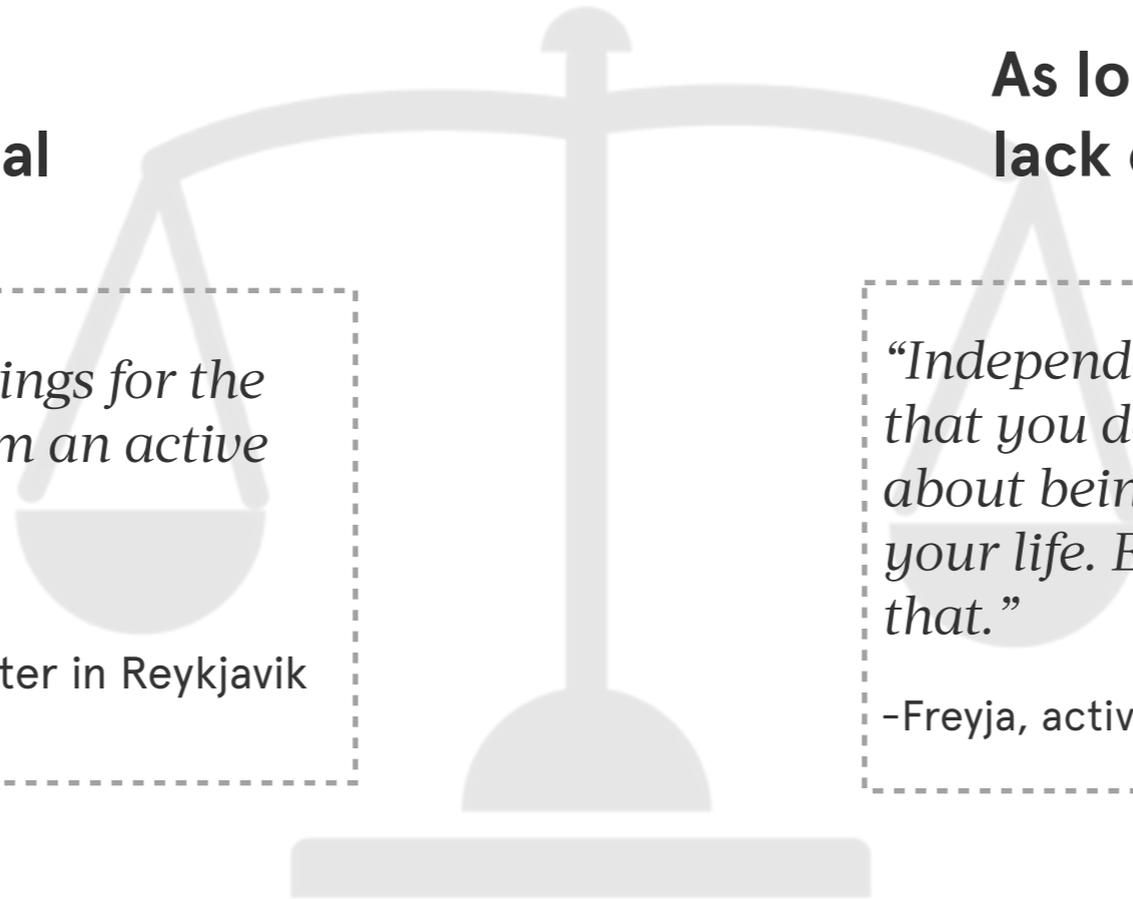
*“If possible we don’t do things for the people, but try to give them an active role by providing tools for empowerment.”*

-Worker at elderly service center in Reykjavik

**As long as it doesn’t mean a lack of help when needed**

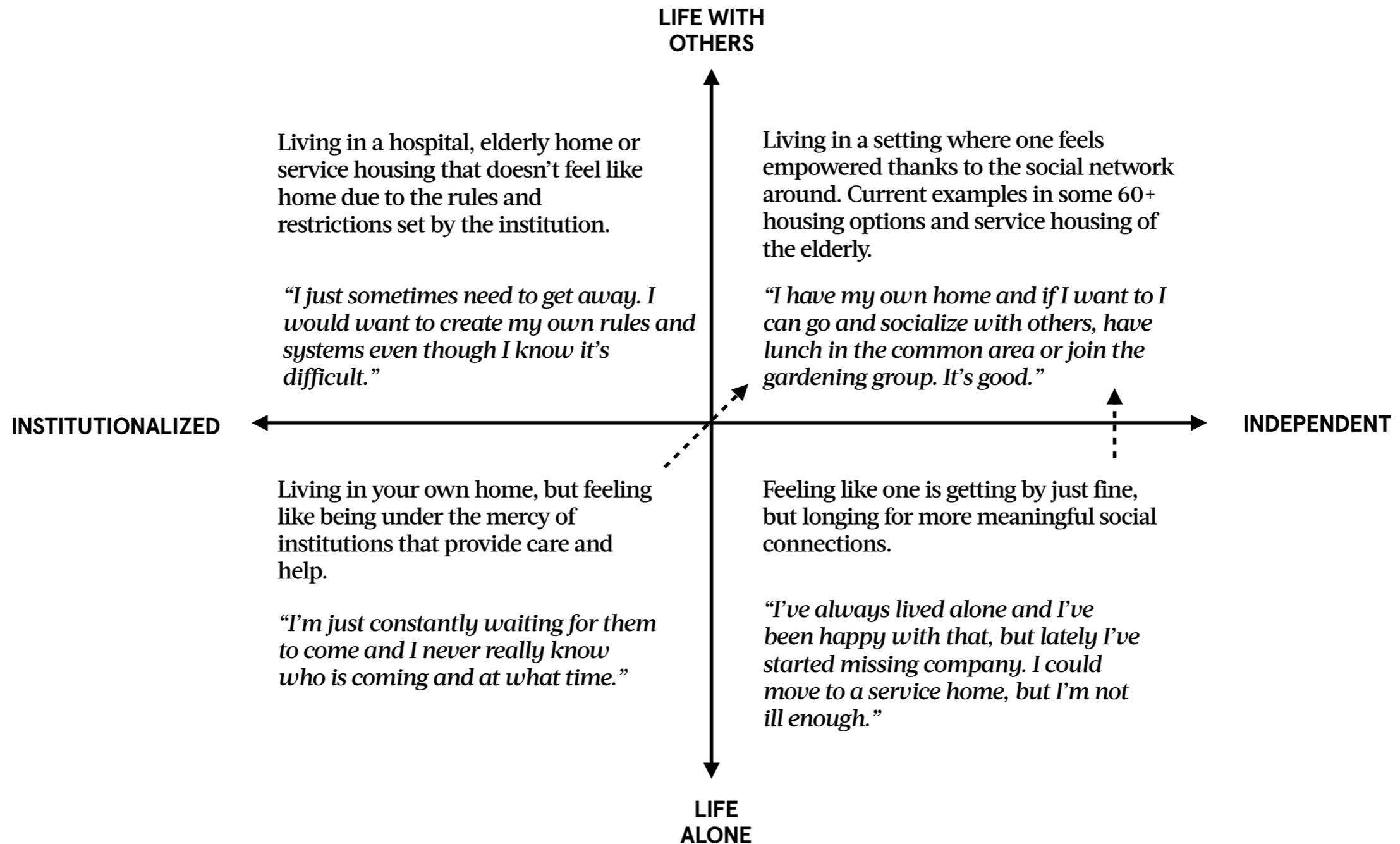
*“Independency doesn’t have to mean that you do everything yourself. It’s about being able to take decisions in your life. Everyone should be entitled to that.”*

-Freyja, activist for the human rights of disabled



*Independency is based on a good network - the needs regarding this network are different for the disabled, frail elderly and care workers*

# How to support the experience of independency by meaningful social connections?



# Independent living takes place in a well functioning network

Frail elderly people



People with variety of disabilities



People who work with care and cure



**Medical services** - health centres, private clinics, home nursing etc.

**Families and friends**

**Service centres with organized activities**

**Home care**

**Organisations and volunteers**

**Private services**

# Old age is an important life stage which all generations go through in changing ways

## It is a life stage we all want to experience and enjoy

Ageing and elderly life is not just about deterioration. It is a unique life stage everybody hopes to live through and make the most of. Media often highlights the active third age but also the later stages in life could be seen as opportunities for important experiences. We should consider how to make the best of ageing for the frail elderly in the Nordic societies.

## Our societies highlight youth and hide ageing and death

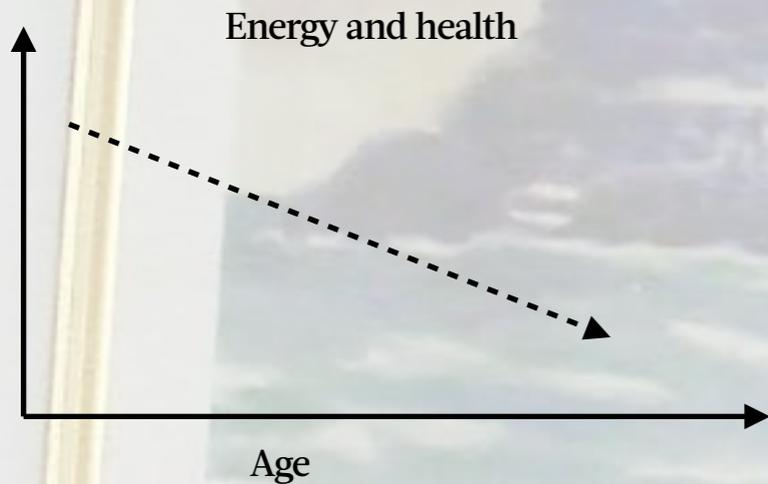
Good ageing and especially a good death is something everyone hopes for but it is rarely discussed or considered in our society. Elderly people share horror stories of their friends losing their minds and ending up institutionalised for the final stage of their life, suffering in hospitals hidden in the backyards of the Nordic societies.

## Different generations become old in different ways

The relation to technology differs a lot for different generations. This is important to take into account when designing across generations. Many elderly feel that learning new technology takes a lot of energy and effort. The now ageing generations have grown up and become adults in very different societies. This also results in different kinds of expectations regarding care. Many care workers expect the elderly to become more demanding and aware of their rights. Even the expectations regarding how long people will live are changing. People who are now 80+ didn't necessarily expect to live that long, but people who are now in their sixties expect to have many active years to come.



# How to soften the "down" life events and enhance the "up" events?



Getting older is traditionally considered as a downward process of deterioration of energy and health. As the life expectancies have become longer the pattern of ageing, health and energy are becoming more diverse with different kinds of ups and downs.

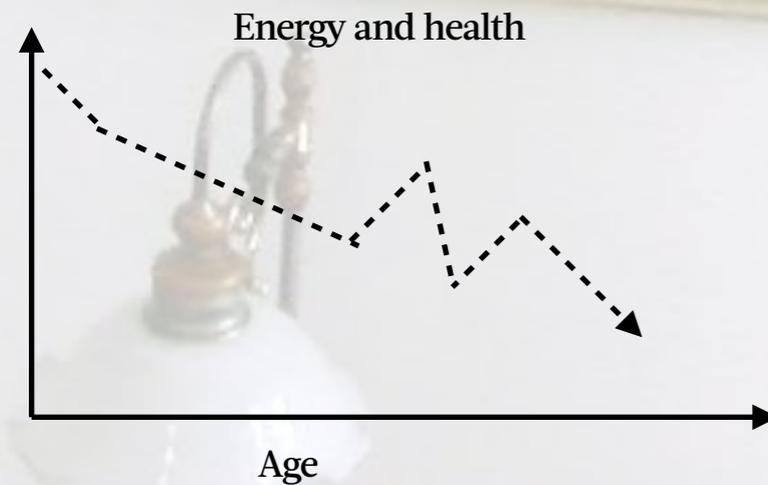


## Typical up events

- Finding a new hobby or a place to spend time
- Learning new skills
- Getting better medication
- Finding a form of care that improves life quality
- Making new friends
- Travelling abroad
- Falling in love

## Typical down events

- Losing a spouse
- Losing an important physical skill (such as cleaning, reading, cooking etc.)
- Medical treatments and recovery times
- Losing friends or family members
- Losing memory (short term and more serious problems)



# **A variety of disabilities means a variety of needs to get by with, with the help of technology and other people**

## **Multiplicity of different ways of being and a variety of challenges**

The disabled are a wide and heterogenous group. Being disabled doesn't mean that you lack something. It is rather that the *society is organized in a way that is not made to best suit your way of being*. Enhancing the access to places and activities is for example very different for people who can't see and for the people who move around by electric wheelchair.

## **Future dreams and opportunities lie ahead in the work life**

Challenges that the disabled experience are different in comparison to the elderly since many younger disabled face the same challenges as other young people, but with the addition of their individual needs. Work life and the social systems built around it are often inflexible. Finding ways to apply one's skills and get a salary and appreciation for it is often challenging because of this.

## **Technology is applied to enable everyday activities**

Many people need to apply technology to aid with accessibility. As technology becomes more ubiquitous it is possible to see a future in which we all become more and more embedded with technology. For many disabled it means that they will have more and more capabilities to take control of their lives. They act as future users for the rest of us.



# Care work is facing a huge challenge which affects the people who do the emotional labor of care

## Care involves compassion

People who do care work at homes mention that the best parts of the work are when people are happy with the help they receive and when you get to a level of meaningful social connection by discussing and hearing their stories. Care work is emotional labor that aims at making people feel and get by better. With some customers it can be very difficult, challenging and even frustrating.

## Costs are to be reduced while the demand is rising

Elderly and disabled who receive care in their homes mention that care workers often seem to be really stressed and busy. Many tell stories of their favourite care worker leaving for another job since home care has been too hectic or hasn't paid well enough. Meanwhile most people notice that due to public cost cutting the resources will probably be even scarcer in the future.

## Care is provided by a multiplicity of different actors

Especially for many elderly it is difficult to keep track of who all the constantly changing people are and where they come from. Knowing where to call and who to contact regarding different issues is problematic. From the perspective of the elderly and disabled receiving the services there also seems to be a lack of coordination between different care providers.



*Key learnings from Damvad report  
and their connection to our findings*



# Key connections between Damvad's strategic report and the findings from the user research phase

## Technological issues regarding independent living

- ▶ Create safety systems that respect the privacy of users.
- ▶ Make technological solutions seamless to use.
- ▶ Find ways for the apartments to be cozy homes and functional workplaces at the same time.

## Service and support for the people living independently

- ▶ Enhance participation and social inclusion.
- ▶ Support the feeling of dignity and capability of the individuals.
- ▶ Create flexible housing solutions for people with physical and cognitive challenges.
- ▶ Personalize services to meet the needs better.

## Providing care for independent living

- ▶ Build better collaboration between different actors providing care.
- ▶ Create better work environments for the care workers.
- ▶ Reduce costs of care.

Based on how the Damvad's TOP10 strategic and practical challenges were perceived at the everyday of the care and service workers and people who aim for independent living.



# Technological issues to enhance independent living in the future

## Technological issues regarding independent living

- ▶ Create safety systems that respect the privacy of users.
- ▶ Make technological solutions seamless to use.
- ▶ Find ways for the apartments to be cozy homes and functional workplaces at the same time.

## How these are present in people's everyday lives:

Most people are happy with safety bracelets and other systems as long as they understand how they work and how they are useful. Concerns of privacy come from legal frameworks, or when the user doesn't understand the safety system.

Especially the elderly consider technology as something problematic and demanding. On the other hand solutions that already seamlessly fit into the everyday life, such as the microwave oven or vacuum cleaner, are considered to be great. Constant rapid change makes technological solutions difficult. This is also mentioned by the workers who for example come across a lot of different user interfaces for aid equipment. Of new technologies, networked touch-based user interfaces (such as iPad) seemed to be very popular among disabled and relatively interesting to the elderly.

As more care takes place in peoples homes there is a need for the homes to adjust to the needs of caretaking activities. Municipalities remodel some apartments to fit hospital beds and to be usable with a walker or wheelchair. Aid devices that enter people's homes should be considered as a part of their interior. Typically problems for the people and the workers come in the form of cramped homes with not enough space. Organization and control of the stuff is important for the coziness of the home and the functionality of caring activities.



# Service and support to enhance independent living in the future

## Service and support for the people living independently

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- ▶ Create flexible housing solutions for people with physical and cognitive challenges.
- ▶ Personalize services to meet the needs better.

## How these are present in people's everyday lives:

Being part of groups that gather regularly, having friends and being able to take part in meaningful activities is important for good independent living.

Being able to do things and take decisions enhances the feeling of capability. Capabilities and social connections serve in finding ways to contribute meaningfully.

You can either live by yourself in your apartment or in different forms of service housing or elderly homes. Many elderly wish they could live in a more social environment but are in too good condition for service housing. Disabled people who live in specifically designed service housing can on the other hand often spot a lot of problems in the layout of their apartment.

A need for more personalized services was stated by both the people who use the services and the workers who provide them. There is currently little room for adjusting the services to best support the individual. The best examples of personalization of services are the systems in which disabled people can hire their own personal assistance staff. This also serves in supporting people outside of their home which typical homecare services rarely manage to do.



# Providing care to enhance independent living in the future

## Providing care for independent living

- ▶ Build better collaboration between different actors providing care.
- ▶ Create better work environments for the care workers.
- ▶ Reduce costs of care.

## How these are present in people's everyday lives:

People who come to people's homes to perform caring tasks come from different institutions that might have little contact between each other. The knowledge that someone gains by cleaning the home of an elderly person could be extremely relevant for example for the physiotherapist of the same person, but they often lack information channels between each other.

The people who work at home care also change very often and in many cases it is a job that people move on from as soon as they find something better. Workers wish that they would be less busy and have more time to build better relationships with the customers in order to be able to better take their social needs into account.

As the amount of people who need care rises the costs need to be reduced. Finding the right ways to do this without compromising the quality of care is extremely important for the future.





# **/Diagonal**