

SELF - ZEELAND

Pilot SELF – structure:

“TOWARDS DEMENTIA FRIENDLY COMMUNITIES IN ZEELAND (NL)”

1. Challenge – problem

Dementia has the highest imaginable disease burden. And as a result of the rapidly growing number of people with dementia in the Netherlands and in Zeeland, and of a decreasing capacity of intramural care (especially nursing homes and assisted daily living facilities) **the number of people with dementia living at home (now already at 70 %!) will rise substantially.**

Against the background of the expected further austerity (national) government policy within the care sector, it is obvious that self-reliance of (older) people in need of help and the role of informal caregivers will become more and more important. **On top of these people’s own coping capacities, an increased sense of community will be needed, and innovative forms of meaningful volunteer work will have to be provided with. Moreover the strengthening of formal and informal support through initiatives in the immediate environment, by individuals and groups who are personally or indirectly involved, will be a necessity.**

2. Solution: activities

THE DREAM

In 2019 the testing ground “Zeeland Bridges” has been realized. People in Zeeland are capable of coping with dementia. Hopelessness is superseded by a new perspective: people with dementia in their environments know what dementia is and how to maintain or restore their integrity, equilibrium and sense of wellbeing when challenged by it.

It is not the organized care sector which is leading on this testing ground, but the citizen power and capacities of all people in their communities. In close cooperation with all stakeholders in the environment of people with dementia, knowingness has led to awareness and to an approach and to activities. All people involved have learned to manage their lives better, and to enjoy collectively a more fulfilling quality of life.

In Zeeland (NL) a core group of people originating from very different parts of society, both from the health & welfare sector and from the regional civil society, is facilitating an intense campaign for two years now, with the goal of enhancing the number of initiatives aiming at **improving the quality of life of people with dementia staying at home** and of their informal caregivers. Quite a few preliminary research projects on different domains throughout the region have shown eagerness and creativity when it comes to invest in activities contributing to the physical, psychological and social resilience of both the people involved and their communities.

So this subproject aims at **co-identifying, co-initiating, co-testing and co-monitoring socially innovative solutions** with the goals as mentioned above and with all relevant participants involved (especially the people with dementia and their caretakers themselves).

The activities include several deliverables, such as:

- expert meetings (Delphi method) including international researchers and SELF partners, on themes such as coping with dementia in daily life, (informal and formal) caretars, role of local communities etc.
- developing community vision, plans and activities (ABCD method, asset based community development), focusing on collecting stories, mapping capacities, mobilizing the communities and leveraging activities also from outside the community
- 'design studios' and micro-convenants, involving all stakeholders, also "Odense house" initiatives, volunteers, 'professional citizens and professionals from organisations, academics, volunteers etc. : organizing vouchers, webinars, workshops etc. in some pilot communities
- Local governance: intermunicipal workshops (civilians and civil servants)
- Education and training: courses and toolkits
- Annual conference, meeting of experts from within and outside SELF, interactive website

3. Innovative and transnational aspects

In this pilot it is clearly and essentially **a social and societal innovation, and not a medical or mere technological innovation** that is strived at. The initiative does not start with the government or the healthcare sector: this is about a bottom-up movement of people with dementia and their caregivers themselves, surrounded by volunteering and professional people in their neighbourhoods and with their typical 'informal' social cohesion. It was the opening of a so-called 'Odense House' in Vlissingen (Zeeland, NL), a meeting and activity house for people with dementia and their caregivers, which actually served (and still serves) as a platform to initiate even further civil society developments. At the very core of every approach to these developments, lies the awareness that all stakeholders and end-users have to be involved and committed from the very start of any initiative of project. And the monitoring, follow-up and dissemination of the process and results is the key factor to enduring success.

4. Barriers

There are many barriers which can make it harder for people with dementia to feel supported and remain involved in their communities. First of all there is the **stigma**: people with dementia want to be accepted for who they are, not defined by their diagnosis. Then there are the **social** barriers: having lost friends following diagnosis, feeling lonely, lacking confidence going out, being worried about becoming confused or about getting lost, or not feeling comfortable talking to a person with dementia, and prejudiced attitudes leading to rejection or even to bluntly rebuffing people with dementia and their carers, etc. And last but not least people with dementia are facing **physical** barriers, ranging from physical health issues to accessibility and mobility issues.

An obstacle of a different kind is situated in the area of a great deal of the **existing financial funding sources** for social innovative projects involving citizen participation. To obtain a substantial amount of money benefiting a group of people who often may be not well to do, project initiators tend to be confronted with **very traditional criteria** used to judge the incoming project proposals: e.g. a clear and definitive description of the envisaged end product or end service, while this reasonably can only be described after the interactive process will have been gone through.

5. (Transferable) models and tools applied

Inspiration will be extracted from the **“Social Innovation Lab for Kent (SILK)”** in the UK. The SILK Methodology provides **creative and innovative ways to approach projects**, and enables a collective ownership and responsibility for project design, delivery and outcomes. It covers three main areas: Strategic and Policy, Service Re-design, and Creating Sustainable Communities. A Method Deck provides with the tools and methods which should be used during each phase of a project (initiate, create, test and define).

A citizen participation method which is ‘home grown’ in Zeeland, called “Zeeland Bridges” (tentative work title for now), is based upon a robust interaction with recent theories and visions such as Appreciative Inquiry, Theory U, Motivational Interviewing, the Scenario Method, Dynamic Mindmapping, and Cooperation Science. The method has been developed during numerous workshops and reality projects with different groups of citizens, volunteers, civil servants and other professionals in Zeeland. It centers around the **variety of dialogue forms and methods** which can be used in cooperation and participation processes to empathize, explore, co-design, co-decide and co-organize in order to co-create community value.