Summary
Over the last decades, long-term care institutions have been challenged to develop client-centered care, meeting the needs and wishes of the people who are dependent on care services. People who live in long-term care facilities, such as residential care homes, are increasingly being considered as clients, consumers and citizens with a valuable voice instead of as vulnerable patients who do not need, cannot have or do not want to have influence.

This thesis is about the influence of older people who live in residential care homes on collective issues that affect their life in the institutional context. It explores how this influence takes place and how it can be developed in a way that is valuable to all who live and work in residential care homes.

The introductory chapter, Chapter 1, describes the background of power and influence of older people who live in residential care homes. On the one hand, this power tends to be limited, due to the impact of totalitarian and repressing environments of health care institutions and ageism, leading to structural dependency, depersonalization, disengagement and frailty of older people who live in residential care homes. On the other hand, new developments can be distinguished that counter the lack of influence of older people in residential care homes, including individualization, the rise of a negotiation culture and liberalization of national health care policy. These developments have led to the coming into existence of patient movements, client-centered/demand-driven care, and patients as ‘third party’ in policymaking. Patients, including older people who live in residential care homes, are increasingly being seen as consumers of care services, whose power is channeled by their consumerist voice, supposedly based on rationally informed decisions. The consumerist approach can be at odds with the possibility of patients acting from a sense of citizenship, with an eye for others, solidarity and contributing something to society.

At the intersection of the consumerist and citizen approach towards patients, the Wet Medezeggenschap Cliënten Zorgsector (WMCZ) is a legal act that obliges every care organization in the Netherlands to commission a client council (resident council in long-term care). The development of this legal act can be seen as part of the increased political and societal attention for supporting vulnerable groups, such as patients, to determine their own lives despite the vulnerable situation (physically, mentally and/or socially) they find themselves in.
At the same time, client councils can be seen as an instrument for voicing the consumerist side of care. They can claim good quality of care and act as a sounding board as well as a watchdog for managers.

In order to assess the influence of older people who live in residential care homes, we make use of Arnstein’s participation ladder of citizen participation that reflects diverse levels of the influence of citizens in policymaking processes, ranging from non-participation, to tokenism, to citizen power. This ladder can be translated to the context of residential care homes given the hierarchy between professionals and residents.

The societal developments that have been described in this introduction chapter show that attempts are being made to strengthen the power position and influence of older people in residential care homes. The question arises to what extent these attempts are successful in addressing the challenges of the existence of hierarchical power relations in care institutions, as well as challenges related to bridging theoretical/ideological/legal support for the influence of older people in residential care homes to the daily practice in these environments. This context led to our research aim and questions. We wanted to investigate the existing form for resident involvement in issues that affect their life in the institutional context (resident councils) and to explore what are good ways for supporting and developing the influence of older people who live in residential care homes on collective issues that affect their life in the institutional context.

The general question that underlies this thesis is formulated as follows:

*How can older people who live in residential care homes influence collective issues that affect their life in the institutional context?*

Departing from this general research question, we formulated five specific questions:

1. To what extent does the formal structure for client participation by resident councils support the influence of residents in the residential care home and how can this situation be improved?
2. What alternative ways and processes for client participation in residential care homes can be developed in order to strengthen the position of residents and their influence on issues affecting their lives?

3. What are barriers for alternative ways for client participation in residential care homes and how can these barriers be explained?

4. What are success factors for alternative ways for client participation in residential care homes?

5. How can insights about barriers and success factors for client participation be used in residential care homes?

In order to answer these questions, we have developed research projects concerning resident councils and managers (evaluating the status quo of resident involvement), and with residents and professionals in residential care homes, exploring new forms of resident involvement (action research). We have used responsive evaluation and action research (including elements of appreciative inquiry) as research approaches, which can be placed within the paradigm of transformative research.

**Part 1 Resident Councils**

*Chapter 2* describes the mutual frustration and ineffective interaction between resident councils and managers. In this chapter we investigate by the use of responsive evaluation to what extent communicative action (as Habermas describes it: herrschaftsfreie Kommunikation) between resident councils and managers in residential elderly care is actually possible. We describe how, according to Habermas, in communicative action, people step out of their strategic, and ego-centric rationality, their formal role and identity. They open up to others as people with a name and a face, and with the willingness to engage in processes towards reaching mutual understanding. Communicative action is an important prerequisite for older people and their representatives in residential care homes to be able to participate in policymaking processes, because this gives room to lifeworld values. The lifeworld can be
considered to be the backdrop against which daily interaction between people takes place, aiming to develop mutual understanding.

In this chapter we depict the shortcomings that resident councils and managers experience in their communication and joint policymaking processes, including a lack of influence of resident councils, complicated long-term policy issues, supposed incapacities of resident council members, differing scopes of what matters the most, top-down communication from managers toward resident councils. The influence of resident councils was experienced as poor and tokenistic.

By comparing two cases (one reflecting strategic rationality, formal identities and hierarchical power structures, the other showing more communicative rationality, lifeworld identities and a shift in hierarchical power structures) we conclude that resident councils find themselves between lifeworld and system. This chapter further shows that communicative action between resident councils and managers, which focuses on mutual understanding and consensus, is complicated, though not impossible. There is room for communicative action between resident councils and managers, but it is easily dominated by strategic action. Therefore, space for communicative action needs to be deliberately created in order to support resident council participation and influence.

In Chapter 3 we build on the insights about the barriers for communicative action between resident councils and managers in order to strengthen the position of resident councils and to create more communicative action and mutual understanding between resident councils and managers. The marginalized position of resident councils asked for a research approach that would also pay attention to, and positively change, the power position of resident councils. We describe how our use of responsive evaluation as a vehicle for social change, enhanced dialogue and mutual understanding between resident councils and managers.

The issues that hamper the communicative action between resident councils and managers, are in this chapter related to the existence of different value stances. By explicating values and experiences, resident councils learned from each other in the homogeneous phase of the responsive evaluation that they could act differently (speaking up for their values and setting
the agenda) in order to change their marginalized position. Managers also exchanged their experiences concerning their collaboration with resident councils (negative ones but also best practices) in their homogenous setting. They learned from each other how they could involve the resident councils more actively and that this could affect their relationship positively. Shared learning processes of resident councils and managers occurred in the heterogeneous phase of the responsive evaluation, resulting in the discovery of common ground (the wellbeing of residents as their shared value). Further, these resident councils and managers formulated prerequisites for improving their interaction together.

In this chapter, we draw the conclusion that resident councils and managers should give room to hermeneutic dialogue (learning processes by exchanging experiences and diverse perspectives) as well as to horizontal and deliberative communication. Further, we recommend that long-term care organizations must find creative ways to place clients' stories about their daily and concrete experiences on the policy agenda.

Part 2 Alternative ways for resident participation

Chapter 4 describes our first endeavor in developing new ways for creating influence of older people who live in residential care homes. This chapter tells the story of a team of professionals in a residential care home, that invited one client in their project team (with the task to implement new care files) in order to give room for resident involvement. This story is presented in the form of an ethnodrama with embodied narratives that represents actual situations that arose. The ethnodrama describes four ‘scenes of confusion’: situations that occurred in chronological order during the existence of this particular project team and that confused the participants about how to connect their good intentions concerning resident involvement to the factual interactions between the members of this project team.

The resident who participated in this team of professionals felt he was standing alone, and this feeling ultimately led to him leaving the project team. The professionals felt frustrated about this failed resident involvement, because they had the sincere intention to make this work. Thus, the question arises why the interaction between this resident and the professionals in
this project team did not work out successfully. Also in this chapter, Habermas’ theory on lifeworld and system turns out to be helpful in analyzing the data from this study.

We explain how the lifeworld and system became entangled in a new way, by the attempt of these professionals and resident to collaborate. The system relates to material reproduction in society and is driven by the economy and the state. It is characterized by instrumental action, directed at profit, the regulation and rationalization of relations between citizens, and the strengthening of one’s own position within the system. The lifeworld refers to the symbolic reproduction in society and is characterized by values that are intrinsically cultural and personal, and by communicative action. The lifeworld can be seen as a coherent set of cultural and social norms and identity structures that form the unproblematic horizon for human interaction. Communicative action is directed at finding agreement and shared understanding.

What happened in this team that consisted of one client and seven professionals is the following. The professionals, who were used to acting instrumentally within the system world of the organization, were confronted with the lifeworld of the client in this team. His personal stories and attempts to discuss with the professionals what he experienced to be core issues of living in a residential care home (such as ‘what does it mean to be ill’, ‘what is good care’, etc.), confused the professionals as it was alien to their usual way of communicating and functioning. The client appealed to the lifeworld values of the professionals, to their presence as human beings rather than as bare representatives of the organization they work for. At the same time, the professionals tried to give the client a place in the system world. This tension confronted the members of this project team with differences concerning power, identity and rationality.

In this chapter we conclude that, in order to develop communicative action between residents and professionals, the differences that exist between them have to be acknowledged first. Another important insight concerning resident involvement is that the Habermasian definition of the ideal speech situation, in which deliberation with a focus on rational arguments is central, is too limited to provide an answer to the reality of power asymmetries in residential care homes. Deliberation that presupposes and prefers rational arguments,
excludes other forms of expression (emotional, embodied, passionate, etc.) and thus excludes people who express themselves differently.

Thus, in this chapter, we argue that real communicative action between clients and professionals can only occur if they are all open about their emotions, share their frustrations and engage in storytelling and the discovery of shared experiences and values. Developing new ways for resident involvement requires that power relations and differences in identities and rationalities are taken into account, as well as different forms of expressions and deliberation, including emotional expressions and storytelling. We argue that to this end, clients should first be supported in developing empowerment and creating space for their own forms of expressions and experiences before going into dialogue with professionals.

In Chapter 5 we build on the insights from the previous chapters and studies, as well as on literature from political theory (enclave deliberation), social psychology (relational empowerment) and evaluation theory (giving room to marginalized groups). From this background, we saw the need for developing collective participation of residents, engaging them in interactions with each other in order to develop a shared vision on issues they want to improve. This chapter describes the action research project concerning the group of female residents who wanted to improve the meals in their residential care home. These residents became ‘The Taste Buddies’ through a process of relational empowerment, which is non-linear in the sense that The Taste Buddies did not exhibit a straight progression from having little influence to feeling empowered.

The chapter presents in detail the phases The Taste Buddies went through during the action research project. In the first phase, a group of residents – later to become The Taste Buddies – were asked to talk about their experiences of living in the residential home. This created the opportunity for these residents to set the agenda for the research project and for practice improvements in the home. In the second phase, the residents got to know each other and the researcher. Their interactions were characterized by carefully exploring shared experiences about the meals and initially downplaying anything negative. A turning point led to the third phase when The Taste Buddies began to feel more comfortable with each other. They felt empowered by the discovery that their discontent about meals was mutual. This led to
a fourth phase in which the repeated sharing of negative experiences resulted in stagnation. However, a bit of creativity (making a collage together about the ideal meals) succeeded in bringing this negative spiral to an end. In the fifth phase, the residents succeeded in turning their discontent into constructive advice and partnership with service providers for improving meals. They developed a sense of ownership and responsibility for creating actions to improve the meals. This was the point when they started to call themselves The Taste Buddies.

The chapter further describes the practical results concerning the meals The Taste Buddies managed to achieve: the re-opening of the kitchen in this residential care home to have fresh meals prepared by a cook; menu choice for those residents who want to have dinner in their own room; care workers now wait outside the restaurant to pick people up instead of urging them to finish their dinner quickly; there is now direct communication between residents and cooks because they walk through the restaurant and chat with residents; the monthly theme dinners have been reinstated; and The Taste Buddies have a say in the menu and regularly meet with the cook and team leader to speak about the quality of the meals.

This study shows the value of group meetings for residents. It is crucial for personal and/or community change that people are supported by a collectivity that provides a new communal narrative that stimulates change. The discovery of common interests and developing a group identity strengthens people's capacity to advocate for themselves. The process of The Taste Buddies indicates that deliberative democracy, participation and empowerment are concepts that closely and mutually influence one another: democracy and participation foster empowerment, and vice versa. The findings of this study lead to insights concerning enabling factors for resident involvement, which are: support and open attitude of managers; creating time and space for the exchange of experiences through narratives within one's own group; and relationally responsible and appreciative facilitation.

The chapter concludes by stating that empowerment amongst a group of residents is needed first, before having dialogue and collaboration with professionals. This chapter shows the value of the process residents can go through together, building interpersonal trust, finding common ground and a communal narrative, developing a social identity, and exploring their ideas and experiences in an environment of mutual encouragement.
In *Chapter 6*, the PARTNER intervention is presented as a work format for resident involvement as partnership development. The theoretical framework of the PARTNER intervention is rooted in ideas on citizenship, collective action, empowerment, and interactive policymaking. The acronym PARTNER refers to the key concepts underlying the intervention: Participation, Action, Relations, Trust, Negotiation, Empowerment and Responsiveness. The PARTNER intervention exists of five steps that are visualized below. The aim of the PARTNER intervention is developing empowerment and partnership relations between clients and professionals.

The steps of the intervention are:

1) *Agenda setting by clients*

The facilitator brings together eight to ten clients with diverse backgrounds, interests and experiences and organizes a meaningful conversation about how they experience living in the residential care home. Values, identity and life-world experiences of clients are shared. On the basis of shared experiences and values, this group of clients set an issue on the agenda for improvement of community life and wellbeing in the residential care home.

2) *Homogeneous groups*

This group of clients comes together eight to ten times with the facilitator to speak about the topic of their interest. In this setting, they learn about each other’s perspectives and to articulate their own voice. Creativity stimulates their conversation, and helps to think in possibilities instead of problems. This client group also enters into dialogue with other clients as well, for example by speaking with the resident council and by organizing group discussions for all residents.

Besides this, the facilitator organizes homogeneous meetings with other stakeholders who are concerned with the topic that is to be addressed (one meeting per stakeholder group). These can be healthcare workers, volunteers, family, managers or other groups, depending on the topic of the action group. These meetings are meant to organize the articulation of other perspectives on the topic and to lay the foundations for partnership development, which
requires the involvement of other groups in the residential care home to work together with the action group of clients.

3) Heterogeneous groups

When the residents in the action group wants to try out their ideas for improvement and they need practical support from and collaboration with employees, resident council, volunteers or managers to organize some (pilot) actions, a first small-scale heterogeneous meeting is organized by the facilitator. The pilot actions that follow from this first small-scale heterogeneous meeting, form input for the action group to further develop their plans and ideas.

During the final heterogeneous group meeting, the action group and other stakeholders meet face-to-face to exchange their ideas for practice improvements (developed during the homogeneous phase of the intervention and by pilot actions), under guidance of the facilitator. The facilitator brings forward the diverse ideas and plans for practice improvements, and first facilitates a dialogue on the values that underlie these ideas and plans. When participants have developed mutual understanding on the underlying values and found common ground, they then speak about possibilities to combine and implement ideas. This way, a joint agenda for practice improvements develops.

4) Formulating ideas and plans

The action group and other groups formulate their ideas and plans for practice improvements during their homogeneous groups and during the heterogeneous group(s). This way, as many action agendas arise as there are stakeholder groups. However, as a result of the deliberative process in the homogeneous groups in which other stakeholders are already introduced to the client perspective and vice versa, there will be overlapping ideas. The facilitator's task is to systematically structure all these ideas and plans and use them as a way to foster a dialogue about values and the creation of mutual understanding in the final heterogeneous group meeting. The next step is that the action group of clients and the others stakeholders come to concrete agreements about ‘who is going to do what and when’ concerning the practice
improvements. This involves negotiation between clients and professionals concerning the possibilities (in terms of money, time, personnel etc.).

5) *Action in practice*

During the heterogeneous group, participants have come to agreements about collaborative actions that improve community life and wellbeing in the residential care home. These actions will be jointly evaluated by the clients and stakeholders after some time. New issues or ideas for practice improvements can develop from this collaboration, which can lead to a new PARTNER cycle.

This chapter described the outcomes of a qualitative evaluation study concerning how residents, volunteers and staff of a residential care home experienced the process and perceived effects of the PARTNER intervention are described. Interviews, participant observations and focus groups were conducted.

In this case, the action group of residents set the topic of strengthening social interaction on the agenda of the PARTNER intervention. The occurrence of exclusion, bullying and other negative interactions was an urgent matter, not only according to residents but also to volunteers and staff members. By means of the PARTNER intervention, the action group started to organize ‘gallery parties’ for residents, in order for them to get to know each other better and to create opportunities for positive interaction. Volunteers provide some practical support during the gallery parties.

The evaluation study sheds light on how the residents, volunteers and staff members who were involved in the PARTNER intervention perceived the process and effects of the intervention. The chapter describes that the intervention helped residents to build a group around an issue that bothered them, in this case negative social interactions. Action plans were developed in the form of gallery parties and a buddy project. With help of volunteers and professionals residents realized their plans which have become a structural part of the institutional activities. The evaluation shows that residents who were involved in the PARTNER intervention developed empowerment. The intervention also had a positive effect
on volunteers and staff members who were involved. Critical elements in the process were the agenda setting by residents, the formation of a cohesive group, the sharing of experiences and stories, the development of collective action, and the development of partnership relations between residents and professionals and other stakeholder groups. These elements are being discussed, as well as the role of the facilitator in guiding the action group in an appreciative manner.

The chapter ends with the conclusion that structural partnerships between residents, volunteers and staff in residential care homes need to be developed further, because this leads to empowerment of residents and to positive effects for volunteers, professionals, and other parties, such as resident councils.

In Chapter 7, the discussion and general conclusion, the research questions are answered by the main findings of this PhD research. Further, this last chapter describes new insights concerning the influence of older people who live in residential care homes on collective issues that affect their life in the institutional context. Finally, this chapter offers a reflection on the transformative research paradigm, methodological issues and suggestions for future research.

A new insight that stems from this thesis concerns the value of partnership. We reflect on the participation ladder that was presented in the introduction chapter and conclude that we developed client participation by climbing up the participation ladder from forms of tokenism to more citizen (resident) power in the form of partnership. We argue that partnership is the desired form of power relations in residential care homes, because this is the rung of the participation ladder that creates most opportunities for learning, communicative democracy and the development of relational empowerment.

Another insight this thesis provides is that the influence of older people who live in residential care homes can be enlarged by forms of involvement that are featured by the starting points of enclave deliberation and communicative democracy in which differences between people are seen as vehicles for mutual learning and collective problem solving. We thus propose a form of representation and involvement of residents which is grounded in deliberation amongst
and between groups of people and the acknowledgment and appreciation of differences so that learning can occur. This is a form of client participation that can form an addition to the interest-based democratic model, where a minority of people is chosen by voting to represent others.

In this final chapter we also reflect on transformative research and the role of the transformative researcher. After mentioning the methodological issues of our studies, this chapter ends with some suggestions for further research concerning applicability and prerequisites of the PARTNER intervention, outcome measurements, and culture change. We conclude that developing partnerships in residential care homes (between residents and between residents and professionals) is an ongoing process. The PARTNER intervention is a means for entering this process. Also in the context of old age and institutional life, room for transformation, learning and human flourishing can be found.