Game over or play it again and again…
participatory design approach within Special Housing

Helena Tobiasson

Industrial Ergonomics

Degree Project
Department of Management and Engineering
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Preface

“As long as I am still in the game I want to play, for laughs, for life, for love”

Thanks Martina, for being such a great coach!
Abstract
Activities that are fun, social, engaging and put something at stake are positive for your health no matter age or condition. What can you do if you suffer from dementia and are living at a Special Housing? According to research you should dance, visit the garden, get tactile massage discuss artworks etc. Still, despite all these proposals there are many voices from this domain, telling stories about living without live. Suffering from dementia may affect your ability to speak for your self and initiate activities. How can we know what they want and not what we think they need but they don’t seem to get or might not even want? Why don’t we ask them?

We propose more focus on participation and design methods to guide the way.
In this report, the author discusses the experience in conducting a Participatory Design research project intended to develop a technological and a related organizational intervention. The aim was to support people with dementia living in a Special Housing with fun and engaging activities. A short description of Participatory Design as an approach within research projects and a description of how it was used in this research study are given. We then discuss the experience in conducting the research, some of the users’ comments and responses, challenges, success stories and drawbacks when trying to design and test an activity in a readymade setting with fixed schema for several weeks ahead. The overall reflection being that Participatory Design has great potential for interventional projects and research focusing on leisure activities in everyday life for people with dementia.

We proposes this being due to the two concepts – participation and design

Keywords: leisure activity, dementia, Special Housing, participation and design
Preface

Abstract

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1 Introduction

The first part of this report will give an orientation and a background of the focus for the report, participatory design as an approach when trying to add to the repertoire of activities for people suffering from dementia and living at Special Housing.

1.1 Background

Activities are a basic need for human beings and there is growing evidence in research literature that leisure activities can have a beneficial effect on dementia (Karp A et al, 2006). Both in postponing the debut and mitigate the effects. The variety of proposed activities in research literature spans from, song, music, dance, gardening, animals and others (Gotell et al, 2002), (Evans and Garner, 2004), (Verus et al, 2008), (Prosser et al., 2008). We live longer and girls born during 2008 are calculated to live 83.15 years while boys have an average life expectancy of 79.10 years. Since 1990 the average life expectancy has increased considerably in Sweden for both men and women (Statistics Sweden, 2009).

Getting older will augment the risk for dementia since age is the dominant risk factor. Protective factors are high education and leisure time activities (SBU, 2006). Apart from the individual aspects and perspectives of getting dementia, it is of major concerns for public health, and the impact is increasing with the aging population. Society puts a lot of resources in this area and in year 2005 the costs for dementia in Sweden were 50,1 billion SEK. Costs for Special Housing constituted 67% of these costs (Wimo et al, 2007).

Dementia is progressive and will affect the ability to think rational and come to conclusions. To execute and to perform intended actions will become more difficult. The physical ability is there but the overall coordination of thoughts and action is broken. This makes it difficult to initiate and perform activities and the person suffering from dementia may seem restless and frustrated. Having dementia may also include aggressive and monotonous behaviour such as screaming, endless fighting and restless walking around (Edberg, 2002). Working with and giving support to people suffering from dementia are very demanding both on a physical and mental level. Relatives and staff are experiencing and report that they do not have the abilities to cope with the situation. Due to this, they are left with feelings of failure, towards the individual but also from society towards the domain (Häggström, 2005).

This project focuses on game and methods for implementing more fun physical activities for people suffering from dementia and living at a Special Housing. Computer games that invite you to be more physically active, that are easy to handle while not heavy have not been at hand for these user groups. We report on a project that has, put the young computer-game technology into the hands of the old, played it “by ear” and observed what happened, letting participatory design methods guide the way.

We used a standard off-the-shelf-technology: a computer game called Nintendo Wii Sports. It has a motion sensitive input device that allows you to play virtual bowling, tennis, boxing and baseball (Nintendo, 2009).

Our approach while introducing computer games as an activity for elderly living in Special Housing has been Participatory design (PD). PD has been used in many research projects within the Human Computer Interaction domain, in a broad variety of contexts and users for developing new technology, software and services (Stappers and Sleeswijk Visser, 2007;
Clemensen et al, 2007; Zaphiris and Constantinou, 2007). In this project we use ourselves and our own knowledge as being part of the project to do the analysis of and the reflection on the material. There is a comparatively strong relation between reflection in and reflection on action. Donald Schön describes this as taking reflection in and on action at the same time (Schön 1983). As practitioners we “think while walking on our feet”, using a repertoire of images, metaphors and theories and traded knowledge and skills. Processes, experiences and understandings generated through reflection on action are drawn upon. In this there is a time issue, on can leave the “material” and let the time between action and reflection be more or less long. Certain things we just take as they are, we fall back on some of the routines previous established in the organisation, sediment from others thoughts. We do create space for reflection both in the present and in the future in that we are researchers present in the real setting. Since we observe, record and discuss with the target group we provide an arena for reflection even for them (Smith, 1994).

Manuel Castells writes that technological innovation takes part among us and reflects our learning by using and by doing:

” The key lesson is that technological innovation is not an isolated instance. It reflects a given state of knowledge, a particular institutional and industrial environment, a certain availability of skills to define a technical problem and to solve it, an economic mentality, to make such application cost-efficient, and a network of producers and users who can communicate these experiences cumulatively, learning by using and by doing.” (Castells, p 35,1998)

We reflect on PD and if it has potential for being an approach also in the domain of Activities for people suffering from dementia and living in a Special Housing.

1.2 Problem Description

We live longer and therefore we risk getting dementia and that is giving society and us inhabitants a dilemma concerning resources. Since the Community Care Reform Ådel, which was enacted in 1992, the responsibility for elderly-care is weighing heavy on the municipalities.

The nursing staff being divided and originally coming from an organisation with heavy focus on healthcare has had difficulties in taking on the new role within the care of elderly organised by the municipalities, since people living at Special Housing not only need healthcare but also support for living a life and not only being alive. Where to draw the line between what is healthcare and what are social/leisure activities is not always obvious.

We know that for aging well we should provide physical activity, good eating habits, support for social interaction and participation in meaningful contexts where one can get the feeling of being needed. When having to move to a Special Housing due to progress in dementia it can be more difficult to preserve the different activities and identities you had when being able to lead your life independently. How is this supported for people suffering from dementia living at Special Housing? There are a broad variety of research on different activities and their relations to and positive effect on people suffering from dementia. Many of these projects are reported on the site Svenskt Demens Centrum (www.demenscentrum.se).

Implementing activities with the purpose to support joy of movement might be a way to save resources within elderly care. There is research trying to investigate the relevance of individual social capital as a resource in the oldest old +85 (Nyqvist, 2006). Also since people suffering from dementia often get their speech affected by the diagnosis, finding ways to communicate through different channels are important (Aremyr and Hallin 2005).
Still the public voice in media is reporting that everyday-life activities are poor in our Special Housings. Recently the Swedish Television program Uppdrag Granskning reports on the conditions on some part of the elderly care in Sweden (SVT, 2009).

The balance is tricky between giving support for living a life or just helping them to be alive.

1.3 Purpose and Research Questions

The purpose of this report is to reflect upon and discuss whether Participatory Design as an approach is appropriate when performing activity interventions within the domain of Special Housing and people with dementia living at Special Housing.

The case we reflect upon, and the material we use as reference, is what was developed together with the broad target group (including users, relatives and personnel) during the introduction of “Wii at Vibacka”. Participatory design are equally grounded on both participation and design methods and we discuss and reflect upon the following questions:

- What can Participatory design as an approach, as a method for interventions, bring to the specified domain of activities for people suffering from dementia and living at Special Housing?
- What can the facilitating factors be?
- What can be the obstacles?

1.4 Delimitations

There are many possible perspectives to focus on in this project including occupational and physio-therapists and their relations to design and design-processes; the fine and tricky balance between care, healthcare and social activities within the domain of Special Housing and elderly care in general; capacity of learning in people suffering from dementia; perspectives on small and large organisations when it comes to planning, action and decision; and methods used in research projects focusing on supporting people with dementia. Other possible issues include the difficulty in transferring information from research to practise; and the gap between research results around activities for people suffering dementia and the real actual situation at Special Housing premises. Activities where something is at stake seem to be of great interest among the elderly. A more detailed analysis of the game and physical aspects of the activity will be dealt with in reports to come. For that reason some of the results of this project are kept out of this report. We will instead focus on the researcher’s perspective of the design approach. We report on the process, approaches and procedures.
1.5 Reader's Guide

In this report we propose that participatory design can be an approach well suited to guide the work when implementing new activities within the domain of elderly-care.

Or more specific, to guide the implementation of new activities for people suffering from dementia and living in Special Housing.

We do this by describing a very vivid project around the computer game Nintendo Wii Sports and its entrance into Vibacka, a Special Housing. We used the Participatory Design approach throughout the project. The positive comments from the broad target group, how they value the result and the fact that the play continued after the end of the project are argued as partly dependent on the method used during the implementation.

In Chapter one, we start by giving a short background to guide the reader into some of the different aspects that we think is of importance for understanding the scenario – being old suffering from dementia and living in a Special Housing and the role of activities. Then we continue with describing the problem area in this scenario – the fine but tricky balance between providing healthcare and care and also care to support them in living their lives. We reflect through our own project what participation design methods can bring to the domain. Then in chapter a more detailed description of life when getting old from some different perspectives is presented, including some information on research methods used in other projects with focus on dementia and activities. After that, in chapter three, it is time to take the reader into the domain of participatory design. We try to give the picture including some history, some techniques used, through to participatory design of today. In chapter four we describe the methods used when collecting data in the Wii at Vibacka project. We give some introduction to the case Vibacka and the game Nintendo Wii Sports, followed by a description of the broad target group and how the selection of players was done. In Participatory Design approaches, being in the real world together with real users in real situations, there are several things occurring at the same time and the classification of these is accordingly complex. We try, anyhow, to divide the results into outcome of playing the game Nintendo Wii Sports for the users, relatives and the personnel, this is described in chapter five, and outcome of using participatory design as an approach while doing this, that is described in chapter six. We then discuss the results both in chapter five and in chapter six. Finally, in chapter seven a conclusion of our findings and some proposed future research.
2 Life when Getting Old

The second part of this report will provide an overview of some of the conditions for the aging population in Sweden. Aging well – how is that supported? If you need care when getting old, who is responsible and who is paying the costs? Age is the major risk factor for developing dementia – brain damage. Here we provide some information from different perspectives on dementia; one of the perspectives being what kind of activities that are at hand for supporting people suffering from dementia and the research methods used.

2.1 Four Cornerstones for Aging Well

In the report around the situation for elderly the Swedish organisation Kommunförbundet has identified four cornerstones for aging well (Thille and Wrammer, 2000). These include physical activity, good eating habits, social interaction/support and having a sense of belonging/participation and meaningfulness.

2.1.1 Physical activity

We have solid evidence for the benefit in many aspects of leading physically active lives. From being active we can improve oxygen uptake, muscle strength, walking ability and balance. This does not lose its relevance with age. Supporting the physical abilities and being physically active in old age can help to hold back functional impairment.

2.1.2 Good eating habits

In gerontology and geriatrics nutrition is an important area. Established eating habit in earlier age seems to follow the individual when getting older. Although many elderly change eating habits due to loneliness, loss of physical activity and other cultural, social, psychological and medical aspects, for well-being and to postpone or prevent disease, good eating habits and access to healthy food is important even for elderly people.

2.1.3 Social interaction/support

When getting old social networks through job, friends and family seems to get smaller. Having good social support and contact are one important parameter also for elderly when it comes to striving for positive effects on health. Local voluntary actors in the community and appointed persons for coordinating and continuity, has proven to be of great value. In some municipalities day centres still exist and are sometimes the only alternative for the elderly.

2.1.4 Participation/meaningfulness/feeling needed

We know from research done by for example Aaron Antonowsky developing the concept of KASAM that a feeling of being needed, having a sense of meaning in our lives is one key factor for health (Antonowsky, 1991). This is still important when getting old (Agahi N, Lagergren M, Thorslund M, Wånell, 2005).

But what if one does not get all that happy to be fit in every respect when getting old – who has the responsibility to care apart from family and friends and who will take the costs?
2.2 Elderly Care

Caring for elderly is a shared responsibility between the family and the society. In 1956 the law was changed and old parents could no longer by law demand care from their children. The Swedish Social Services Act gave the individual legal right to get assistance from society in 1982. 15 years later more then 90% of the care for the elderly was given by the state (Lechner, Neal, 1999).

In Sweden about 2.8 percent of the gross domestic product (GDP) is invested in the elderly care sector. Special Housing, where the municipalities are responsible for basic health and medical care for 24-hours, is the home for around 16 percent of the inhabitants over 80 years of age. Dementia is common among those in need for support day and night. But many of the disabilities that the older population are facing and experience do not at first relate to the fact that they are getting old but to passive lifestyle, lack of stimulation and a changed role and function in the society. (National Institute of Public Health, 1998)

In 2005, elderly care in Sweden cost a total of SEK 80.3 billion. The distribution of the costs is shown in figure 1. In fixed prices, costs were down 1.7 percent compared with the previous year. Health and social care in Special Housing accounted for the bulk of elderly care costs in 2005. The cost per care recipient is more than twice as high in Special Housing as in regular housing.

Around 75% of the costs for health and medical care come from tax revenue. About 20% is covered by government grants. The costs for Special Housing are mainly covered through municipal taxes. 3% and more of the total costs come from patients’ fees.

![Figure 1 Distribution of costs for elderly-care in Sweden, 2005.](image)

Guiding the regulations around elderly-care – what laws are there?
2.3 Responsibility

In 1992, the Community Care Reform (Ädel-reformen) was enacted. The responsibility for care of the elderly moved from the municipality councils to the municipalities. Since the Community Care Reform there has been several changes within the elderly care. During the 1990s, when the economy was weaken by the economic recession there was major cut-backs within service and care for elderly. Many municipalities had to re-allocate resources from expensive institutional care to home-based care. There are some factors to consider elderly people seems to have improved health, the health and medical care is becoming more and more advanced. This makes it possible to get treatment while still staying at home for quite severe medical problems even for elderly persons.

Since 2007, there are three laws that form the basis on how elderly persons can receive care in Sweden. The Social Service Act, home-help services, pending on needs assessment are available. Municipalities have, since 2006, the possibility to provide persons aged 67 years and older with services without needs assessment. Additional legislation gave everyone and the elderly in 2007 the opportunity to get tax deductions when buying services such as cleaning, washing and shopping from whatever supplier they chose. (socialstyrelsen, 2007)

The municipality has the responsibility up to the level of the skill of a nurse for people living in Special Housing. There are occupational and Physiotherapists responsible for the rehabilitation present part of the week. Their assignment is to assist in activity of daily life, support activity and promote an approach of rehabilitation in the work at Special Housings.

Treatment and specific training is supervised by the occupational therapists and the physiotherapists. They instruct and advice enrolled nurse and auxiliary in some part of the training.

To support the elderly and let them perform activities of daily life that they can perform is the part of the job and responsibility for the enrolled nurse and auxiliary.

A questionnaire survey was done on the work situation of registered nurses in municipal elderly care in Sweden. It was published in the International journal of nursing studies in January 2007. The results indicates that:

“The specialisation in dementia care divided elderly care into two groups: dementia and general care. This change has had a significant impact on the work situation of registered nurses” (Josefsson K, Sonde L, Winblad B, Robins Wahlin TB, 2007).

So fare we have provided some information around the care, costs, and staff involved in working with people suffering from dementia. Below will follow some more details on the diagnosis.
2.4 Dementia

Dementia is used as a general terminology for many diseases caused by damage and or changes to the brain (neuron death). Alzheimer’s diseases, vascular dementia, dementia with Lewy bodies and frontotemporal dementia are among the most common diagnosis. Having dementia will affect the person in multiply ways and decrease ones ability to handle everyday situations that includes thinking, reasoning, communication, orientation, practical abilities such as activities of daily lives ADL and learned skills such as handling of tools or playing a musical instrument. It has also affect on a nursing personality level by causing lack of insight and judgment, aggressiveness, emotional bluntness and lack of empathy. Anxiety, depression, suspiciousness and obstinacy seems more to be related to the person being aware of and reacting against the cerebral dysfunction she or he is facing. There is not a clear line between normal and abnormal cognitive impairments due to ageing. There are no medical cure for dementia and attending and caring for people with dementia is difficult and special skills and specific knowledge will help in guiding the work. For family members, friends and relatives it can be frightening not to be able to “recognise the behaviour” of ones dear and near. Dementia is of major concerns for public health due to the growing numbers of aging people that are diagnosed with various types of dementia. Approximately 140 000 Swedes have a dementia disorder. Two thirds of this group have Alzheimer’s disease.

The Swedish Council on Technology Assessment in Health Care made a systematic review, published in June 2008, where they report on the etiology and epidemiology of dementia. Below are some of their findings.

- Age is the primary risk factor for developing dementia.
- Rising life expectancies are increasing the number of people who develop dementia disorders. Approximately 1% of 65-year-olds and more than 50% of 90-year-olds have a dementia disorder.
- Among people older than 85, a greater percentage of women than men have Alzheimer’s disease.
- Although known genetic changes that cause Alzheimer’s disease are rare, the Apolipoprotein E (ApoE) e4 allele is known to increase the risk.
- The progression of dementia can be delayed among older people who continue to lead active lives.
- Approximately half of all people with dementia move to assisted living facilities within 2–3 years after diagnosis.
- Approximately half of all people with dementia are in assisted living facilities.
- The burden of dementia in Sweden corresponds to approximately sek 40 billion a year, a figure that is likely to grow as the size of the elderly population continues to increase.
- Municipalities bear more than 80% of the costs, which cover care at assisted living facilities and support for those who remain at home.

There are reports on the struggling work to prevent these groups from being more and more passive (SBU, 2006). The problem is, for example, the coordination from the brain to execute specific action and movements and not the movement itself, like a car that has lost its driver.


and is standing with the motor running high but no action, or running forward without any
given direction. What activities can then be done and supported?

With the long lists of impairment that can occur due to dementia it can be difficult to find
activities that are appropriate for these groups of patients. Since learning abilities are affected
it may be the case that there is almost no focus on new activities for people suffering from
dementia and staying in Special Housing.

2.5 Dementia and Activities

When moving to a Special Housing the possibilities to maintain your interests is declining.
You become part of an organisation and are more or less dependent on what is provided
within that culture of work. The main focus is on care and healthcare. Activities offered are
mostly tranquil. Reading, sitting gymnastics, song and music are some examples. There are
often no expert, no professional appointed for the activities apart from occupational and
physiotherapists. They also have their focus and expertise in rehabilitation, although through
activities, their presence at the site, are less frequent. There are quite a body of work in
research around activities that can have positive effects on dementia. We refer to some of
these studies further down the text in the next section. There is work done on music, dance,
storytelling, artwork, and communication around art paintings among others. But other body
of research report in high level of stress among workers at the every day basis at work in the
domain and part of the solution seems to be thought to be in technology. We propose a study
on what positive effect nursing staff with pedagogical skills could bring to the domain. Those
who did study to become a nurse or a orderlies and enrolled nurses might not be the ones best
suited to also be expert in activities and since occupational therapists and physiotherapists
also have a more caring focus it might be worth consider a pedagogically skilled person with
focus on leisure and fun for those staying in Special Housing and do not have the ability to
organise such situations or leisure activities themselves.

Physical exercise and having confidence towards one’s own abilities is key to support the
self-esteem and mental health for elderly (Lindwall and Hassmén, 2006). Activities that
entertain, engage, create excitement and learning are not common within Special Housing for
people with dementia. The everyday-life provides few occasions of stimuli other than basic
activities of daily life. Often they cannot cope with the fact that they loose in level of
function. They tend to be more and more passive in their life (Norlund, 2008).

When working with people suffering from dementia one needs to be flexible in ways of
communication. Let the body communicate with movements since spoken language decline is
often present in dementia diagnosis as described in (Burke, 2008).

Body movements can support cognitive processes and therefore the benefit of introducing
activities such as these can be seen on several levels (Brown and Cairns, 2004). Playing
games can also be part of the way to mediate social and affective communication and balance
and regulates emotions (Lazzaro, 2004).

Krister Nyström PhD, dancer and dance-therapists describe in an article that builds on his
research work with dance as a mean for communication and activities among people with
dementia. He proposes that one ought to focus on abilities instead of disabilities. He discusses
cultural aspects such as “old people should sit still with their hands in their laps”. He argues
that we all need to focus on more non-verbal communication while being around people with
dementia (Nyström K and Olin Lauritzen S 2005).

Although quite debated and criticised, Lars Tornstam has co-developed a concept called
gerotranscendence, in which one of the main findings is that old people need less social
contacts and want to be left and need solitude. Gerotrancedence seems to add to this perspective that old people are travelling in their minds from old memories from their childhood to their aging days and that this is best done in solitude, silence and not through activities here and now that needs your focus to be present (Tornstam, 2003).

According to Fratiglioni och von Strauss, who have studied dementia from a preventive perspective, one of the two preventative strategies that can be proposed from the current scientific evidence is to lead a mentally active life and adequate social integration in old age.

There is an increased risk of dementia due to a person’s genetic predisposition. Life-time risk determinants such as low education, low socioeconomic status and high blood pressure are also increasing the risk for dementia. These factors may be regulated through psychosocial factors such as a being integrated in a rich social network and mental stimulation during old age (Fratiglioni and von Strauss, 2006).

On the site “äldreportalen” there are reports from projects called “Genombrottsprojekt” were several site in Sweden has done work to focus on positive changes in the care of patients with dementia. Among them only a few focus on activities such as games. One though, found “Fia med Knuff” being very popular among the users (http://www.kompetensstegen.se/page____1143.aspx).

Using artworks as basis for communication has been studied by Britt-Maj Wikström. She reports that, new possibilities for communication occur between the caregiver and the caretakers and that the patients’ state of emotion becomes visible (Wikström B-M, 2005).

Ragneskog has studied projects that include music within Special Housing and the effect on people with or without dementia. He reports that people enjoy and profit in a positive way from having music in their everyday life. It can stimulate to contacts, social relations, decrease motorical stress among people with dementia having a behaviour of walking all the time and also bring a sense of peace and calmness around bed-time (Ragneskog, 2006).

Agahi and Paillard-Borg both look at leisure activities for elderly and they come to similar conclusions in their dissertations:

“The expanding leisure pursuits of new cohorts will increase demands on authorities and organizations to provide opportunities for activity participation and to address accessibility issues. Considering the accumulated evidence suggesting health benefits from activities, especially physical and social activities, health promotion programs targeting middle-aged and older individuals may be worthwhile” (Agahi, 2008 p5).

“Even in the advanced age, elderly persons are still active, being limited in their participation only by mental disorders or by physical limitation. An active lifestyle, defined as a higher level of participation in leisure activities with either mental, social or physical component may decrease the risk of dementia and postpone its onset” (Paillard-Borg, 2009 p5).

Karp proposes that to reduce the risk of getting dementia, from what we know from research today, one should, chose fun activities, keep the body active and on the move, challenge the brain and gladly do this together with others (Karp, 2005).
2.6 Research-methods with Focus on Dementia and Activities

Many of the examples above are pointing towards that activities is of great value for well-being even if one is staying in a Special Housing and suffering from dementia.

The method of “Break through” (in Swedish: genombrottmetoden) is a method for work of improvement within healthcare. The Swedish Association of Local Authorities and Regions (SALAR) decided in 1996 to use it in Sweden. The method was modified according to the situation in Sweden. It origins from the US were it was developed by The Institute for Health Care Improvement (IHI) in Cambridge, Massachusett. The purpose of the method is spread knowledge within the healthcare organizations that is there but is not used and to promote new knowledge that does not find its way fast enough to get through. At focus within the method is that the participant themselves specifies the goal and target at focus. Then these ideas are rapidly tested in small scale and evaluate according to the instrument provided within the method. Key point being that many small changes will be the way towards the goal and end up providing big changes.

During the years 2003-2005 two projects with focus on dementia was done on a national level. The work did a dissemination phase during 2006 and 2007. The project was a joint effort between The Swedish Association of Local Authorities and Regions (SALAR) and social department. In total there were 41 team from different places around the country (http://www.kompetensstegen.se/page____1143.aspx).

An anthology edited by Topo and Östlund called “Dementia design and Technology” states on the front page that it is “time to get involved”:

“People with dementia have often played a passive role in the investigation of their condition. The contributors to this book look at ways of redressing the balance and involving them in the research process. They describe the skills that researchers and care staff need, and the methods they can use, when seeking to draw out and validate the views of people with dementia successfully, and discuss the ways in which such views can be included in debates about dementia methodology and policy” (Topo and Östlund, 2009).

In the book “The Perspectives of People with Dementia - Research Methods and Motivations”, one of the core messages is that:

“We are at risk of not delivering adequate care to our patients and their families. If we do not get to know our patients’ experience of the illness beyond the results of medical, cognitive and functional tests and assessments, our clinical decisions will not represent patient needs equitably”. (Cohen 1991, p7)

K Fahlander G Karlsson D Vikström has written a book on the basis of knowledge that came out of a project called “licence for dementia care”. The method is personas and easy-to-read stories around people with different types of dementia. The purpose of the book is to support good communications between caregivers, caretakers and their families and friends. The book and the project were done in cooperation between the County Council in Norrbotten and the municipality of Luleå (K Fahlander G Karlsson D Vikström 2009).
3 Participatory design

The third part of the report provides a background of the design approach, from its origin to what it is today.

The field of participatory design (PD) is a quite fuzzy area and very diverse drawing together professionals, practitioners and researcher from a broad variety of backgrounds. Most of them share the values of participation and the power of design methods. We use Participatory design as our Theoretical Frame of references.

3.1 The start in Scandinavia

Scandinavia has a long tradition dating back to the 1970s of research projects focusing on user participation, cooperative design and participatory design (Bødker 1996). Focusing on and developing strategies to involve users early in the design phase and throughout all stages in the design process were the goal. The core idea was that the workers, the user, had valuable experiences and were well suited to influence design and functionality of new systems and tools. New technology, new ideas around desktop publishing were invented and tested with Graphic workers through low-tech prototypes, a new method at that time. (Bødker et al., 1987).

3.2 Design Centre

Participatory design has followed and adjusted its methods according to trends and technology development. We do tend to use more and more technology and not only in work-context it spans over a whole range of different settings such as schools, leisure activities, fixed and on the move. One centre that developed and used participatory design in joint projects with various companies and organisations (both governmental and non-governmental) has been The Centre for user-oriented IT-design, CID at KTH, Stockholm, Sweden. Yngve Sundblad professor, director of CID and former participant researcher within the UTOPIA-project has a broad experience and knowledge in practise when it comes to participatory design in real for real.

Greenbaum and Kyng tried already in 1991 (Greenbaum and Kyng, 1991) to boil down the core concept of participatory design. They are worth mentioning even today. They proposed four issues for design:

- The need for designers to take work practice seriously—to see the current ways that work is done as an evolved solution to a complex work situation that the designer only partially understands
- The fact that we are dealing with human actors, rather than cut-and-dried human factors—systems need to deal with users' concerns, treating them as people, rather than as performers of functions in a defined work role.
- The idea that work tasks must be seen within their context and are therefore situated actions, whose meaning and effectiveness cannot be evaluated in isolation from the context
- The recognition that work is fundamentally social, involving extensive cooperation and communication
3.3 **Techniques and approaches**

Within PD there are a broad diversity of techniques to enable participation and reassure that everyone have a voice, pick up ideas through observations, hands on workshops with low tech material acting out scenarios, body storming brainstorming, ethno-methodology or “ethnography light”

This study has been done using participatory design. This method involves end-users in all stages of the project. It is widely used within Human Computer-interaction HCI research-projects and originates in Scandinavia. It has proved to be a very successful method in research and development projects and has been used, developed and evaluated over more then 20 years, (Bødker et al, 2000, Bødker and Sundblad, 2008).

Participatory design is an iterative process and design, testing and evaluation is done concurrently and iteratively and as an interaction and collaboration between all the persons involved in the project. Human-Computer Interaction (HCI) is applied research on novel forms and use of technology and novel ways of working together with users in all stages of the design process. The HCI department at KTH has been focusing on research and education in HCI on all levels since 1985, heavily influenced by experience from participation in the early Scandinavian participatory design projects. The department has been part of and co-ordinated several collaborative projects (national and within EU) with industry, authorities and user organisations. It combines competencies in technology with competencies in human sciences and design. See [http://hci.csc.kth.se](http://hci.csc.kth.se)

PD is more of an approach then a detailed fixed set of methods. It focuses on the process and is therefore very broad in its diversity. You can not as you might be able to do other design traditions say that its a typical Gaudi. Participatory design stands on the believes that users should be involved in the design process in products and services they will be using in order to suit them and be of direct use. It has been used in a broad variety of context and user-groups.

There are a diverse tool-box of methods for data-collecting and evaluation used within projects that claim to have PD as the overall design. Among these brainstorming for early design ideas, design briefs, different types of prototypes in different types of material, probes, scenarios, wizard of oz trials, observations, diaries, body-storming are some examples. The main idea is that end-users participation and power to affect is central and at focus along the whole lifespan of the project. PD as an approach has some similarities with and some roots together with action research. To use in order using PD as a tool in projects placed in real life settings with users in their real situations one need to have an open mind and address situations and people with great respect.

The UTOPIA-project desktop publishing in newspaper it was grounded in democratic ideas to give the user/workers power over their work situation. It was done in close collaboration with the union. Starting with graphic workers in Utopia 1981-85 ICT 2009 is full of software for collaboration, freeware, open content provider, webb.2.0 user-driven software and content development.

PD has been used in ICT developments at museum settings, intergenerational communication, healthcare, schools, homecare, authorities, banking, media, governmental, and non-governmental organisations. It has grown in and outside the research community in a very pragmatic way and is used, evaluated and further developed with no strict line between theory and practise in many domains. Still most often with some kind of technology development at hand but in collaboration with many other disciplines.
Researcher from University of Aarhus in Denmark, and University of Oslo in Norway has worked with PD in a research project within home healthcare focusing on a technological and to that related organizational intervention for people with diabetes suffering from foot ulcers. They proposes that PD as a research approach has the potential to maybe merge, in an effectively way, computer technology and health-related interventional research (Clemensen J, Larsen SB, Kung M, and Kirkevold, 2007).

PD practitioners and researchers being so diverse in their perspectives, backgrounds, and areas of concern, there can be no single definition of PD. The organisation “Computer Professionals for Social Responsibility” (http://cpsr.org/) formulates some statements that most PD practitioners’ researchers may have in common.

- Respect the users of technology, regardless of their status in the workplace, technical know-how, or access to their organization's purse strings. View every participant in a PD project as an expert in what they do, as a stakeholder whose voice needs to be heard.
- Recognize that workers are a prime source of innovation, that design ideas arise in collaboration with participants from diverse backgrounds, and that technology is but one option in addressing emergent problems.
- View a "system" as more than a collection of software encased in hardware boxes. In PD, we see systems as networks of people, practices, and technology embedded in particular organizational contexts.
- Understand the organization and the relevant work on its own terms, in its own settings. This is why PD practitioners prefer to spend time with users in their workplaces rather than "test" them in laboratories.
- Address problems that exist and arise in the workplace, articulated by or in collaboration with the affected parties, rather than attributed from the outside.
- Find concrete ways to improve the working lives of co-participants by, for example, reducing the tedium associated with work tasks; co-designing new opportunities for exercising creativity; increasing worker control over work content, measurement and reporting; and helping workers communicate and organize across hierarchical lines within the organization and with peers elsewhere.
- Be conscious of one's own role in PD processes; try to be a "reflective practitioner."

3.4 Participatory Design of Today

From the information material around the PDC2008 conference, held every second year since 1990 (http://www.pdc2008.org/) one could read about how PD has evolved the last 20 years:

“PD approaches have been used in traditional application domains (such as computer systems for business, CSCW, healthcare and government) and more recently in areas such as web-portal design, e-government services, community networks, enterprise resource planning, social administration and community development, university/community partnerships, tele-health, communities of practice and political deliberation/mobilization (e-democracy), digital arts and design, scholarship and teaching with mediated technologies (e-learning), the experience of a sense of place, PD in developing countries, cultural production and cultural institutions”.
4 Methods

The fourth part of the report deals with the case, the play and the method used during “Wii at Vibacka”. We start by giving a short introduction of how the municipality is describing their Special Housing Vibacka. Then we provide an orientation about the computer game Nintendo Wii Sports. After that, with that context in mind, the case, the game or the play “Wii at Vibacka” begins.

4.1 Selection of the Case

Since our research interest is in physical activities and participatory design and participatory design focus on real people in real situations we were happy when asked, through a research colleague with connections in the municipality, if we would like to work with Vibacka in the municipality of Ockelbo around Wii and dementia. The manager had seen the Nintendo Wii Sports during an event in Stockholm and thought it could be worth trying at Vibacka. That was the way the selection of the case or the playground and the selection of the game was done.

4.2 Vibacka, a Special Housing in Ockelbo

For those individuals that no longer can be provided support for living at home there are two Special Housing facilities in Ockelbo municipality. In order to have access to that opportunity the local authorities are dealing with the matter through an investigation performed by a handling officer. If the person is granted access to a Special Housing, he or she can have a private room, a shared room or a flat with coining facilities. The Special Housing provides the bed, but any other furniture is provided for by the individual. The handling officer, a nurse, other care nursing staff together with the person and or their family/relatives are setting up a care-planning document. This document will be changed according to level of assistance needed.

Vibacka is the largest Special Housing in the municipality of Ockelbo. It can host sixty persons in residence. Ten of these places are within a department specialized in dementia.

At Vibacka you will be under the supervision of registered nurses, Enrolled Nurse and assistance 24hour (http://www.ockelbo.se/kommun/aldreandhandikappomsorg.html).

4.3 Nintendo Wii Sports, a Computer Game

In Sweden Nintendo Wii Sports was launched on December 8, 2006. The design of the system is a counter-example to those game-systems that focus mostly on the graphics and where the core interaction is static with regard to body motion. Target group for Wii is the average gamer 9-18 years old but Nintendo also aims for those over 30 years old that are non-gamers. Up to four Wii Remote can be in use at the same time allowing for quite a busy arena. The communication between the Wii Remote and the box is done using wireless Bluetooth-technology. The limit is 10 metres. The Wii Remote and the Nunchuk can both track movements in three axes. The Nunchuk is the device used in the boxing game. Included in the Wii Remote are a loudspeaker, an IR-camera and a shaking function. For the tracking, in order to know what and where you are pointing, the Wii Remote has PixArt optical sensor (Wisniowski, 2006). With the new technology development the use of ICT can become more physical and in some ways therefore more easy to use and more accessible for the elderly (Magnusson, Hanson and Nolan, 2005).
“Computer games are developed and designed for young target groups – old people should sit still and dream about ancient days” that may be the presumptions of many of us but there is a growing bulk of reports on the net were the Nintendo Wii have played a leading role of change regarding this respect. Find below some examples that we found on the net.

On the site Wii Gaming a person named Angela January 21st, 2008 reports on the outcome of a questionnaire she did around how do elderly playing Nintendo Wii perceive the game. She writes about an 85 year old gent she refers to as James:

“When asked why he likes playing the Wii James had a simple response “it gets me moving and keeps my mind active”. He states “I read the papers, go for walks, make my tea, but the Wii means I can do some things that in reality I’m a little past [laughs]… a game of bowling is my favourite and I’m actually fairly good” (http://www.Wiicentre.com/Wii-for-the-elderly--a-report-441/).

On the blog hosted by Marcus Yam there is an article posted February 22, 2007 on “Wii Invades Retirement Home”. He writes: “Wii Bowling has become so well received that more than 20 residents signed up to participate in a virtual bowling tournament without the need to leave the clubhouse lounge. Sedgebrook's entertainment committee said that they even have a fan for people to dry their hands before they bowl, just like at a real bowling alley” (http://www.dailytech.com/article.aspx?newsid=6191).

On the internet version of “The British Journal of Healthcare Computing and Information Management” there is an article on “Wii keeps elderly active in care homes” were the leader of Neath Port Talbot Council, Derek Vaughan gives the motivation why they have purchased the Nintendo Wii for their residential care homes: “The council provides itself on the standard of care provided in our residential care homes. As well as caring for their physical needs, we encourage residents to join in activ ities designed to help them keep mobile, mentally alert, self confident and socially interactive” (http://www.bjhcim.co.uk/news/2008/n802012.htm).

The last example is from the net-version of CNN were By Anouk Lorie writes an article on the Nintendo Wii FIT balance board. She reports on a project using the balance board improve balance and help avoid falls in seniors (http://edition.cnn.com/2009/HEALTH/02/11/Wii.fit.elderly/index.html).

4.4 Target Group and Selected Players

There were two coordinators in the “Wii at Vibacka” project. One was the person appointed project leader for the greater project with focus on activities for people living at the two Special Housings in Ockelbo Municipality, an enrolled nurse with several years of experience from different part of the domain elderly care. She was working and living in the municipality of Ockelbo. She has been part of data-colllecting but the reflection described in this report is done by the research-student. The other, a physiotherapist and research student from Kungliga Tekniska Högskolan in Stockholm, with ten years experience in projects using the participatory design approach.

When we talk about the target group we include the users, their relatives, the caregivers and other categories of staff. In the target group a special focus was on the ten individuals selected for the study. They were all living at the Special Housing Vibacka. They all had different stages of dementia and six of them were staying at a locked department. Many more of the people living at the Special Housing were playing the Wii Nintendo Sports but only the ten mentioned above were part of the study. There were eight female and two male with age spanning from 80 to 91 years old. The users were selected in a mixed way of direct question if they were willing to join a computer game study, in dialogue with their care-givers and their
relatives on basis of their knowledge of these users. They got possibilities to try and watch for them selves before entering the project. Of course did they get the information that they could access the game without being part of the project. Data-collecting and information given from other members in the target group was granted acceptance for on orally basis.

4.5 Playtime and Design-Meetings

The project was initially estimated to take approximately four weeks. Due to large interest for the game from the players the project was expanded. Starting up December 18, 2007, the actual study on playing was undertaken during four months from February to end of May in 2008. Although it was not until February 2008 that everyone was introduced to the game. The elderly were allowed to play several times a week. Mondays and Fridays between 1 and 4 p.m. were scheduled for the study. From December 2007 through May 2008 there were 90 hours of active playtime. The active playing time was recorded automatically in the Nintendo Wii system. Figure 2 illustrates one of the game-situations. We organised several initial meetings with different groups in order to make people aware about the idea around computer games as an activity. We continued to arrange design-meetings with different groups selected and sometimes a mix of stakeholders such as staff, relatives, managers and players. The point-of-start for the study, the meetings, planning discussions, playing, testing, finding out different ways to use the game, changing to match/competitions, arrange “who wants to play with whom” – everything has been guided form wishes, ideas and needs from the participants. During the project time most of the dialogue and ideas came during participating in the gameplay. We arranged meetings with the caregivers to make them a try and to get familiar with how to handle the game. We arranged a meeting with the users and their relatives in order to get them interested to participate and to decide if they wanted to be part of the study or just play. Those who want to be part of the study had to sign a document in order to accept that we documented the study with photos, video, being interviewed and quoted. For some of the users the relatives signed the document in consensus with them.

There were nine arranged meetings with more or less attendances.

They are still playing and we will go back and make an introduction film during autumn 2009 for those other Special Housing that asked us to support them in their start-up. This has been made possible through funding from the Swedish Institute of Assistive Technology SIAT.
4.6 Playing the Game

We got help from a janitor to set up the system. The system includes a projector, a screen, loud speakers, the Nintendo Wii box and three consoles for the game Sports.

We discussed with the caregivers and leaders about the appropriate spot to place the system. Figure 3 and figure 4 shows the work around physically setting up the system. We agreed on an area where people normally meet and where it was likely that others could pass by and join. It was an area where they have other activities such as Friday café, bingo, sitting-gymnastics and singing. We used a projector with screen instead of a TV-screen as projection surface with the motivation that the bigger the better immersion and also allowing for people keen on watching the game.

The consol aims at giving an intuitive feeling of control and natural movements. The aesthetics is somewhat like a remote control of a TV or stereo set. The projector was attached to the ceiling and the screen was fixed to a wall. The Wii box and the consoles (there were three to start with) are put in a minor cupboard that is locked with a key easily accessed from the receptionist.

After getting to know the system we produced our own manual for starting up and closing down the system. In the manual we used our own simple words and pictures in order to make it obvious what steps to take to make the system work. Since none of us had prior knowledge or skills in computer games we needed ourselves to figure out how to manage the system.

Being together playing games such as Nintendo Wii at the Special Housing could open up possibilities for social interaction and use of the physical movement among the individuals, their relatives, friends and care-givers. Our research approach being participation and fun physical activities we had no hidden agenda. Designing for participation since this is their “thing” not an intervention over a short period of time.

One idea for the starting point of the project was to record the physical movement status at the start, during and at the end of the study. We planned then to compare the results with the ones in the record, and to add the results to the record and maybe follow the assessment already at hand. The motivation being to make the results more accessible and more straight-forward to communicate the results in communities were interventions of physical-ergonomic parameters are the main focus.

During one of the design-Meetings we found out that the Special Housing Vibacka did not have case records with physical parameters and assessments on the user (inhabitant). That idea was dropped in favour of just playing, observing and go along with focus on
participation. We would study how the physical status evolved during the time of the study by observations from the people involved in the project. We have not done any physical measurements other than that.

We involved the caregivers and the users and their relatives around reflection and discussion about their physical ability and wellbeing. As the name participatory design indicates, this approach emphasizes the participation of the users in design.

What the relatives and friends have noticed is from their perspective of knowing the player over time. What the players themselves noticed is from their perspective as being the experts. Elsa and her daughter, as shown in figure 5, were invited to inspire other elderly care centres to start up similar activities. This places PD as part of a larger trend in which the role of the “practitioner” as an active subject in research has gained growing importance over the past 60 years. In order to get everyone involved since that is core in change intervention to have the activity to be theirs and in that way continue to play after the project end.

We used the participatory design approach, more on the way we introduced the game and the activity itself, then on the actual design of the game since that was already developed. We did redesign the consol, we did redesign the way we played.

**4.7 Collecting Data**

In the design of this study we have chosen to use observations, interviews in an open dialogue format, video, photos, cultural probe, with diaries and disposal cameras, field notes and diaries in order to document and collect data. We also put together one workshop for a
specific design case of the consol. These means of collecting data are proven to be useful in participatory design projects and are therefore often the way data collection is being done. This is due to that PD address also the understanding of tacit knowledge and its importance and central role in understanding action (Ehn and Kyng 1987). As such it can be difficult to extract and make visible for designers/researchers in PD. Taking PD out is for example the domain of elderly care were the real situation are stuffed with skills of tacit knowledge faces the obstacles of addressing the fact that an essential part of the work is tacit and therefore hard to describe in words, problematic to communicate to others not being at the site at the time when the action took place. On way that PD uses is to reflect upon prototypes being done, “design in doing”, observation by participation. (Iivari et al., 1998).

4.7.1 Observations

We used observations, because that method is good for getting information about the setting, both the human and the social environment (to see some of the interaction situations between caregivers, caretakers and others). Observations is also of value to get information about what the actors in the projects actually do and not do and who is doing what). Last to mention around observations is the non-verbal communication. Since some of the players did not have a fluent language due to dementia (or had difficulties to express in words all the nuances). Nonverbal cues such as how did they position themselves in the room, where they smiling or looking away or did they followed the game happening on the screen and between the players, did they interact in a non-verbal way with their competitors and so on.

![Figure 6 Focussed and immersed in Wii-bowling.](image-url)
During the observations we have looked for change in body posture, range of motion and flow in movement. What we have noticed has been coloured by our different background knowledge as experts in physical ergonomics, design and healthcare. Signs of wellbeing such as smiles, laughter, hints and eye-glimpses while competing have also been in focus for the observations. Expressions of concentration and immersion, as in figure 6 were also noticed. Ninety hour of observed playtime.

The Nintendo Wii Sports system saved a record of playtime, high score, etc. Even so, we put up a scoreboard illustrated in figure 7. When the nursing staff were finding out about this they started to show some of the players their own record of personal best.

Since we, as mentioned in the report, did not ask for written approval nor did have equal focus on the other stake-holders in the target group, analysis of those observations are from the accepted interviews. They themselves have spontaneous contributed to the report with comments and reflections given to us.

We used video, because it is of great help for analysis since it is difficult to remember all the details. It is also of great value as a mean to collaboratively discuss, do analysis and evaluate. One aspect we did not think of but that our players asked for was to see themselves on the video while playing. Also because video can be a quite non-intrusive way to collect data with a small fixed video camera rolling during the activities.

Eight one-hour tapes (not everyone is fully used) with 6-8 hours activity and interview.

4.7.2 Semi-structured Interviews

Semi-structured interviews or interviews in an open dialogue format because that direct dialog and specifically given moment and time to talk and express ideas and reflections around the Wii-game activity. Often the dialogue with the players took place during the playtime.

Four video-recorded interviews with;

Staff manager
Programme manager
Social manager
Enrolled Nurse
Two video-recorded interviews with
Two of our players (the other players were observed and communicated with while playing)

4.7.3 Culture Probe
Culture probe because that is a more diverse way of letting the users leave information of any matters they feel is connected to the activity. We left disposal cameras, pencils and a notebook and a note saying just use it – document the play or ideas that come up before, during or after the play. We encouraged our players and their care-givers that they while playing other times then during project-time could use the culture probe to document, leave stories, reflections and comments of any sort.

Culture probe is a concept originally developed by Bill Gaver at that time at Royal College of Art in London Uk as a mean to collect data of use in a non-intrusive way (Gaver et al 2004). We used a modified way of the culture probe concept. It was kept present and available most of the project. In figure 8 our version Culture Probe for collecting data are illustrated.

![Figure 8 “Leave your comment via the culture probe”](image)

4.7.4 Field Notes
Field notes because that gives you as researcher a track to follow when to do the analysis and describe the way the project has been conducted since it falls under the qualitative method genre. We tried to take a time after each play-session was over to discuss and put down notes
about what had just happened. Since one of us were travelling by train (Stockholm – Ockelbo) there were also time during travel to take down notes about the project.

We were two of us, the coordinators of the Wii at Vibacka” project, taking field notes and keeping diaries.

### 4.7.5 Workshop

Workshop since that provides a focused arena for collaborative work, co-designing and problem-solving.

We did one workshop designing a lid to cover some of the buttons on the consol since some of our players managed to press too many buttons at the same time. We did the redesign, following a workshop format together with the occupational therapist, the enrolled nurse, the researcher and took the mock-up and the prototypes to the players and got feedback, went into a new iteration of design, tested and modified.

We worked with different materials and mock-ups that we tested in play. After a while the solution was there and on the consol was added a cover, a lid over the a button since it was a problem that they pushed that button when playing bowling, which stopped the game and made the users in the beginning loose motivation or express that they could not handle the consol and therefore did not want to play or try. The consol with a rubber cover is easier to manipulate and has a more stable position. It does not slide in the palm. We then made the same cover on the other consols. After some iterations and we managed to find a solution that worked for this setting and that they accepted.
5  Wii at Vibacka

In this part, the fifth part of the report, we describe the outcome of the use of Nintendo Wii Sports at Vibacka Special Housing. Part five and part six, are both describing the outcome from the project but trying to separate the perspective from using the Wii and using PD in implementing the Wii game. As PD being a design approach the evaluation is merged together and intertwined with the different iterations but to make it more visible we will here try to separate the discussions.

5.1  Outcome of the Implementation of Wii

Below we will give the results emanating from the different data-collecting methods that were used.

5.1.1  Observations

At the beginning we introduced the users one at a time to give them our full attention and for the extra observations around the study. They gave no indication that they found it odd that something they did with a consol had implications on a screen. Immersion came more or less without questioning.

We observed a development in the way they seemed to trust their own movements. They moved from sitting to standing and from using the Zimmer frame to leave that to the side. In the golf game they did more or less use a full range of motion in arm and shoulders. Those
that stand up bended their knees in the swing (we did not “correct” tem telling them to stand sideways as in ordinary golf). They balanced and adjusted the movements in the different games. The movements get more secure, direct, and precise. The users focus more on the game itself instead of on the movement. Even failures, when shared, can bring joy as shown in figure 9 and 10.

Figure 10 “no strike this time but a happy failure”.

Many of the players have difficulties in that they press too many buttons at the same time causing the game to stop. This make them frustrated and they say no I can not manage to do this. Even so most of them continue with some assistance from us or the caregivers. We start to think in terms of redesign of the consol. Also there are problems in fine tuning the movements in order to for example throw the bowling in the exact right moment. There is a button for us to press in order to let them try again from the same position.
They start to comment on each other’s actions. High score and failures are equally noticed and they give full attention to each other. They start to develop a jargon and a language.

They try out new vocabulary new expressions. Up to three players are active at the same time. Spectators, demonstrated in figure 11, are very involved and supportive and co-move with the players. When the time is over many of the players hang around and cheer-up the others.

The time they need to learn the game varies a lot, but we are amazed by their rapid adoption and skills. Although some of them every time they come start by saying “I have never done this before” one can tell by the way they handle the consol and the smoothness in the movements and the adequate force they put in that they have definitely done this before.

The bowling game was more direct since the time it takes for the ball to go down the line and hit the pins is quite minor as well as the time to do adjustments. The bowling game gave the most direct feedback.
Golf can sometimes take too long and the users lose focus. The users attain new competence, better balance, eye-hand coordination, use their muscles and their physical ability. Endurance is there since they sometimes played for over two hours without interruption, with repetitions of big arm movements extending their range of motion. Figure 12 provides one example of physical perspective of playing the game. I observed what they said and how they said it and how strenuous it seemed to be for them from breathing, colour in their faces etc…and how they relate or not relate to each other while playing. Since it is a competition the outcome is not clear or not given, which is part of the excitement that keeps them alert and motivated to continue and strive for improvements.

*Figure 12 Intensive and energetic goal-focus – including full swing of physical movements.*

Often in the different sports game there are music in the background. This is sometimes, for some of the players quite disturbing. It is not possible to turn the sound off since then you also lose the sound indicating throwing a ball and the sound from the virtual audience giving you sound of praise when scoring and sound of disgust when failing. After some weeks of playing we as coordinators are really fed up by the sound and even with the game. But the feed-back from our players keeps us still motivated. Some of the staff is more active then others in participating in the game and activities around the game. Also in the way they address us and leave comments from the players during play or back at the department concerning the play.
They comment on details in the game, the competitors’ Mii’s and we get amazed that they even see those details. In figure 13 one of the reactions are visualised and in figure 14 some of the designed Miis’ are demonstrated.

![Figure 13 “This was fun”](image1.png) ![Figure 14 Some Mii's on the move.](image2.png)

They got red in the face, breathing became faster, and some reported, with a smile, sour muscles. Immersed in the game, time flies, even for the caregivers. Sometimes, when they looked at the watch they realised that they had finished work, that their work hour time was over. The users got feelings running through their veins, something was at stake, being at stage, win or loose, to gain and not only loose abilities.

5.1.2 Comments and Interviews
We have received comments spontaneously and from semi-structured interviews. Directly or via someone else passing the word. The comments are from a wide spectrum of perspectives. From the head of the municipality, director of social welfare, from most of the different occupations working at Vibacka Special Housing, secretary, healthcare, janitor and the two managers included. Comments derive also from relatives during meetings and phone-calls. Last but not least most of the comments are from the gamers during playtime, interviews and other time during the day.

The comments below are extracts from diaries, video, recorded interviews, dialogue while playing, phone calls from relatives etc. We have put the comments from the players in categories of competition, fun and learning new skills. The comments from caregivers and
managers are in categories of fun, learning new skills, organisational change, physical movements.

The comments from the users/caretakers, caregivers and managers, were originally in Swedish, below freely translated by the author:

**players:**

**competition/something at stake**
"you have been playing more often than me"
"look how good she is"
"the winner instinct is still present despite that I am over 90 years old"
"of course I am in to win"
"now I sweep the floor and clean the house - score"
"you have had more opportunities to practice"
"oh no; I think that the pins are glued"

**fun**
"this was fun"
"just like a kid again playing marbles"
"that bowling-game we would like to play more often but the nursing staff does not have the time"
"it is nice just to get out of the room and get some variety"

**learning new skills**
"last time I played I got three strikes in a row"

**Caregivers and managers:**

**Fun**
"It has been good to see them watch them – you could tell they had fun"
"they become more alert after playing and seems carry a feeling-good feeling for quite some time after"
"I did not have the expectations that it would become such a success"

**Learning new skills**
"It was a little bit nervous since you were not used to this game but you learn if you do it for a couple of times"
"The thing I like the most is to see how they wake up by learning something new. In their case it is otherwise more the situation of preserving skills such as getting dressed and manage the situation with eating"
"For the users having dementia that often get stressed and worried during other activities we see that they can concentrate under a longer period of time then they usually can"
"They have difficulties learning new skills but to some extent they can learn something new"
"it is great to see how they get excited about learning and trying something new. For them it is all about to try to preserve skills such as get dressed, eat and use the bathroom"

**Organisational change**
we who are working with this must get into a new mind-set”
“it is hard to find the time to play”
“in bad mood because some has got to play more often”
“We have decided for the new house to have a better approach towards our users with dementia that they also should be included in the rehabilitation approach.”
“On the municipality level we shall provide a good elderly care and this is a part of the mission to not only provide healthcare but care. Sometimes there is to heavy focus on healthcare. If you need to move into an elderly-care centre you should be able to have a rich everyday life. The caregivers are doing a lot and fix and arrange but the users would like to be a part of this arrangement and fix themselves. There is so much that we never see or use. We should never be too narrow-minded”
“this is a common thing kids play it - it is not something specific for old people, everyone is playing”

Physical movements
“The boxing they did not like. Then they wanted to go home”
“Last time they stood up when they should manipulate the consol – that gives them some opportunity to put some load on their legs to practise and everything”
“They did not say oh no now I will sit they were all red in the face”
“The movement improves if standing – they can feel it”
“You could see and tell when they are sitting there that they are excited: is it my turn now The game invites them to move. They automatically get the physical movement”

There are comments from the relatives either direct to us when being at Vibacka or through the staff that transferred them to us.
One example is when one of the players called her relative saying I won, I won. The relative not getting, whether it is from bingo, or what from what?. The player being unable to explain what but all excited. The relative calls the Special Housing to find out.

The Interviews
The overall aim of the interview was, to have their reflection on the project, on game and Special housing, on physical activities. The different categories of staff all mentioned something around need of change within the way elderly –care normally are organised. Also the way we have been seeing people suffering from dementia and their possibilities to be active. The interviews with two of the players, (as mentioned before, the other players were observed and communicated with while playing) underlined their saying during active playtime that they enjoyed being physically active and compete but that some of the games they did not like and some of the games were to difficult.

5.1.3 Culture probe
The outcome from the Culture probe was that although we many times tried to point out that it was theirs and there for them to use in whatever way they wanted it was hardly used. Some pictures that does not show anything and there were not even one note in the notebook.
5.1.4 Field notes

The outcome from the field notes are very divers and we will discuss that under the heading of discussion in this report. The field notes describe sometimes what action took place during the playtime, sometimes they report on a reminder of action to be taken into consideration. By writing the field notes as somewhat a story we hope to be able to give a picture of the actions that are hard to communicate in words when the reader does not have the memory of the action to relate to.

We also had to try out words and ways to instruct and teach the handling of the consol and the system interaction. In order to reach and teach our users the way to handle the system we had to individually adopt different ways of introducing them to the game and support them in the movements. We made the movements ourselves in order to give for them a visual clue and used words, sounds, gestures and we guided them in their movements by giving physical support and led them through the movements. We took away the armrest from the armchair for the users that have lost the ability to stand in order to have more free movement space. We provided chairs for those that are stable to stand giving free space to move the arms freely.

After a while they felt more secure and more motivated to perform and we helped them to stand up and then after some time of playing they stood for themselves. Then they got to play against each other, sometimes against someone they know and sometimes against someone that they did not know.

An example from a field note (we have changed the names although they have accepted to be quoted we feel that we want to do this as a courtesy to our players:

March 28, 2009 expert from the field notes:

Anna-Lena and Alva played happily for about an hour. Somewhat disappointed when they were asked to change and let Elvira and Anneli the caregiver play. I was going to follow Alva up to her room but she asked to be left watching the other play if it was not time yet for dinner. Elvira and Anneli competed in bowling. The joy were big "lyckan var stor" at the part from Elvira when she after half-time in the match was at lead. She pushed at Anneli to make her attentive to that situation. Alva was sitting to the side and commenting. After a while Mona from the manager department came around and did a boxing match with Anneli.

5.1.5 Workshop

The outcome from the workshop was a lid a cover to put on the consol in order not to press too many buttons at the same time (since that would block the game). The lid and the material used is demonstrated in figure 15 and figure 16. We also established good contact with the occupational therapist that most of her time worked in another house and in that house she also had the office.
We chose to report under workshop-heading one of the spontaneous activity that the staff did: After some time the nursing staff started to share their ideas around improvements. A board was put up with the results from the fights. We realised that we had anticipated that they did not want to compete but the nursing staff had got comments around the matches and thought it would be a good idea to mark them down and show them.

5.2 Discussion

From observations, analysis of video and photos, from the note books, from comments from the players, relatives, the caregivers and other staff at the Special Housing the overall impression indicates that Wii provides an opportunity to move, to compete, to improve, to focus, to learn and to interact in ways that are not easy to provide within the usual repertoire of activities for elderly suffering from dementia and living in a Special Housing. As reported in for example the Swedish Television “Uppdrag granskning” there still seems to be problematic to implement activities that people suffering from dementia and living in a Special Housing find meaningful to engage in (SVT, 2009)

They "learnt" how to interact with the system.

The game gave the users a possibility to act on a different arena than as caregivers and caretakers. They are no longer the ex police or ex nurse or current nurse, they are the winner of the day in Wii-bowling. Relatives commented that they were so happy to see how their grandma told them about what they had been doing, winning, playing etc. This finding is supported by Thille and Wrammer writing about “four Cornerstones for Aging Well” were physical activity and having a sense of belonging and engaging in activities that one find meaningful, are two of the four cornerstones mentioned (Thille and Wrammer, 2000).
We planned the project together with the ordinary caregivers in order to have it work smoothly with the normal agenda.

After a while it was decided that this should be part of the normal job activities and the caregivers added it into their ordinary planning. This decision was taken as a result from the caregivers’ discussion with the manager during some of the design-sessions.

Wii is easy to adjust in order to support the user’s level of coordination and strength. Due to this it gives a quick access to the game and we do not need to put too much of effort and time into learning and training to get going. Although we might think that our users have all the time in the world to do this they are not interested if it looks too complicated and if they do not see the benefit. Immersion in a game were the action you do or the movement you perform has a direct outcome seems to be something they liked.

In a game such as Wii Sports the focus is outside ones body. The body and mind “co-work” in order to score – to get at strike or a hole in one. In terms of balance, focus, adjustment of force and tempo. This is a major advantage from gymnastics, where the movement itself is in focus. The users stretch the arms and move their legs in sitting gymnastics. It can be seen as more of a check-up that the function is still there but they seldom get a chance to use their physical ability in an activity that is more motivating for them. The caregivers commented that their users had become more alert and more active also back at the departments. They told us that the users say that they have won but do not always remember what. According to findings by Fratiglioni and von Strauss, being involved in activities that one perceive as mentally stimulating seems to have a regulation effect on the level of risk for dementia (Fratiglioni and von Strauss, 2006).

The method throughout the project has been participatory design methods and user involvement. In Ockelbo the users almost directly discarded the boxing game, although we, as therapists, would have loved them to make the movements involved in boxing. We were careful not to persuade them to play since they were very clear on not wanting to do boxing. They said yes to bowling and golf. Topo and Österlund reports that, people with dementia have often played a passive role in the investigation of their conditions (Topo and Österlund, 2009). We tried hard to avoid this in the Wii at Vibacka project.

Game over or play it again and again…The study is over but the game continues and other sites in Sweden has been in contact to receive information and support. Media cover has been big and it has drawn attention to the elderly care that otherwise often only get public attention when something is wrong. We refer again to “Uppdrag granskning” and the program “the last sweet years” in Swedish “De sista ljuva åren (SVT, 2009). Subject for discussions during the project, with the different stakeholders has often been concerning the difficulties around people with dementia and activities that motivate and involve them to be active. There has been sometimes almost too positive and we as being the coordinator reflect upon thought as “do they really have that boring in their everyday life that this is getting so much positive comments?” To this we have no answer. We observed that they seems to enjoy to compete that their motivating and strive to coordinate their movements to score seems to augment in front of the Wii-screen.
6 Wi at Vibacka through Participatory Design

In this part we will try to communicate the outcome of the design approach. It was its drawbacks to be done in text as it is a very much a knowledge that is visible in the action. We report on level of participation and the notion of something not being ready from the start.

6.1 Outcome of the use of Participatory Design

The aim of this report has been to evaluate and reflect on participatory design as an approach for interventions within elderly care. Real people real situations open mind and: Involvement avoid design-assumptions being made that not meet the real user. Evolves by the step that are taken and we are all following and on the same arena of understanding.

Outcome from PD is that the number of participants kept growing during the project and from professionals we did not actively involve. We did address a variety of groups but were happy to notice that many more entered the game and did participate in discussions and at play. As an example we mention the secretaries of Vibacka. It was hard to attract interest from the assistant occupational therapists appointed to focus on activities they show no interest although we tried several times to invite them to participate.

To the outcome of PD we also have the design aspect. Wii being a ready-made product but Wii at Vibacka being something new it was not clear from the start how this would work out. In that way it inspires and motivates to participate – we could all join in to make it work and be something that fit the organisation and the site Vibacka.

Paper copies about the schema are being sent out and on the different corridors one has been appointed Wii-responsible. This was something that came up during the design meetings that the caregivers had a detailed fixed schema and that in order to make the Wii happen it needed to be incorporated in their routines. They took this information to the manager that gave a “go” on the proposal. After some paper-works and more discussions, the Wii were part of the schema. The target group do participate! To our surprise they seem to like this and adopt much faster than we had ever expected. The game attracted caregivers from other departments and other areas. The house-keeper, managers, service nursing staff, secretary and visiting relatives did not only join in the design-meetings for planning and introduction. They stopped by and were invited to try it out, play and see for themselves. They were at the beginning saying that they could only join in on the design session. The players, the gamers, the users tell us that they enjoy to compete and to fight. This was something that we had not anticipated and the design of the study was modified accordingly. We ask the caregivers to match them in competence to have a match going. Seeing them, our players, as experts in the design.

Provide means of communication and something at present to “talk” about through body-language since for some of the players speech ability language had been affected by dementia.

Some of the research methods when focusing on activities and dementia do not include contact with the people staying or living at a Special Housing. The real people and methods used at Special Housing when focusing on dementia and activities for implementing new activities at Special Housing. Information about research results but how shall it reach the will it be implemented.

We used the possibility in the game to design the user’s own player. Some make made them look alike some make made them extra “cool”. Some took the opportunity to have full make-up and hairstyles that really stand out. This was an extra activity that we did not anticipate.
They commented each others’ player and seem to enjoy teasing each other about the style on hair and eyes etc. Producing a player did provide input to many side-discussions. Often the situation was that one of us was in control of the consol (since one had to use many different commands in order to make these so called Miis’) and the players sat watching and giving a go or no-go on whatever came up on the projection screen.

Erling Bjarki Björgvinsson states that

“The validity of the participatory design research results is therefore partly judged by how the involved stakeholders value the results” (Björgvinsson, 2007).

We chose also to mention that the project got huge cover the project in Swedish media, both on a local and on a national level. We have not been able to spot who passed the work on to media. We just want to point out that we did not act in any way to draw their attention.

Fine balance between care and life fine balance between public care and nursing staff responsibility for our family members. But less effort on the actual situation in the daily care and resources allocated and design of society that is partly to blame for the difficulties in caring for our dear and near ones when they get old and in need of help. Families tend to live quite a distance from each other.

Participatory Design as an approach when performing interventions within the domain of elderly care and dementia might seem initially unclear and fuzzy this may provoke some and get negative attitudes from others. It is time consuming since every stakeholder will be giving time to reflect and participate. Participation risk the agenda being full of ambiguities and PD being seen as an approach with multiple possibilities for different methods being deployed it can be discussed if different projects pursuing that they use PD can be compared.

Successes in suing PD may be due to that one can call it design and use concept of design methods as a filter between and as an arena for development and discussion were the subject in focus can be to hot and therefore not so easy to put out on the open on the table. To see it as a model of design can make otherwise tuff discussions and fight for power to be less dramatic. Working through some of the methods used in PD could be of great value in a traditional culture such as that within elderly care. All these methods could be of great value to break traditional patterns in work-culture that keep

We decided at the start of the study to try to follow as smoothly as possible the present work culture and to be careful not to “take over”. The purpose of this was that we wanted the institution, if the result would be positive, to incorporate the game in the care that they provided for the users. That is part of the reason that we chose the participatory design methods for this project. We also believe that such methods are very well suited for these kinds of interventions and actions, in order to observe, listen and co-develop the activity together with the users in a broad perspective involving the manager, the caregivers, the users, the service nursing staff, caregivers and relatives.

6.2 Discussion

Step by step we got more and more skilled in handling the system. We spent a lot of time introducing caregivers and the users. We were no experts in the computer game field and tried to overcome problems as they did occur. The fact that we ourselves had no prior experience of this game or for that matter any other computer or TV-game had its advantages and drawbacks. On the one hand we often felt that our lack of technology skill was time-consuming. On the other hand we discussed that that might have had a positive impact on the others since being a computer game-novices was representative for the nursing staff in this domain. When they realized that we did not come as experts the step was a little smaller for
them to be active in the development of this activity within their workplace. Rather them being the experts on their situation and as Bødker et al., involve them in the design process (Bødker et al., 1987).

We see also that when involving the users in the design of their everyday activities they might not ask for luxury activities. We know both from research and from stories form real life that Fia med knuff is very popular and that is not expensive See one of the project reported under “Genombrotsprojekt” at “Åldreportalen” (www.kompetensstegen.se/page___1143.aspx).

Fia med knuff or wii we don’t mind but just we do mind the users being left outside the power of their own life and just left with living. We should not think that they want to do the dishes or just do bingo or go on very artistic track….they may just want to play fia med knuff and other games…

Using PD can be very time consuming and frustrating in that one sometimes think lets just do it this is the way it should be done. Then to set your own ideas aside in order to listen and collect information from other stakeholders in the project and let their voice colour the outcome can be very demanding on everyone involved. Also to use PD will test your ability to endure unclear situations over a long period of time. Since from the beginning almost nothing is decided or clear. The time to orientate and get to know each other and the design material and the site are often time consuming. Time being money it takes resources to do this. On a practical level PD has proven to be an approach well suited to make change that lasts since there is a reflection going on and since real people in real places are involved. It is not something the researcher do and then when she or he leaves the game is over.

We reflected on all the positive comments around the joy to compete, that something is at stake, that they reported positive on the “stress” of possible failure in the game. Behind the dizzy gaze and the stiff movement there seems to be a real fighter and that will do the uttermost to perform. If possible we should consider to let them take part in their own everyday environment if the wish to do so.

On the other hand it can, while writing scientific report, be difficult to sort out and define results from method. That instrument for analysing the data might be tricky. To track who were the origin of what idea and what design-suggestions could be difficult but in real world and in a design oriented environment it is the same situation and that it is the same issues also within design research.

When reading about interventions and research in this domain there seems to be a gap between the way the research are being conducted and the way information about results travel to the real settings. Judging form research results, staying at a Special Housing seems almost tempting. What are the link between research and reality? Does the result have any impact on the agenda at Special Housings? When it comes to research focusing on social innovation or the agenda of activities we might consider the research is done on, for or with them. When it comes to what they want and what we think they want can be quite fare from each other. We are the first to admit that even with participatory design as approach we ran into being caught by our own prejudices telling us “no they do not want to compete they just want to play without stress and without any pressure or demand”. When being open a guided by our observations with focus on the users, by the users comments and in other way expressed will, we realised that we had got it all wrong. They like having something at stake. Something that is now, and not then or never. We felt sometimes that we had put a flame on very dry wood, because it took off so big.
7 Conclusion and Future Research

Chapter seven, the last part, in which we will sum up and conclude our findings and propose future research.

7.1 Conclusion

Participatory design as an approach when introducing new activities for people suffering from dementia and living in Special Housing has proven to be successful in this project.

We could, however, also identify some obstacles. It can be quite frustrating and stressful to handle the situation of starting off with nothing more then an approach of participation and design to guide the way. This may seem quite blurry both from the inside and from outside.

Participatory design proved to be successful in terms of the outcome for the players and the broader target group in trying to provide fun, engaging movements where something is at stake. Regarding the use of Participatory Design to achieve this it was found that Participatory Design could lead the way through the design of such an intervention and inviting many different stakeholders to participate and be actively part of the game.

We conclude with five points that we found being part of leading towards the success:

1. Participation in all stages and on all levels
   invite, include and introduce everyone
2. Close way to management
   establish a mean for communication, make “way” to/from the top as direct as possible
3. Communication through design - design through communication will bring front and get the knowledge out to produce/organise elderly care – not good methods to see afterwards if the care we provide is good
4. The approach blends cultures and give opportunities for learning and reflection in action and will feed into future changes and improvements
5. Since PD is an approach and not method it is something that comes form within and therefore avoid being taken as something that is put on from above.

PD as a method we found very well suited for intervention and organizational change work and for research projects in development change and learning it has a democratic base that one could argue is well grounded and suited for the Scandinavian culture.
7.2 Future Research

Based on the findings from this research it is possible to identity a number of issues for future research. We would like so see more focus on participation and we do mind the gap between fancy ideas in research studies and the fact that everyday life for people with dementia is darn boring and that there are very little resources.

We would very much like to encourage further research and development into fun as a tool within elderly-care. This could be done together with game developers designing or redesigning games to fit a specific purpose and a broader target group. The golfer in figure 17 is a man in his 80-ties. Too often the technology-oriented development-projects and systems for elderly put focus on monitoring and assisting in assessments, as in smart/intelligent homes, fall prevention, safety alarms etc.

Although we know that in many countries outside Scandinavia this is quite established. Sweden being seen as an IT- mature country with high knowledge in Healthcare should speed up and join the Games for Health Community more then it has today. There is a conference on the subject. Find more information on www.gamesforhealth.org/archives/000250.html.

Experiences and Challenges – there have been some comments on the Wii at Vibacka on the net that we would like to include as curiosa in this report. It shows that participation has been much broader then we had ever expected.

Comments on game-community sites about the Wii at Vibacka
http://www.gamesforhealth.org/archives/000250.html

A blog in Swedish about the game development within elderly care
http://tvspel365.bloggagratis.se/

The Queen of England plays in gold! What shall we give to “royal” Ockelbo?
http://videogames.yahoo.com/events/plugged-in/the-royal-Wii/1316670

Figure 17 "As long as I am still in the game I want to play, for laughs, for life, for love”
one of our players Miis’ out on the Golf Court
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