

# MANAGING EVERYDAY LIFE

Exploring the Essential Components of  
Reablement and User Experiences



Ines Mouchaers



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and User Experiences

**Ines Mouchaers**

The research presented in this dissertation was conducted at the Care and Public Health Research Institute (CAPHRI), department of Health Services Research, Maastricht University. CAPHRI is part of The Netherlands School of Public Health and Care Research (CaRe).

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**Maastricht University**



**CAPHRI**



living lab  
in ageing and  
long-term care



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# MANAGING EVERYDAY LIFE

## Exploring the Essential Components of Reablement and User Experiences

PROEFSCHRIFT

voor het behalen van de graad van doctor aan de Universiteit Maastricht, onder gezag van Rector Magnificus, Prof. Dr. Pamela Habibović, overeenkomstig met het besluit van het College van Decanen, en ter verkrijging van de graad van doctor in de biomedische wetenschappen aan de KU Leuven, op gezag van de Rector, Prof. Dr. Luc Sels, te verdedigen in het openbaar op vrijdag 13 september 2024 om 10:00 uur

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# Chapter 1

## General introduction

The concept of ‘ageing in place’ is becoming increasingly popular, both in policy and research. This is defined as enabling older adults to remain living at home independently for as long as possible,<sup>1-3</sup> which is also preferred by most older adults, even when they face financial challenges or require care and support.<sup>4-6</sup> To successfully age in place, sustainable initiatives are needed. One of these initiatives is reablement, a person-centred, holistic approach that promotes active participation in daily activities through social, leisure, and physical activities chosen by the older adult in line with their preferences.<sup>7</sup> Reablement is attracting growing interest worldwide, including in the Netherlands, and is, therefore, the focus of this thesis. Next to studying its essential components, the experiences of professionals, clients, and family caregivers with reablement are evaluated to inform and advance reablement programmes and their future implementation.

The research presented in this thesis is part of the European Union’s Horizon 2020 TRANS-SENIOR research and innovation programme. TRANS-SENIOR aims to improve care for the growing population of care-dependent older adults by avoiding unnecessary care transitions and optimising care transitions that are actually needed.<sup>8</sup> This thesis is embedded in the work package on avoiding unnecessary care transitions by providing the right care at the right place at the right time.

## **Ageing and its challenges**

The globally ageing population creates one of the greatest challenges of the twenty-first century<sup>9,10</sup>; and although people are living longer, it is not guaranteed that these added years are spent in good health.<sup>11</sup> The amount of older adults experiencing disabilities or face significant losses in physical and mental capacities will increase over time and, while a sizeable proportion of the older population will continue to be independent, others will require more support.<sup>12</sup> Moreover, 50% of people aged 85 years or older need care and/or assistance with daily activities.<sup>13</sup> In the Netherlands, when older adults need support at home, they can apply for nursing (i.e. medical assistance – for example, administering injections) and personal care (i.e. assistance with activities of daily living – for example, washing).<sup>14</sup> In the Netherlands in 2016, approximately 28% of the community-dwelling adults aged 75 and older received nursing and/or personal care.<sup>15</sup> Additionally, they can rely on domestic services (i.e. assistance with instrumental activities of daily living (IADL) – for example, doing laundry) and social support, which enables them to participate in society and, if necessary, the provision of assistive devices

(e.g. mobility scooter) and home adjustments.<sup>14</sup> In the Netherlands, approximately 16% of the community-dwelling adults aged 75 and older received domestic support, and 25% received assistive devices and home adjustments.<sup>15</sup> Due to the rapidly growing older population, the need for long-term care services will only increase, while financial and workforce resources are shrinking.<sup>1,16,17</sup>

The current Dutch health and social care system is inadequately prepared to deal with these complex challenges in health care.<sup>9</sup> Long-term care is often fragmented, with a split between the health and social care sectors and a lack of coordination between the different entities.<sup>10</sup> Additionally, as previously stated, the need for care services will increase and become more complex.<sup>10,12</sup> The current disease-oriented, curative view does not match the needs of this population, requiring a shift to a more holistic, chronic care model.<sup>9,10,18</sup> Moreover, there is a necessity for a greater emphasis on social health and well-being, for example, as highlighted in the principles of positive health.<sup>19</sup> Subsequently, this will also increase the pressure on informal care,<sup>9,10</sup> which could lead to an escalation in the levels of anxiety and stress, social isolation, decreased quality of life, financial difficulties, and worse perceived health of the caregiver.<sup>20-24</sup> This, in combination with the earlier described financial and labour shortages, demands a larger focus on the prevention of care needs and more autonomy for older adults and their informal caregivers within their care process.

## No place like home

Facing these challenges, many countries stimulate ageing in place. Being able to continue living at home supports older adults in dealing with age-related challenges and changes. Ageing in place offers them a sense of familiarity, freedom, and stability when everything else is changing.<sup>25-27</sup> Being able to perform activities independently at home makes older adults feel proud, self-confident, and satisfied; it attributes to their self-identity, they feel like they have a place in the world.<sup>26,28</sup> However, this retained autonomy is not merely about performing tasks independently, it is also about having the agency to choose.<sup>29</sup> Being able to make autonomous decisions about daily life at home also attributes to older adults' sense of identity and gives them control and ownership of their daily life.<sup>27,28,30</sup>

'Home' is more than a physical space; it captures an environment where autonomy is cherished, meaningful activities are pursued, and social connections thrive.<sup>26,31,32</sup> Therefore, the 'place' we refer to in 'ageing in place' also entails the community they reside in as well as the social

networks of which they are a part.<sup>27,29</sup> The community older adults reside in is often connected with meaningful social contact, being able to stay in touch (i.e. with family and friends, but also local services), which increases their social connectedness and provides them with meaning and purpose.<sup>26,29</sup> This is closely linked to the World Health Organization's (WHO) concept of 'Healthy Ageing', which is described as the process of promoting and maintaining functional ability to enable well-being in older age,<sup>1,6,11</sup> and is seen as fostering an individual's functional ability to be and do what they value.<sup>33</sup> The WHO further defines functional abilities as: meeting basic needs, making decisions, being mobile, building and maintaining relationships, and contributing to society.<sup>11</sup> In light of these concepts, supporting older adults to maintain these abilities and adhere to their needs and wishes regarding ageing becomes all the more important, and care professionals play a big role in this process. Moreover, more and more policies and research are moving towards the concept of ageing well in the right place, which is considered to not merely refer to ageing in one's own home, but rather in an environment that fulfils individuals' needs and wishes, and matches their capabilities in order to attribute to their retained quality of life; ageing well in the right place, rather than ageing in place.<sup>1,29,34</sup> A concept closely related to this is age-friendly cities and communities. These places adapt their services and physical structures to foster greater inclusivity and receptiveness to their population, aiming to enhance their quality of life and promote active participation as they age.<sup>35</sup>

## Reablement

One strategy to enable older adults to age in place and support healthy ageing is reablement. Reablement is defined by means of an international consensus study<sup>7</sup> as

*“a person-centred, holistic approach that aims to enhance an individual's physical and/or other functioning, to increase or maintain their independence in meaningful activities of daily living at their place of residence and to reduce their need for long-term services. Reablement consists of multiple visits and is delivered by a trained and coordinated interdisciplinary team. The approach includes an initial comprehensive assessment followed by regular reassessments and the development of goal-oriented support plans. Reablement supports an individual to achieve their goals, if applicable, through participation in daily activities, home modifications and assistive devices as well as involvement of their social network. Reablement is an inclusive approach irrespective of age, capacity, diagnosis or setting.”*<sup>7</sup>

Over the past years, principles of reablement are increasingly being integrated into intervention programmes, meaning that the philosophy is translated into concrete actions (e.g. setting personal goals, training, and providing support). In general, this means that care professionals will focus on doing things with, rather than for the older adult.<sup>36</sup> Instead of creating dependency by taking over tasks, care professionals identify individuals' capabilities and opportunities to maximise their independence by supporting them to achieve their goals, through participation in daily activities, home modifications, assistive devices, and the involvement of their social network.<sup>7,36-38</sup> The evidence on the effectiveness of reablement compared to traditional home care is inconclusive. While some literature reviews highlight promising results,<sup>39-42</sup> especially in terms of daily functioning, health-related quality of life, and health-care utilisation; others report significant ambiguity regarding its effects and costs.<sup>43-46</sup> However, outcomes were rarely found to be worse for older adults, while user satisfaction was most often high.<sup>47</sup> In particular, qualitative studies show that older adults, informal caregivers, and care professionals value reablement over traditional care.<sup>48-51</sup> Moreover, there are indications that reablement could possibly result in cost-effectiveness and cost savings compared to usual home care.<sup>52</sup>

Reablement has been researched and implemented internationally for more than 20 years, starting in the United States and the United Kingdom, followed by Australasia and Scandinavia.<sup>53</sup> Some countries have even successfully implemented reablement across the whole country – for example, in Denmark reablement has been included in community care by law since 2015, meaning that all applicants for home care in all municipalities are assessed for their potential for reablement before being offered conventional home care.<sup>54</sup> Starting in 2014, research on reablement has been conducted in the Netherlands.<sup>55</sup> It began with the development and evaluation of a reablement training programme for home-care workers, the 'Stay Active at Home' programme.<sup>36</sup> The insights obtained from this research were used as a starting point for the research presented in this thesis.

## **Reablement as a complex intervention**

Despite the amount of research that is being conducted concerning reablement, there is still a lot that needs to be unravelled. Many reablement programmes lack a solid theoretical foundation.<sup>56,57</sup> Moreover, the content of reablement programmes is often insufficiently described in scientific literature,<sup>37,46,58,59</sup> offering little guidance in terms of replicating or building on previous research, despite this being essential for the development of new – and

implementation of existing – programmes. Both a theoretical foundation, as well as a detailed description of the content of reablement are essential to hypothesise which elements of the intervention would lead to the desired outcomes.<sup>60,61</sup> In addition, although the internationally accepted definition of reablement emphasises the role of both the physical and social environment of the older adult, this is often neglected in practice.<sup>62,63</sup> Optimal use of the environment is essential, since the environment can either stimulate or hinder a person's participation in meaningful activities.<sup>64,65</sup> Reablement is not a 'one size fits all' approach, meaning it is tailored to both the individual (i.e. their needs, preferences, and capabilities) and their environment.<sup>46,66</sup> Therefore, it is also important to understand the implementation of reablement and determinants that could influence this process (e.g. organisational culture or resources).<sup>67</sup>

Reablement programmes can be considered a complex intervention, due to its many interrelated components and the interaction between these components, the context, those delivering the intervention, and the target groups, which all could have a major influence on achieving the desired outcomes.<sup>68-71</sup> Therefore, the Medical Research Council (MRC) framework for developing and evaluating complex interventions was used as guidance for the research presented in this thesis.<sup>68,71</sup> The framework consists of four phases (i.e. development, feasibility and piloting, evaluation, and implementation) and guides the process of the development and evaluation of complex interventions in making appropriate methodological and practical decisions.<sup>68,72</sup> Using a structural and systematic approach in the development (and evaluation) of interventions is essential to avoid 'research waste', which results from poor question selection, insufficient attention for existing evidence, inadequate reporting, and poor description.<sup>73</sup> The MRC framework was chosen because it is well known and well cited, and it offers useful practical guidance.<sup>68,72</sup> In this thesis, we used the version described by Bleijenberg et al,<sup>72</sup> who adapted the development phase of the MRC framework with elements from other intervention development guidelines, creating a comprehensive approach to enhance intervention design, increase value, and reduce the risk of ineffective interventions. Using this approach helps to develop a theory- and evidence-based programme, allows for co-creation with practice, and the inclusion of the voice of end-users, and encourages early testing, adjustments, and fine-tuning in an iterative process.<sup>68,71,72</sup>

## Objectives and outline of this thesis

Due to the growing interest in reablement worldwide, it is vital to gain insight into the essential components of community-based reablement and user experiences. These insights will provide invaluable information for future policy and practice. The objectives of this thesis are: 1) to investigate community-based reablement and its essential components for future intervention programmes; and 2) to explore the experiences of older adults and their family caregivers and professionals with reablement programmes to inform and advance future implementation. These programmes aim to improve older adults' self-management and participation in daily life, while also increasing the quality of life, and decreasing the informal caregivers' burden, and potentially avoiding unnecessary care transitions to institutional care.

**Chapter 2** presents the evolution of the concept of disability throughout the years and its underlying causal mechanisms. **Chapter 3** sheds light on the content and different components of various international reablement programmes, as well as their effectiveness. **Chapter 4** describes the development and content of I-MANAGE, a model presenting essential components for community-based reablement. **Chapter 5** examines the needs and wishes of family caregivers regarding support for and involvement in reablement programmes. **Chapter 6** presents clients' experiences with reablement, and more specifically with the goal setting and goal attainment element of reablement. **Chapter 7** describes the experiences of professionals with the implementation of reablement in the Dutch community care setting. Lastly, **Chapter 8** summarises and discusses the main findings of this thesis, reflects on the methodological and theoretical considerations, and provides recommendations for future policy, practice, and research.

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## Chapter 2

# The concept of disability and its causal mechanisms in older people over time from a theoretical perspective: a literature review

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## **Abstract**

Ageing with a disability increases the risk of hospitalisation and nursing home admission. Ageing in place interventions aiming to reduce disability are often not sufficiently effective and inadequately theory-based. There are many models available on disability, but it is unclear how they define disability, what their differences are, and how they evolved throughout the years. This paper aims to provide an overview of the evolution of these models and to elaborate on the causal mechanisms of disability. A literature review was conducted as part of the TRANS-SENIOR international training and research network. PubMed and Google Scholar were searched, and snowball sampling was applied to eligible publications. Data was extracted from the included publications and a thematic analysis was performed on the retrieved data. Overall, 29 publications were included in the final sample. All included models arose from three original models and could be divided into two types: linear models and models on the interaction between the person and the environment. Thematic analysis led to three distinct evolutionary trends: 1) from a unidirectional linear path to a multidirectional non-linear path; 2) from the consequences of disease toward the consequences of person-environment interaction; and 3) from disability toward health and functioning. Our findings suggest that by optimising the use of personal as well as environmental resources, and focusing on health and functioning, rather than disability, an older adult's independence and wellbeing can be improved, especially while performing meaningful daily activities in accordance with the older adult's needs and preferences.

## Introduction

Increasing age is generally accompanied by an increased prevalence of disability. In the United States, for example, approximately 58.5% of the population aged 65 years and older suffer from disability, of whom 41.6% experience severe disability.<sup>1</sup> In 2014, in the EU member states, 23.7% of the population aged 65 and over experienced a limitation in activities of daily living (ADL).<sup>2</sup> Disability is defined as difficulty or dependency in carrying out ADL, mostly related to self-care and other activities that are essential to living independently.<sup>3,4</sup> Disability is not simply a result of the older adult's diminished abilities to perform ADL. A demanding social and physical environment can also stimulate or hinder participation in meaningful activities and the fulfilment of roles set by the older adult's environment.<sup>5</sup> Ageing with a disability can lead to an accumulation of health risks, loss of independence, poor quality of life (QoL), and depression; which can in turn lead to an increased risk of hospitalisation and (permanent) nursing home admission.<sup>6,7</sup> Consequently, this increased need for acute and long-term care is a challenge for society, which is already operating with financial and workforce constraints,<sup>8</sup> and makes the prevention of disability a key research topic.<sup>9,10</sup>

Many older adults also prefer to 'age in place' and thus remain in their own homes independently for as long as possible.<sup>11</sup> Over the last years, there has been a shift from residential to home-based care to meet the needs of the older population in a potentially more effective and financially sustainable way.<sup>12</sup> To support the ageing in place policy and avoid hospitalisations and (permanent) nursing home admission, various interventions have been developed aiming to promote daily functioning and reduce disability. However, current ageing in place interventions are not always sufficiently effective. One important reason for this seems to be that current interventions are inadequately theory-based, although theory has proven to be advantageous when developing effective interventions. Nonetheless, various studies on ageing in place interventions only refer loosely to theory rather than describing how theory helped inform the development process.<sup>13,14</sup>

There are many models, theories and concepts (referred to as models from here on out) available on the onset and course of disability.<sup>15</sup> It is, however, unclear how they define disability, what their differences are, and how these have evolved throughout the years. Therefore, there is a need for an overview of how theory explains the concept of disability, the onset of disability, and its causal mechanisms.

The aim of this paper is to: 1) provide an overview of theoretical models explaining the concept of disability; 2) gain insight in their development throughout the years; and 3) elaborate on the causal mechanisms of disability in older adults. This review could serve as a theoretical foundation for future interventions and policies aiming to reduce disability and its negative consequences in community-dwelling older adults, and ultimately promote ageing in place.

## **Methods**

For this paper, a literature review was conducted focusing on the analysis of theoretical models explaining the concept of disability throughout the years.

### **Search procedure**

This review combines two search techniques, electronic database search and snowball sampling, which were applied simultaneously. The search was performed between November 2019 and May 2020. Both scientific and grey literature were included.

#### ***Electronic database search***

An electronic database search was performed to identify relevant literature using search terms such as 'disability', 'disablement', 'person-environment fit', combined with search terms such as 'theory', 'theoretical framework', 'concept', 'conceptual framework', 'model', and 'conceptualisation'. It was anticipated that the literature of interest would not only be found in regular databases, therefore, the search was conducted in PubMed (for scientific publications) and Google Scholar (for scientific and grey literature). There was no limitation regarding publication date because of the historical character of some key publications and the aim to map the evolution of the theoretical models included.

#### ***Snowball sampling***

The snowball sampling technique was based on the guidelines for snowballing in systematic literature studies described by Wohlin.<sup>16</sup> Firstly, to identify the initial set of papers, we appealed to the expertise of the research team, who work in the field of social gerontology, public health and primary care, and long-term care. The papers they suggested in combination with the results of the electronic database search were used as a starting point for the review process. The next step was backward snowballing, where the reference lists were used to identify new



papers to include. Next, to complete the results, PubMed and Google Scholar were used for forward snowballing, wherein new papers were identified based on papers citing the examined paper. This process was done until no new publications were identified.

## **Selection procedure**

### ***Screening***

An initial screening took place during which articles were screened for eligibility based on the title, and in cases where there was doubt, on the abstract as well. After this initial screening, eligible articles were again screened at title and abstract level to identify the publications that would potentially meet the inclusion and exclusion criteria as described below. If no abstract was available, for example in book chapters, the introduction or summary information provided by Google Scholar was used. Subsequently, the full-text of the selected publications was reviewed for eligibility. Screening was initially performed by one person (IM), after which the results of the screening process were discussed within the research team and adjusted based on consensus.

### ***Inclusion and exclusion criteria***

Publications were included when they: a) developed and described a new model, theory, or concept (subsequently referred to as model) of disability, daily functioning (ADL and instrumental ADL), or person-environment fit, or analysed and refined an existing one; and/or b) performed a literature review of one or more models in the domain of disability and contributed to the analysis of conceptual development of these models; and c) were published in English. Publications were excluded when they did not contribute to the information retrieved from the original models and therefore did not add anything to the analysis of the theoretical models or their conceptual development over time (e.g. study protocols, or book chapters which merely provide a description of a theoretical model).

### **Data extraction and analysis**

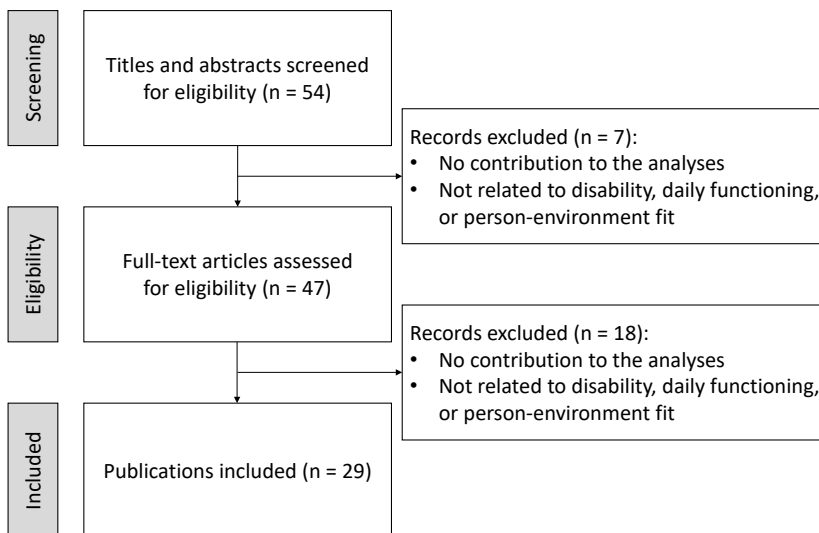
After selection, data extraction was done using a data extraction spreadsheet in Microsoft Excel 2016 (Microsoft Corporation, Redmond, WA, USA). The following information was retrieved: a) the goal of the publication; b) the pathway or process described in the model; c) the concepts

defined, and other elements included in this pathway; (d) strengths and shortcomings of the model identified during further development; and (e) underlying assumptions made on the causal mechanism of disability. Following data extraction, a thematic analysis was performed, during which results were grouped into themes. Eventually, possible trends in the evolution of these theoretical models were observed. This was an iterative process, during which results were reviewed, discussed and adjusted within the research team.

## Results

### Study characteristics

After a prior screening of the literature, 54 titles and abstracts of core publications were screened. Of this final selection, 47 full-text articles were assessed for eligibility, resulting in 29 publications that met the inclusion criteria (Figure 1). These 29 publications included 15 models and 14 literature reviews. Nine of the 29 publications were book chapters, two were government reports, one was a research report and the remaining 17 were scientific papers. The publications included were published between 1965 and 2018. The characteristics of all included publications are listed in Table 1.



**Figure 1.** Flowchart of literature search process

**Table 1.** Characteristics and content of included publications

<b>Theoretical models explaining the concept of disability</b>	
<b>Author (year) Name (if applicable)</b>	<b>Contribution</b>
Nagi (1965) <sup>17</sup> <i>Disability Model</i>	<ul style="list-style-type: none"> <li>• Describes a linear main pathway consisting of four distinct concepts: active pathology, impairment, functional limitation, and disability.</li> <li>• Mainly focusing on the internal process of disability, without considering the role of the environment.</li> </ul>
Lawton and Nahemow (1973) <sup>18</sup> <i>Competence-environmental press model</i>	<ul style="list-style-type: none"> <li>• Presents the relationship between ageing individuals and their environment.</li> <li>• The interaction between the individual's competences and the pressure that is put upon the individual by the environment determines how the individual functions in that environment.</li> </ul>
World Health Organization (1980) <sup>19</sup> <i>ICIDH</i>	<ul style="list-style-type: none"> <li>• Describes a linear main pathway consisting of four distinct concepts: disease, impairment, disability, and handicap.</li> <li>• Mainly focusing on the internal process of disability, without considering the role of the environment.</li> </ul>
Kahana (1982) <sup>20</sup> <i>Congruence model of person-environment interaction</i>	<ul style="list-style-type: none"> <li>• Comment on Lawton and Nahemow's model: a fit between the individual and their environment is based on both the environment's characteristics and the individual's preferences and needs, rather than their competences.</li> </ul>
Nagi (1991) <sup>21</sup>	<ul style="list-style-type: none"> <li>• Redefines the term disability as "an inability or limitation in performing socially defined roles and tasks expected of an individual within the sociocultural and physical environment", meaning it was not merely inherent in the individual.</li> <li>• Lists several factors that could interfere with the links between different stages of the linear pathway (both individual characteristics, as well as the role of the individual's social and physical environment and the individual's reaction to this)</li> </ul>
Pope and Tarlov (IOM) <sup>22</sup>	<ul style="list-style-type: none"> <li>• Adds risk factors to the ICIDH model, which could predispose the individual to disability. These factors could interfere with each stage of the main pathway.</li> <li>• Adds QoL to the model as an integral part. QoL affects and is affected by the outcomes of each stage of the main pathway.</li> </ul>
National Center for Medical Rehabilitation Research (1993) <sup>23</sup>	<ul style="list-style-type: none"> <li>• Extends the model presented by the IOM with societal limitations, defined as "restrictions attributable to social policy or barriers which limit fulfillment of roles or deny access to services and opportunities associated with full participation in society".</li> </ul>
Verbrugge and Jette (1994) <sup>24</sup> <i>The disablement process</i>	<ul style="list-style-type: none"> <li>• Elaborates the linear pathway with Lawton's environmental-press model. The main pathway is extended with personal and environmental factors that speed up or slow down disability by altering the demand of the environment or the capabilities of the individual.</li> </ul>

Table 1. Continued

Author (year) <i>Name (if applicable)</i>	Contribution
Brandt and Pope (1997) <sup>25</sup> <i>Enabling – disabling process</i>	<ul style="list-style-type: none"> <li>• Adds bidirectional arrows between the concepts of the main pathway described by Nagi, allowing the pathway to be reversed toward rehabilitation.</li> <li>• Presents disability as an interaction of the individual with the environment and not solely an inherent part of the individual.</li> <li>• Focuses on health and functioning and therefore, deletes the term ‘disability’ in the main pathway. The concept ‘no disabling condition’ is added at the beginning of the main pathway, indicating that there is also an ending to the pathway when no pathology, impairment, or functional limitation is present.</li> </ul>
Lawton (2000) <sup>26</sup>	<ul style="list-style-type: none"> <li>• Comments on the criticism of Kahana in 1982, and notes that the greater the competence of individuals, the more environmental resources are available to fulfil their needs and wishes.</li> </ul>
World Health Organization (2001) <sup>27</sup> <i>ICF</i>	<ul style="list-style-type: none"> <li>• Provides a bidirectional and non-linear representation instead of the linear main pathway. This allows for a more dynamic interaction between the individual’s functioning, and their health condition and environmental factors.</li> <li>• Introduces different concepts: health condition, functions/structure, activity, and participation.</li> <li>• Counters the view that people’s disability is a natural consequence of disease and presents a functional model instead of a medical model by including the positive aspects of functioning.</li> </ul>
Kahana et al (2003) <sup>28</sup>	<ul style="list-style-type: none"> <li>• Extends the previous model from the institutional setting to the community setting.</li> </ul>
McDougall et al (2010) <sup>29</sup>	<ul style="list-style-type: none"> <li>• Includes QoL in the graphical representation of the ICF as an outer subsystem around the original scheme, implying that it is incorporated in all aspects of functioning.</li> </ul>
Ravenek et al (2013) <sup>30</sup>	<ul style="list-style-type: none"> <li>• Changes ‘health condition’ to ‘health’ to be all-inclusive.</li> <li>• Presents the model as concentric circles, emphasising the relationship between components and their potential interaction that takes place as part of human functioning.</li> <li>• Presents human functioning as an interaction between body functions and structures, activities, and participation.</li> </ul>
Heerkens et al (2018) <sup>31</sup>	<ul style="list-style-type: none"> <li>• Deletes the concept of ‘health’ and includes it in the component ‘personal factors’ as a (co)morbidity instead.</li> <li>• Averts the emphasis from the biological components of the model by putting participation at the centre of the model.</li> </ul>
<b>Literature reviews of one or more theoretical models</b>	
Author (year)	Contribution
Kennedy and Minkler (1998) <sup>32</sup>	<ul style="list-style-type: none"> <li>• Highlights the lack of attention given to the role of the environment in both linear models presented by Nagi (1965) and the World Health Organization (WHO) (1980).</li> </ul>

Author (year)	Contribution
Jette and Badley (2000) <sup>33</sup>	<ul style="list-style-type: none"> <li>• Criticises the linear models for failing to see disablement as a dynamic process that is not unidirectional or linear. The linear models view disabling conditions as a simple linear progression that is a response to diseases.</li> <li>• Highlights the negative connotation of the ICIDH presented in 1980 by the WHO. The focus of this classification was on deficiencies resulting from health conditions.</li> </ul>
Nordenfelt (2003) <sup>34</sup>	<ul style="list-style-type: none"> <li>• Notes that the terms ‘disability’ and ‘handicap’ in the ICIDH are viewed as completely independent from the environment and the relationship between the person and his or her environment.</li> <li>• Highlights two major changes made in the ICF: (1) includes positive aspects of functioning, and (2) grants a crucial role to the environment in this classification.</li> </ul>
Ustün et al (2003) <sup>35</sup>	<ul style="list-style-type: none"> <li>• Criticised the ICIDH for being too focused on the disabilities, rather than being a neutral classification of human functioning.</li> <li>• Notes the lack of personal and environmental factors in the progression toward handicap throughout the ICIDH.</li> <li>• States that the ICF combines the medical model of disability with the social model, meaning that disability is a combination of something inherent in the individual as well as a socially created problem due to an unaccommodating social environment.</li> </ul>
Schneidert et al (2003) <sup>36</sup>	<ul style="list-style-type: none"> <li>• Criticises the ICIDH for its limited role of the environment and its focus on the individual in the path of disability.</li> </ul>
Scheidt and Norris-Baker (2004) <sup>37</sup>	<ul style="list-style-type: none"> <li>• Elaborates on the development of Lawton and Nahemow’s competence-environmental press model after criticism received by Kahana (1982) on the lack of inclusion of needs and preferences of the individual.</li> </ul>
Heikkinen (2006) <sup>38</sup>	<ul style="list-style-type: none"> <li>• Notes the linear and unidirectional character of Nagi’s Disablement Model where the main pathway is assumed a sequence of events leading toward disability.</li> </ul>
Whiteneck (2006) <sup>39</sup>	<ul style="list-style-type: none"> <li>• Criticises the ICIDH for not incorporating the role of environmental factors into the classification.</li> <li>• States that the ICF improved by including environmental factors into their classification.</li> <li>• Criticises the ICF for not distinguishing ‘activities’ and ‘participation’ enough from each other. ‘Activities’ needs to be defined as something on the individual’s level, whereas ‘participation’ needs to be defined as something on a societal level.</li> </ul>
Nordenfelt (2006) <sup>40</sup>	<ul style="list-style-type: none"> <li>• States that the focus of the ICIDH was mainly on the tasks individuals are unable to do because of diseases or injuries.</li> </ul>
Jette (2006) <sup>41</sup>	<ul style="list-style-type: none"> <li>• Criticises the linear models for failing to see disablement as a dynamic process that is not unidirectional or linear. The linear models view disabling conditions as a simple linear progression that is a response to diseases.</li> </ul>

Table 1. Continued

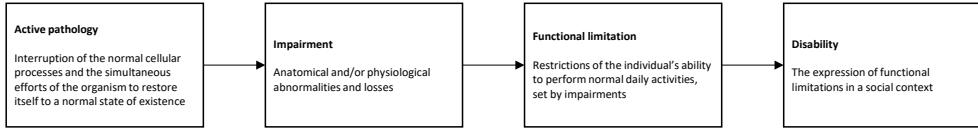
Author (year)	Contribution
Masala and Petretto (2008) <sup>42</sup>	<ul style="list-style-type: none"> <li>• Emphasises the lack of acknowledgement of the role played by the environment in the linear models of Nagi and the WHO.</li> <li>• Highlights the improvements Nagi made to his Disablement Model in 1991, namely the recognition of the role of the characteristics of the individual and the environment in the disablement process.</li> <li>• Notes that the role of the environment described in Nagi (1991) only refers to the demand it puts on an individual and therefore, disability is still viewed as part of the individual.</li> <li>• Criticises the model presented by the IOM in 1991 for its linearity without the possibility of reversing in the pathway.</li> <li>• Criticises the model presented by the IOM in 1991 for the limited role played by the environment, especially the social environment. The environment is only included as a risk factor instead of progression in the pathway.</li> </ul>
Iecovich (2014) <sup>43</sup>	<ul style="list-style-type: none"> <li>• Criticises the competence-environmental press model for not considering the individual's attributes. The model does not acknowledge that the individual can manipulate the environment to reduce the press, or that they can use the environment as a resource to fulfil their needs and wishes.</li> <li>• Highlights that the competence-environmental press model does not provide strategies to measure person-environment linkages.</li> </ul>
Petretto et al (2017) <sup>44</sup>	<ul style="list-style-type: none"> <li>• Highlights the importance of the ICF in terms of shifting the focus away from disability being a static event, toward a dynamic process that may vary over a life course.</li> </ul>
Vaz et al (2017) <sup>45</sup>	<ul style="list-style-type: none"> <li>• Criticises Nagi's Disablement Model and the ICIDH for their linear and unidirectional character, implying that a pathology triggers the disabling process consisting of stepwise negative consequences. This also highlights that the focus is on the disease and the negative consequences instead of health and functioning.</li> <li>• Criticises both linear models for being too organism-limited, meaning that they fail to identify the role played by the environment during this process.</li> <li>• Highlights the major improvements made when developing the ICF: <ul style="list-style-type: none"> <li>• The interactive and bidirectional character of the ICF emphasises that the nature of disability and functioning lies within the interaction between health conditions and contextual factors;</li> <li>• The ICF counters the medical point of view, which states that disability is a natural consequence of diseases;</li> <li>• The ICF considers different influences on health and functioning (biological, individual, and social factors).</li> </ul> </li> </ul>

Note. ICIDH = International Classification of Impairments, Disabilities, and Handicap; ICF = International Classification of Functioning, Disability, and Health; IOM = Institute of Medicine; NCMRR = National Center for Medical Rehabilitation Research; QoL = Quality of Life; WHO = World Health Organization

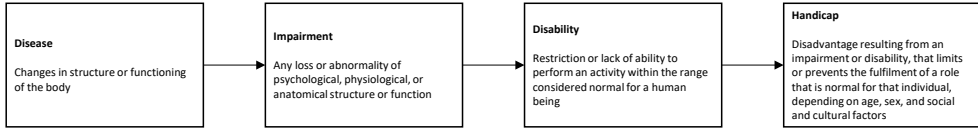
### Three original models

Three original models could be identified throughout the 29 included publications: 1) Nagi's Disablement Model; 2) the WHO's International Classification of Impairments, Disabilities, and Handicaps; and 3) Lawton's competence-environmental press model. These original models are described below. First, in the 1960s, sociologist Saad Nagi described the process of disablement as the Disablement Model. To provide clarity on the terms and concepts surrounding disability, Nagi described the process of disablement as a linear main pathway consisting of four distinct stages: active pathology, impairment, functional limitation, and disability (Figure 2a).<sup>17</sup> Second, in 1980, the World Health Organization (WHO) published the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). Similar to Nagi's Disablement Model, this conceptual framework follows a linear main pathway, consisting of four concepts that classify the consequences of disease and their implications for the lives of individuals (Figure 2b).<sup>19</sup> In 2001, the WHO revised its classification and developed the International Classification of Functioning, Disability and Health (ICF).<sup>27</sup> This revision is considered a major turning point in the evolution of disability models as it is the first model to attempt to address all of the ICIDH's major shortcomings. These shortcomings and how the ICF addressed them are described in the section later on. The new classification also introduced the terms 'health condition', 'functions/structure', 'activity', and 'participation' in their presentation next to the environmental and personal factors (Figure 2c).<sup>27</sup> Moreover, the ICF presents the individual's functioning as a dynamic, bidirectional, and non-linear interaction between an individual's health condition and environmental factors.<sup>27,45</sup> It is therefore the most widely accepted model of functioning and disability.<sup>45</sup> The third original model is Lawton's competence-environmental press model, described in the 1970s, which presents the relationship between ageing individuals and their environment. This model conceptualises the individual as having a set of competences and the environment putting pressure upon that individual. Both the individual competences and environmental pressures may fluctuate over time, resulting in positive or negative effects.<sup>18</sup> The interaction between both individual competences and environmental pressure determines the extent to which individuals are able to function optimally in that environment. To achieve a good fit between the personal competences and the environmental pressure, it is possible to interfere with both factors.<sup>18,43</sup>

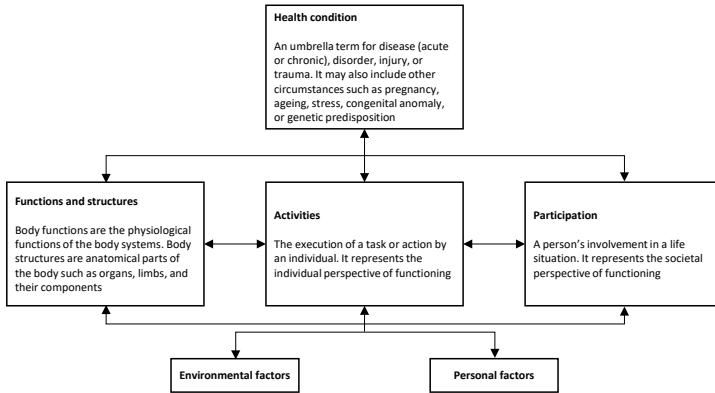
a. Nagi's Disablement Model (1965, 1991)



b. WHO's International Classification of Impairments, Disabilities, and Handicaps (1980)



c. WHO's International Classification of Functioning, Disability, and Health (2001)



**Figure 2.** (a) Graphical representation of Nagi's Disablement Model (1965, 1991).<sup>17,21</sup> (b) the WHO's ICIDH (1980),<sup>19</sup> and (c) the WHO's ICF (2001).<sup>27</sup> Fig 2b and 2c are adapted with permission from the World Health Organization (1980, 2001)

Based on these three models two types of models can be distinguished. First, Nagi's Disablement Model and the WHO's ICIDH present a clear linear pathway build of distinct concepts. Both models generally describe the same process but use different terms to do so; for example, Nagi uses functional limitations to describe a restriction of the individual's abilities to perform activities of daily living, whereas the WHO uses the term 'disability' to define these restrictions. Additionally, both models mainly focus on the internal process of disability related to the person themselves and do not consider the role of the outer physical and social environment.<sup>45</sup> Secondly, there is Lawton's competence-environmental press model presenting the relationship between the individual and the environment, and thus, focusing on more than solely the internal process of disability.



## **Disability over time**

Over the years, these three models underwent further development following progressive insights into disability and its underlying causal mechanisms. To elaborate on these developments and new insights, a thematic analysis was performed, identifying three trends: 1) from a unidirectional linear path to a multidirectional non-linear path; 2) from the consequence of disease toward the consequence of person-environment interaction; and 3) from disablement toward health and functioning. Figure 3 presents the evolution of the models throughout the years.

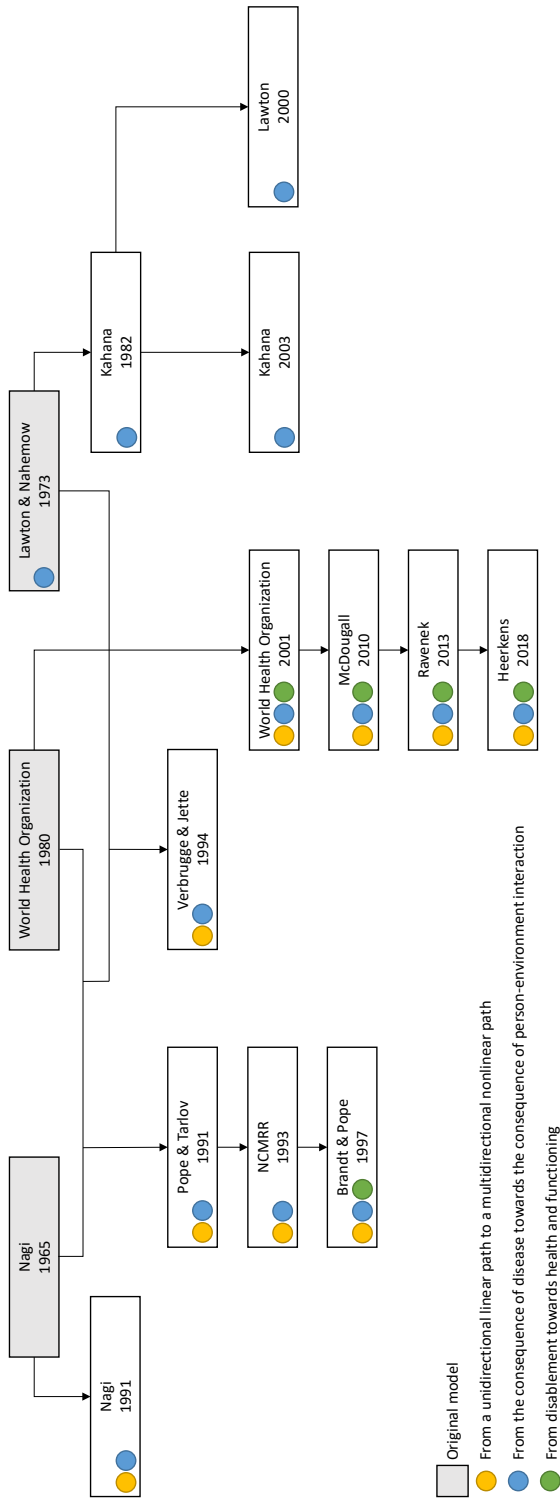
### ***From a unidirectional linear path to a multidirectional non-linear path***

The static, linear, and unidirectional presentation of both Nagi's Disablement Model and the ICIDH were considered overly simplistic.<sup>19,38,45</sup> This unidirectional, linear presentation claims that the presence of a pathology or disease initiates the disablement process with its stepwise negative consequences as an inevitable and irreversible result.<sup>33,38,41,45</sup> These insights led to several revisions of the unidirectional, linear pathway (Figure 3, yellow boxes). At first, authors mentioned the issue of the unidirectional process and that there were possibilities to return in the pathway, but this was never addressed in the graphical presentation.<sup>21-24</sup> The unidirectional and linear presentation was only addressed in later revisions by Brandt and Pope<sup>25</sup> and the World Health Organization.<sup>27</sup>

By adding bidirectional arrows between the concepts of the linear pathway, Brandt and Pope<sup>25</sup> allow the pathway to be reversed toward rehabilitation. This is important to acknowledge since it clarifies that disability is not necessarily an end stage. With the correct treatment or interventions, this pathway can be halted or even reversed. The WHO not only addressed the unidirectional but also the linear character of the models when developing the ICF (Figure 2c).<sup>27</sup> The ICF does not present the 'process' of functioning and disability, but rather presents the individuals' functioning as a dynamic, multidirectional, and non-linear interaction between an individual's health condition and environmental factors (for example, the attitudes of the society, architectural characteristics, the legal system).<sup>27,44,45</sup>

### ***From the consequence of disease toward the consequence of person-environment interaction***

Early models described disability mainly as a consequence of diseases.<sup>17,19</sup> Models adhering to this principle described the disablement process as something that is unleashed from pathology or disease and runs through different stages until it results in disability.<sup>45</sup> However, when



**Figure 3.** Flowchart presenting the development of theoretical models explaining the concept of disability throughout the years. The figure also presents the results from the thematic analysis; three main trends throughout the evolution: (1) from a unidirectional linear path to a multidirectional non-linear path (yellow); (2) from the consequence of disease toward the consequence of person-environment interaction (blue); and (3) from disablement toward health and functioning (green). The colour code indicates which evolutionary trend is represented in this model, either by a visual representation or in the description. The three models at the top present the original models (green frame). NCMRR stands for National Center for Medical Rehabilitation Research

looking into the causal mechanism of disability, it was noted that disability is not inherent in the individual. Therefore, it was concluded that the early linear models lacked a construct to identify the role played by the environment in this process.<sup>32,34-36,39,42,45</sup> This led to several revisions and further development of both linear models, being Nagi's Disablement Model and the WHO's ICIDH (Figure 3, blue boxes).

In a first attempt to acknowledge the role played by the environment on the process of disability, risk factors were added that could predispose the individual to disability.<sup>21,22,24</sup> However, the contribution of the environment was still considered limited in the influence it had on the possible progression in the pathway instead of interacting with the individual.<sup>44</sup> Two models attempted to make the disablement process more of a social construct, meaning it was not solely related to the physiological and physical state of the individual, but how these restrictions present themselves in society.<sup>21,23</sup>

It was not until later that disability and functioning were seen as an interaction between the individual and the environment they reside in.<sup>25,27</sup> This means that the environment will play a critical role in the outcome of the person's health condition and degree of functioning since an individual will experience greater disability in a less supportive environment than they would in a more supportive environment or context.<sup>25</sup> The support can come either from the physical environment or from the social environment, making disability and functioning a social construct that is holistic and not only inherent in the individual.<sup>25,27</sup>

In contrast to linear models, the model of Lawton and Nahemow<sup>18</sup> already addressed the environmental influence early on. This model was also revised several times. In 1994, Verbrugge and Jette integrated the competence – environmental press model to elaborate the linear models to a full sociomedical concept.<sup>24</sup> Both Lawton and Nahemow<sup>18</sup> and Verbrugge and Jette<sup>24</sup> indicate that the process of disability can be altered on both the individual level as well as the environmental level by changing the demand of the environment or the capabilities of the individual. This is highly important when designing interventions aiming to reduce or overcome disability. These interventions should aim for a perfect fit between the individual and the environment where they reside.<sup>43</sup> Later it was emphasised that a fit between individuals and their environment is based on the environment's characteristics and the individual's preferences and needs, rather than their competences and that the environment provides resources and opportunities for the individual instead of only demanding something from the individual.<sup>20,26,28,37,43</sup>

### ***From disablement toward health and functioning***

During the evolution of the linear models, it was considered important to divert the focus away from the person's disability and what they were no longer able to do, and instead to focus on health and functioning, as well as participation in a community and a person's wellbeing.<sup>33,35,40,45</sup> As presented in Figure 3 (green boxes), this focus only changed after several revisions. Brandt and Pope<sup>25</sup> attempted to tailor the model toward rehabilitation by creating the possibility to return to a state of 'no disabling condition'. By introducing new terms into their dynamic model, the WHO included the positive aspects of functioning, which was considered being a major improvement from the ICIDH.<sup>27,34</sup> A major step forward in averting the focus toward health and functioning was made in the ICF. In this classification, they introduced the terms 'health condition', 'functions/structure', 'activity', and 'participation' in their presentation next to the environmental and personal factors described earlier (Figure 2c).<sup>27</sup> By introducing these terms, they included the positive aspects of functioning, and focused on the role someone plays or wishes to play in the community.

Several authors tried to build on the graphical representation of the ICF after some minor shortcomings were defined,<sup>29-31</sup> their contributions are listed in Table 1. For example, the model does not include the subjective experience of health or quality of life. It is, however, important to consider the person's wellbeing when assessing health and functioning.<sup>29,30,39</sup> Additionally, the term 'health condition' might be confusing as it may imply that there is a condition to consider, therefore making the scheme not universally applicable since there are also people without any conditions.<sup>30,31</sup> Lastly, the graphical representation emphasises 'health conditions' because it is put at the top of the scheme, giving priority to the biological components of the model.<sup>30,31</sup> Despite these shortcomings and the attempts to overcome these, the ICF remains the most widely accepted model in terms of disability, health and functioning.<sup>45</sup>

## **Discussion**

This literature review provided an overview of theoretical models explaining the concept of disability, provided insight into their development throughout the years and elaborated on the causal mechanisms of disability in older adults. The results showed that all models originate from three models: Nagi's Disablement Model, the WHO's ICIDH, and Lawton and Nahemow's competence-environmental press model. These early models can be classified into two types,

the linear models on one hand<sup>17,19</sup> and a model focusing on the interaction between the individual and their environment on the other.<sup>18</sup> All three of these models were further developed throughout the years, resulting in an evolution from a medical to a biopsychosocial concept. Throughout this evolution, there were three clear trends visible: 1) from a unidirectional linear path to a multidirectional non-linear path; 2) from the consequence of disease to the consequence of person-environment interaction; and 3) from disablement toward health and functioning. Analysing these themes led to a better insight into the causal mechanisms of disability in older adults, and how these should be considered and applied in current practices. These insights are especially important when aiming to promote ageing in place and avoid unnecessary care transitions.

The results of this review indicate that disability is not a static concept, but a dynamic and interactive process that may fluctuate over a life course. Moving away from the linear and unidirectional graphical presentation of disability and functioning has several advantages. Firstly, it reflects the fact that disability is not automatically an end stage but can be reversible. Secondly, the more dynamic and non-linear concept of disability reflects the opportunities of individuals to move away from a disabled state supported by interventions or other influences. This is supported by the results of Whitehead et al<sup>46</sup> and Resnick et al<sup>47</sup> both performed a literature review of interventions aiming to maintain or optimise functional abilities and reduce dependency in ADL. Both concluded that these interventions were effective in improving functional abilities.<sup>46,47</sup>

Additionally, changing the medical perspective of disability to a more social and integrated perspective adequately reflects the individual as part of an environmental context or a community wherein they function. Obtaining an optimal fit between the individual and their environment is key for this individual to function adequately in this environment and can contribute to the individual's well-being. Since adequate functioning and well-being are determined by the interaction between the individual and the environment, both can be targeted when designing interventions aiming to reduce disability and promote ageing in place. It is important to note that the environment can be seen as both a resource to support the individual in daily life and a burden to the individual's functional state. For example, an older adult living in a deprived neighbourhood with few services and a poorly accessible built environment will face barriers to his or her mobility and social participation on a daily basis. However, when this person would live in a neighbourhood with more services close by, for example a community centre, the person would have access to a broader social network whose

support might compensate the burden of the poorly accessible built environment. Moreover, going to the community centre could encourage the person to push the boundaries of their functional state. The concept of person-environment fit is also reflected in WHO's Healthy Ageing framework. Healthy Ageing is described as *"the process of developing and maintaining the functional ability that enables well-being in older age"*.<sup>48</sup> Functional ability is the interaction between intrinsic capacity, defined by genetic, personal and health characteristics, and the environment. Healthy ageing is something that can be achieved for everyone, where 'healthy ageing' is not viewed as the absence of a disease but is seen as fostering an individual's functional ability to be and do what they value.<sup>49</sup> When aiming for ageing in place, an environment should be created in which the individual can age safely and independently, in line with their intrinsic capacity. This principle was described by the WHO as 'age-friendly environments' which aim to encourage active and healthy ageing by optimising health, stimulating inclusion, and enabling well-being in older age by adapting physical and social environments and municipal services to the needs and wishes of older adults with varying capacities.<sup>50</sup> The Homestead Care Model described by de Boer et al<sup>51</sup> is an illustrative example of how care facilities can develop age-friendly environments. It aims to provide opportunities for senior citizens for an active, meaningful daily life. It enables senior citizens to be part of society by ensuring a congruent physical, social, and organisational environment.<sup>51</sup> It should be noted that ageing in place may be experienced differently in different countries and cultural environments due to differences in health-care systems, health policies, and access. This indicates that it requires a non-uniform approach tailored to the specific circumstances in different countries or regions.<sup>52</sup> Other, personal factors can also influence the individual's capacity to age in place, for example, the social network or socio-economic status.<sup>53,54</sup> Furthermore, it is considered important to acknowledge the individual's needs and wishes alongside their competences. This is related to the construct of agency, which is an individual's capacity to make their own decisions related to future plans.<sup>55</sup>

Lastly, changing the perspective toward health and functioning, rather than disability, reflects the current focus on well-being and positive aspects of individuals' health. Not only does this emphasise what a person is able to do, it also reflects the opportunity to focus on what they would like to do in their own social and physical environment. When aiming to support the person to age in place, it is necessary to consider their capabilities and emphasise these, rather than only focusing on their limitations in daily life. This will ultimately contribute to a person's wellbeing and quality of life. This is supported by Huber et al,<sup>56</sup> who proposed a new concept of social health, which is characterised by having the capacity to fulfil one's potential and

obligations; the ability to manage life with some degree of independence, despite a medical condition; and participation in social activities. Based on this concept of social health, Dröes et al<sup>57</sup> proposed the operationalisation of this concept in people living with dementia, together with an overview of factors and interventions that could influence or improve social health in this population.

The ICF is, despite its shortcomings, still the most widely accepted model regarding disability, health and functioning; meaning that the overall perspective of disability being a dynamic interaction between an individual's health and the environment where they reside in, has not changed for over a decade.<sup>27,45</sup> This has had several consequences for policy and treatment. For example, nowadays many countries stimulate an ageing in place policy to enable older adults to remain at home independently for as long as possible.<sup>12,58</sup> Ultimately, this translates to several interventions aiming to encourage independent living at home. However, many interventions only focus on either the individual or the environment and not the ageing individual as part of their physical and social environment. An intervention that aims to incorporate both is the CAPABLE intervention, which has proven its effectiveness with regard to (I)ADL disability scores.<sup>59</sup> The CAPABLE intervention targets both modifiable intrinsic (person-based) as well as extrinsic (environmental-based) factors that contribute to disability to achieve clients' individual goals.<sup>59</sup> Even the CAPABLE intervention, despite the wide implementation, only focuses on the person's individual capabilities and the optimisation of the home environment without inclusion of the community or social environment.<sup>60</sup> Providing interventions that address both the individual and the environment requires new roles and tasks of professionals, strong collaboration among all partners involved in the care process and funding model that facilitate the new way of working. Consequently, despite attempts to shift the focus toward this new perspective, it remains a challenge to change existing organisational structures and achieve successful behavioural change of care professionals.<sup>61,62</sup> Ultimately, this also explains why currently there is still a big gap between theory and practice. Translating theory in a practical real-world setting is often challenging<sup>62</sup> and requires time and effort of many stakeholders in health care, which possibly explains the lack of theoretical foundation when developing interventions aiming to reduce disability and promote ageing in place.

### **Limitations and strengths**

One of the limitations of this literature review is that only two databases were used to complete the literature search. Therefore, it is possible that some key publications were missed. However, this risk was limited by consulting the research team during the search process and the use of snowballing. An additional limitation is that the scientific substantiation of the included publications was not systematically analysed and no quality assessment was performed. However, nearly all included theoretical models are widely acknowledged by the research team, who are considered experts in the field.

Notwithstanding these limitations, this literature review contributes to the current literature by providing an all-inclusive overview that also presents the development of these models throughout the years, which to our knowledge has never been done before. Additionally, the literature review provides insights into the causal mechanisms of disability and translates this into practical implications for future research and practices for supporting the upcoming ageing in place policy. This literature review may serve as a theoretical foundation and rationale for multiple future initiatives.

### **Implications**

Despite the ICF being the most widely accepted classification of functioning, disability and health until today, it dates from 2001 and literature has proven that it has some shortcomings. To our knowledge, no attempt to improve and further develop this classification has been picked up in international literature to become the newest, most accepted theoretical model regarding functioning, disability and health. Therefore, there is a possibility for future research to address these shortcomings when developing new theoretical models. For instance, the ICF in its current form is not universally applicable because the term 'health condition' implies that people without any conditions are not considered in this classification. Additionally, the classification does not include a subjective perception of health and functioning, such as well-being and quality of life. These shortcomings emphasise that the ICF is still a classification, which is mainly focused on functioning and more specifically on the restrictions and limitations individuals experience when performing an activity or during participation in a social role.

Future revisions of the ICF model should attribute sufficient attention to the abilities and strengths of the individual, how these can be enhanced or supported, and how they contribute to the person's well-being and quality of life. Furthermore, it should become a universally



applicable model that does not exclude people without any health conditions. When considering how these abilities and strengths can be promoted, both individual factors (such as age, gender, social status, etc.) and environmental factors, which is not only the built and physical environment, but also the social environment and support network of the individual should be considered. In fact, the social environment plays an important role in the perception and acceptance of having a disability and how one deals with such disability. The theoretical model should provide a base for the development of future interventions or programs to support older adults in their daily life. However, the assumptions made by the theoretical model regarding these strategies and implications need to be sufficiently supported by scientific evidence.

The current research also provides several important implications for future initiatives that aim to support the ageing in place policy and avoid hospitalisations and (permanent) nursing home admission. Firstly, it is essential to not only focus on treating disease, but also on the person's capabilities. Treating the diseases alone is not the correct strategy to support a person to remain living at home independently; there also needs to be more attention to what the person is still able to do and how to highlight this during meaningful daily activities. However, treating underlying diseases remains important. If these diseases are left untreated, strengthening the person's capabilities will become more difficult and progression can be undone quickly.

Secondly, when emphasising the person's capabilities during meaningful daily activities, both the person and their environment should be considered as resources to do this. This can be done in several ways. Firstly, one can use the current environment to support the person during their daily activities, for example by learning to use public transportation so that the person can travel longer distances independently, which enhances the participation of the person in the community. Secondly, one can alter the environment in such a way that it becomes more supportive for the person, for example installing grab bars in the bathroom.

Thirdly, individual support or treatment plans should be tailored to the person's preferences, needs, and wishes, rather than his or her health condition. Treating underlying diseases, enhancing physical functioning, and promoting independence during meaningful daily activities alone is not sufficient for a person to remain at home independently. It is highly important to also focus on the well-being and quality of life of the individual and to do this it is necessary to adhere to what the person really wants in life and to what they draw energy from.

Lastly, following the implications mentioned above, it is important to consider the right outcome measures when evaluating an intervention or programme that supports the ageing in place policy and possibly avoids hospitalisations and (permanent) nursing home admission. As indicated previously, functional outcome measures such as ADL or physical performance are useful to consider and are currently the most used evaluation measures. However, quality of life and participation measures should also have an important role in the evaluation of such programs. Ultimately, the goal is not only to remain living at home independently for as long as possible but also to experience a good quality of life. This goes beyond physical performance and independent functioning.

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## Chapter 3

### Reablement as a therapeutic strategy to offer community-dwelling older adults a good quality of life at home after geriatric rehabilitation\*

*Reablement comme outil thérapeutique pour offrir aux personnes âgées une  
vie de qualité à domicile après une réadaptation gériatrique*

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## Abstract

**Introduction:** Returning home after geriatric rehabilitation is often accompanied by many challenges, which threaten the continuity of care and might lead to institutionalisation. As part of the TRANS-SENIOR international training and research network, an intervention is in development to meet these challenges and ensure that older adults can remain living at home independently. To develop this intervention, we wanted to gain insight into reablement programmes, a promising concept for promoting independent living among older adults.

**Methods:** Publications describing reablement programmes were included if they reported a community-based program, were tested in a (randomised) controlled trial, provided enough detail on programme components, and evaluated effects on participant level. The data extracted were related to programme characteristics and components, such as target group, duration, team composition and coordination, intake assessment, goal setting, strategies to achieve these goals, and outcomes assessed.

**Results:** Thirteen programmes were identified from six countries, all intended for (I)ADL-impaired community-dwelling older adults. Common features were delivery by a trained and coordinated multidisciplinary team and implementation of an intake assessment and goal-setting tool. The main procedures applied focused on supporting (I)ADL and physical functioning and improving home safety. Nine programmes showed a statistically significant improvement on at least one of the outcome measures.

**Conclusion:** Despite not all favourable results reaching statistical significance, reablement programmes seem promising, and have the potential to improve health-related quality of life and reduce health-care utilisation. Therefore, we used input from these programmes for the development of our intervention for people returning home after geriatric rehabilitation.

## Introduction

Older adults, who have been confronted with a deterioration in their health status, due to a trauma, acute, or chronic illness, can temporarily be admitted to a geriatric rehabilitation facility to improve their functional capacity and prepare them for discharge to their previous home situation. Geriatric rehabilitation is defined as “*a multidimensional approach of diagnostic and therapeutic interventions, the purpose of which is to optimise functional capacity, promote activity and preserve functional reserve and social participation in older people with disabling impairments*”.<sup>1</sup> Geriatric rehabilitation often follows hospitalisation because the patient is not yet able to return home. It focuses on maintaining or restoring the independence of older adults in terms of mobility, activities of daily living, participation, and quality of life.<sup>2</sup> When patients are not able to return home after geriatric rehabilitation, they are either admitted to a nursing home, admitted to a residential care facility, or readmitted to a hospital.<sup>3</sup> Patients who are able to return home after geriatric rehabilitation often face various challenges.<sup>4</sup> First, when moving across care settings, patients are confronted with different caregivers and organisations providing care, threatening the continuity of care.<sup>5-7</sup> There are different causes for this lack of continuity, such as insufficient communication between care professionals from different organisations and disciplines,<sup>4,8</sup> and delay or absence of the handover of patient discharge summaries.<sup>5,7-10</sup> Additionally, there may be a lack of sufficient communication between care professionals and patients and their informal caregivers. Patients and informal caregivers are often inadequately informed about what to expect after discharge and are therefore insufficiently prepared for the transition back home.<sup>5,7,8</sup> This might lead to insufficient functional improvement, disease exacerbations, unnecessary hospital readmissions, additional costs, permanent nursing home placement, and even death.<sup>5,6,10-12</sup> These challenges will only increase due to the rapidly growing older population,<sup>13</sup> which may lead to an increasing need for (long-term) care services at a time when financial and workforce resources are shrinking,<sup>14-16</sup> and thus, remaining at home for as long as possible should be facilitated.

To meet these challenges, an intervention is being developed for older adults returning home after geriatric rehabilitation. The goal of this intervention is to ensure that older adults can remain living at home independently for as long as possible and avoid unnecessary transitions to institutional care after geriatric rehabilitation. In order to develop this intervention, we wanted to gain insight in the current evidence on effective programmes aimed at improving independent living of older persons. A concept attracting growing interest in promoting

independent living among older adults is reablement. Reablement is a person-centred, holistic approach that promotes older adults' active participation in daily activities through preferred social, leisure, and physical activities, either at home or in the community. It aims to enhance the individual's (physical) functioning, increase or maintain independence in meaningful activities of daily living, and reduce their need for long-term services.<sup>17</sup> Instead of creating dependency by taking over tasks, the focus of care professionals is more on identifying capabilities and opportunities of the individual and on maximising their independence by supporting an individual to achieve their goals, through participation in daily activities, home modifications and assistive devices as well as involvement of their social network.<sup>17-20</sup> Reablement is a promising concept because it aims to improve the older adult's independence inside their own home, but also to reconnect them with the community they reside in by supporting their independence and participation.<sup>19</sup> Additionally, reablement has potential to improve health-related quality of life and reduce health-care utilisation.<sup>21</sup> Therefore, the concept of reablement contributes to the growing ageing in place policy, and supports the shift in health care from residential to home-based care in order to meet the needs of older adults in a sustainable way.<sup>22</sup> Recently, several reviews have been performed to look into the definition and effectiveness of reablement,<sup>18,19,21,23</sup> but they did not provide sufficient insight in the content and different components of programmes, or how they are delivered. Therefore, we performed a literature search to gain an understanding of the content and different components, as well as the effectiveness of different reablement programmes.

## Methods

As part of the development process, we sought to gain a general understanding of different reablement programmes, their content and different components, and their effectiveness. Therefore, relevant reablement publications were selected from a fact sheet of the Australian Association of Gerontology, which provides a list and brief summaries of research studies on reablement approaches.<sup>24</sup> In addition, publications that were known within our network of reablement experts affiliated with the ReAble network were added. Publications were included in our review if they reported on a community-based reablement programme, provided enough detail on the programme components, and evaluated effects of the programme on the level of the client (such as activities of daily living and quality of life) in a (randomised) controlled trial. The articles and any original programme materials, if available, were analysed. The extracted data was related to characteristics of the target population, the duration of the program, the

composition of the team providing the program, the type of training received by the team, the assessment and goal-setting instruments used, the communication and coordination strategies applied, the specific programme components offered (e.g. fall prevention program, medication management, etc.), and the outcomes assessed.

## Results

As a result of this literature search, we identified 13 reablement programmes. The programmes originate from six different countries: New Zealand (5), Australia (3), the United States (2), Denmark (1), the United Kingdom (1), and Norway (1) and were evaluated in (randomised) controlled trials that were published between the year 2002 and 2020.

### Programme characteristics and components

All programmes were designed for community-dwelling older adults with some (I)ADL impairment.<sup>25-37</sup> Three programmes were aimed at older adults with mild cognitive impairment and moderate stages of dementia.<sup>34-36</sup> Table 1 summarises the most important programme characteristics and components. Most programmes had a fixed duration, ranging from 6 until 12 weeks.<sup>26,27,31-33,35,37</sup> However, some programmes deviated from this and had a fixed duration of 4 months<sup>34</sup> or 5 months.<sup>25</sup> The remaining four programmes had a variable duration which was tailored to the participant's needs and ended after specific goals were achieved.<sup>28-30,36</sup> All programmes were delivered by a multidisciplinary team, often consisting of community nursing staff and an occupational therapist.<sup>25,27,29,31-37</sup> Eight programmes also included physiotherapists.<sup>29,31-37</sup> Additionally, one programme included a handy man in the team,<sup>25</sup> one programme included a psychologist and a speech therapist,<sup>34</sup> and one programme included a dietician.<sup>36</sup> In nine out of the thirteen programmes, a case manager was appointed to coordinate the program.<sup>26-32,36,37</sup> Multidisciplinary team meetings were introduced in five of the programmes.<sup>30-32,34,35</sup> In one program, a shared online platform was implemented to facilitate communication among care professionals.<sup>25</sup> In seven out of the thirteen programmes, teams received an extensive training before the start of the program.<sup>28-30,32-34,37</sup> The training was mainly focused on the use of the goal-setting and assessment tools,<sup>30,33,37</sup> the principles of reablement,<sup>30,33</sup> and the correct delivery of the program.<sup>28,29,32-34</sup> All reablement programmes consisted of multiple components, such as an intake assessment, goal setting, and several

procedures and strategies to achieve these goals. All programmes started with an intake assessment.<sup>25-37</sup> For this, the following assessment tools were used: Client-Clinical Assessment Protocol,<sup>25</sup> Canadian Occupational Performance Measure,<sup>37</sup> and Support Needs Assessment.<sup>30,36</sup> In the remaining studies, the assessment tools were not specified.<sup>26-29,31-35</sup> Based on the assessment, individual goals were set using the following tools: the Bangor-Goal Setting interview,<sup>34</sup> Canadian Occupational Performance Measure,<sup>37</sup> TARGET,<sup>27,28,30</sup> interRAI CA,<sup>35</sup> and Goal-Attainment Scale.<sup>33</sup> In the remaining studies, the goal-setting tools were not specified.<sup>25,26,29,31,32,36</sup> To reach clients' goals the following procedures were applied: (I)ADL support and training of physical functioning,<sup>25-35,37</sup> improving home safety,<sup>25-27,29,31-34,37</sup> informal caregiver support,<sup>33,34</sup> medication management,<sup>25,31,32,34</sup> pain management,<sup>25,34</sup> and nutritional advice.<sup>31,32</sup> Box 1 provides a detailed description of one of these programmes as a practical example.

### **Programme effectiveness**

Table 1 provides an overview of the outcomes of the programmes. The table also indicates whether a statistically significant improvement was found in the intervention group compared to the control group. Common outcome measures were (I)ADL functioning, physical functioning, quality of life of the client as well as the informal caregiver, and health-care utilisation. Nearly all trials concluded that their programme had positive features and could be beneficial for older adults, although not all positive results were statistically significant. Nine out of the 13 programmes showed a statistically significant improvement on at least one of the outcome measures.<sup>25,26,28,30-33,35,37</sup> Five programmes showed a statistically significant improvement in (I)ADL functioning,<sup>25,26,31,32,37</sup> two in physical functioning,<sup>30,32</sup> three in quality of life of the client,<sup>28,30,32</sup> and none of the studies found a significant result on quality of life of the informal caregiver. Lastly, three programmes found a significant decrease in health-care utilisation.<sup>31,33,35</sup>

**Box 1.** A detailed description of CAPABLE, an American reablement programme

An example of a reablement programme is CAPABLE, developed in the United States by Sarah Szanton. CAPABLE stands for 'Community Aging in Place, Advancing Better Living for Elders' and aims to improve function and health-related quality of life in disabled, older adults and in the long term, reducing hospitalisations and nursing home admissions.<sup>38</sup> The CAPABLE intervention targets both modifiable intrinsic (person-based) as well as extrinsic (environmental-based) factors that contribute to disability to achieve clients' individual goals.<sup>25,39</sup> A multidisciplinary team of a registered nurse (RN), an occupational therapist (OT) and a handy man (HM) performs the intervention, consisting out of 10 in-home visits where the therapists work towards the goals of the participant. In addition, the handy man conducts home modifications.<sup>39</sup> The programme starts with a multidisciplinary assessment. This assessment is performed by the OT, who evaluates the functional disability, home safety, and functional goals of the participant, and by the RN who evaluates participant goals regarding pain level, depression, medication understanding, primary care practitioner communication, and strength and balance. Based on these assessments an integrated plan is developed consisting of tailored strategies to address these goals. Additionally, in close consultation with the client, the OT provides the HM with an agreed list on which home repair, environmental modifications, and assistive devices should be conducted or installed that support the participant in the achievement of their functional goals. Eventually, during the remaining 8 sessions with the OT or the RN, the participant works on strategies in order to achieve his or her functional and participant goals.<sup>25,39</sup> For example, when a participant's goal is to take a shower individually rather than with the help from a nurse, then in consultation with the team, the HM will install bathroom safety rails. Afterwards, the OT can train with the participant to use these rails efficiently and train energy-conserving approaches for showering. In the meantime, the RN helps the participant to manage his or her fear of falling and balance issues. The CAPABLE intervention proved to be effective in reducing ADL and IADL disability scores, by 30 and 17 percent respectively compared to the control group after 5 months. Additionally, participants in the intervention group reported that it 'made their life easier' and 'kept them living at home'.<sup>25</sup>

**Table 1.** Overview of the identified rehabilitation programmes with an indication of the duration and follow-up periods, team composition and coordination, programme components, their evaluated outcome measures and effectiveness

Programme reference	Duration Follow up	Team (composition and coordination)	Programme components (intake assessment, goal-setting tool, strategies to achieve goals)	Outcome measures			
				(I)ADL functioning	Physical functioning	QoL (informal caregiver)	Health-care utilisation
Jeon, 2019 <sup>34</sup>	4 months	<u>Composition:</u> OT, PT, RN, speech pathologist, psychologist	<ol style="list-style-type: none"> <li>1. Intake assessment not specified</li> <li>2. Bangor-Goal-setting tool interview</li> <li>3. Strategies to achieve goals:                             <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> <li>· Improving home safety</li> <li>· Informal caregiver support</li> <li>· Medication management</li> <li>· Pain management</li> </ul> </li> </ol>	•	•	•	•
	FU 4 and 12 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>· Multidisciplinary team meetings</li> <li>· Training in programme delivery</li> </ul>		•	•	•	•
King, 2012 <sup>28</sup>	Variable duration	<u>Composition:</u> Paid caregivers, coordinator (experienced RN), and referrals to OT, PT, meal preparation, etc.	<ol style="list-style-type: none"> <li>1. Intake assessment not specified</li> <li>2. TARGET</li> <li>3. Strategies to achieve goals:                             <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> </ul> </li> </ol>	•	•	• <sup>a</sup>	
	FU 4 and 7 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>· Case manager</li> <li>· Training in programme delivery</li> </ul>		•	•	•	



Programme reference	Duration Follow up	Team (composition and coordination)	Programme components (intake assessment, goal-setting tool, strategies to achieve goals)	Outcome measures				
				(I)ADL functioning	Physical functioning	QoL (client)	QoL (informal caregiver)	Health-care utilisation
Lewin, 2013 <sup>31</sup>	12 weeks	Composition: OT, PT, nurse, care manager (interdisciplinary team member)	1. Intake assessment not specified 2. Goal-setting tool not specified 3. Strategies to achieve goals: <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> <li>· Improving home safety</li> <li>· Medication management</li> <li>· Nutritional advice</li> </ul>	• <sup>a</sup>	•	•		• <sup>a</sup>
	FU 3 and 12 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>· Case manager</li> <li>· Multidisciplinary team meetings</li> </ul>	1. Intake assessment not specified 2. Goal-setting tool not specified 3. Strategies to achieve goals: <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> <li>· Improving home safety</li> <li>· Medication management</li> <li>· Nutritional advice</li> </ul>	• <sup>a</sup>	•	• <sup>a</sup>		•
Lewin, 2016 <sup>32</sup>	12 weeks	Composition: OT, PT, nurse, care manager (non-health professional)	1. Intake assessment not specified 2. Goal-setting tool not specified 3. Strategies to achieve goals: <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> <li>· Improving home safety</li> <li>· Medication management</li> <li>· Nutritional advice</li> </ul>	• <sup>a</sup>	•	• <sup>a</sup>		•
	FU 3 and 12 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>· Case manager</li> <li>· Multidisciplinary team meetings</li> <li>· Training in programme delivery</li> </ul>	1. Support Needs Assessment 2. Goal-setting tool not specified 3. Strategies to achieve goals not specified	•	•	•		•
Parsons, 2012 <sup>36</sup>	Variable duration	Composition: OT, PT, RN (care manager)	1. Support Needs Assessment 2. Goal-setting tool not specified 3. Strategies to achieve goals not specified	•	•	•		•
	FU 3, 6, 12, 18, and 24 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>· Case manager</li> </ul>						

Table 1. Continued

Programme reference	Duration Follow up	Team (composition and coordination)	Programme components (intake assessment, goal-setting tool, strategies to achieve goals)	Outcome measures				
				(I)ADL functioning	Physical functioning	QoL (client)	QoL (informal caregiver)	Health-care utilisation
Parsons, 2013 <sup>30</sup>	Variable duration	Composition: Needs assessor, home care aide, RN (coordinated home care and the use of allied health professionals (OT, PT, speech-language pathologist, dietician))	1. Support Needs Assessment 2. TARGET					
	FU 6 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>Case manager</li> <li>Multidisciplinary team meetings</li> <li>Training in goal-setting and assessment tools</li> <li>Training in the principles of reablement</li> </ul>	<ul style="list-style-type: none"> <li>(I)ADL support and training of physical functioning</li> </ul>	• <sup>a</sup>	• <sup>a</sup>	• <sup>a</sup>		
Parsons, 2020 <sup>35</sup>	6 weeks	Composition: OT, PT, RNs, health-care assistants, consultant geriatricians	1. Intake assessment not specified					
	FU 12 months	<u>Coordination:</u> <ul style="list-style-type: none"> <li>Multidisciplinary team meetings</li> </ul>	<ul style="list-style-type: none"> <li>InterRAI CA</li> <li>Strategies to achieve goals:                             <ul style="list-style-type: none"> <li>(I)ADL support and training of physical functioning</li> </ul> </li> </ul>	•				• <sup>a</sup>

Programme reference	Duration Follow up	Team (composition and coordination)	Programme components (intake assessment, goal-setting tool, strategies to achieve goals)	Outcome measures			
				(I)ADL functioning	Physical functioning	QoL (informal caregiver)	Health-care utilisation
Senior, 2014 <sup>29</sup>	Variable duration FU 3, 6, 12, 18, and 24 months	<u>Composition:</u> OT, PT, nurse, case manager <u>Coordination:</u> · Case manager Training in programme delivery	<ol style="list-style-type: none"> <li>1. Intake assessment not specified</li> <li>2. Goal-setting tool not specified</li> <li>3. Strategies to achieve goals:                             <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> </ul> </li> <li>1. Improving home safety</li> </ol>	•	•	•	•
Szanton, 2019 <sup>25</sup>	5 months FU 5 and 12 months	<u>Composition:</u> OT, RN, handy man <u>Coordination:</u> Shared online platform	<ol style="list-style-type: none"> <li>2. Client-Clinical Assessment Protocol</li> <li>3. Goal-setting tool not specified</li> <li>4. Strategies to achieve goals:                             <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> <li>· Improving home safety</li> <li>· Medication management</li> <li>5. Pain management</li> </ul> </li> </ol>	• <sup>a</sup>			
Timetti, 2002 <sup>33</sup>	3 months FU every 60 days + at discharge from home care	<u>Composition:</u> Home care nurses, therapists (OT and PT), home health aides <u>Coordination:</u> · Training in goal-setting and assessment tools · Training in the principles of reablement · Training in programme delivery	<ol style="list-style-type: none"> <li>1. Intake assessment not specified</li> <li>2. Goal-Attainment Scale</li> <li>3. Strategies to achieve goals:                             <ul style="list-style-type: none"> <li>· (I)ADL support and training of physical functioning</li> <li>· Improving home safety</li> <li>· Informal caregiver support</li> </ul> </li> </ol>	•	•		• <sup>a</sup>

**Table 1.** Continued

Programme reference	Duration Follow up	Team (composition and coordination)	Programme components (intake assessment, goal-setting tool, strategies to achieve goals)	Outcome measures				
				(I)ADL functioning	Physical functioning	QoL (client)	QoL (informal caregiver)	Health-care utilisation
Tuntland, 2015 <sup>37</sup>	3 months	Composition: OT, PT, (auxiliary) nurses, social educators, home helpers and assistants	1. Canadian Occupational Performance Measure 2. Canadian Occupational Performance Measure 3. Strategies to achieve goals:	• <sup>a</sup>	•	•	•	•
	FU 3 and 9 months	Coordination: • Case manager • Training in goal-setting and assessment tools	• (I)ADL support and training of physical functioning • Improving home safety					
Whitehead, 2016 <sup>27</sup>	6 weeks	Composition: OT, home carer, community equipment service (for modifications)	1. Intake assessment not specified 2. TARGET 3. Strategies to achieve goals:	•	•	•	•	•
	FU 2 weeks, 3 and 6 months	Coordination: • Case manager	• (I)ADL support and training of physical functioning • Improving home safety					
Winkel, 2015 <sup>26</sup>	12 weeks	Composition: OT, home carer	1. Intake assessment not specified 2. Goal-setting tool not specified					
	FU 3 and > 12 months	Coordination: • Case manager	3. Strategies to achieve goals: • (I)ADL support and training of physical functioning • Improving home safety	• <sup>a</sup>				

Note. FU = follow-up, OT = occupational therapist, PT = physiotherapist, RN = registered nurse, QoL = quality of life; (I)ADL = (instrumental) activities of daily living

<sup>a</sup> Statistically significant improvement was found in favour of the intervention group

## Discussion

As part of the development process of an intervention for older adults returning home after geriatric rehabilitation, literature review was performed to gain insight in the current evidence on effective reablement programmes aimed at improving independent living of older persons. We specifically sought to gain a general understanding of different reablement programmes, their content, and their effectiveness.

Several common features were identified amongst the 13 programmes. All programmes were intended for community-dwelling older adults with some sort of (I)ADL impairment and delivered by a multidisciplinary team who were under the coordination of a case manager and trained beforehand. Additionally, all programmes included a form of intake assessment and goal setting. The main procedures that were applied focused on supporting (I)ADL and physical functioning and improving home safety. These features are in line with what was recommended by the recently published definition of reablement, which describes the characteristics, components, aims, and target groups of reablement programmes.<sup>17</sup>

Nearly all programmes concluded that their programme had promising positive effects on at least one of the outcomes, despite not all changes being statistically significant. This is in line with the results of previous reviews, which assessed the effectiveness of the reablement approach and concluded that this approach has significant advantages over traditional home care. For instance, it improves health-related quality of life and reduces health-care service utilisation in the short term.<sup>21,23</sup> The power of reablement programmes seem to lie in its multicomponent character. Both Blankevoort et al<sup>40</sup> and Daniels et al<sup>41</sup> confirmed the importance and effectiveness of multicomponent programmes in community care. Other outcome measures should be considered when evaluating reablement programmes, which are more specific for a person instead of a generic outcome – for example, the progress in achieving goals or participation. Although not all favourable results reached statistical significance, reablement programmes seem certainly promising, and have the potential to improve health-related quality of life and reduce health-care utilisation. Moreover, stimulating an individual's independence to ensure they can remain at home for as long as possible is beneficial for the scarcity of resources mentioned earlier.<sup>19,21</sup>

Following the positive and promising effects of reablement programmes, we decided to use input from these programmes for the further development of our intervention for older adults returning home after geriatric rehabilitation.

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# Chapter 4

## Development and content of a community-based reablement programme (I-MANAGE): a co-creation study

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## Abstract

**Objectives:** As age increases, people generally start experiencing problems related to independent living, resulting in an increased need for long-term care services. Investing in sustainable solutions to promote independent living is therefore essential. Subsequently, reablement is a concept attracting growing interest. Reablement is a person-centred, holistic approach promoting older adults' active participation through daily, social, leisure, and physical activities. The aim of this paper is to describe the development and content of I-MANAGE, a model for a reablement programme for community-dwelling older adults.

**Design:** The development of the programme was performed according to the Medical Research Council framework as part of the TRANS-SENIOR international training and research network. A co-creation design was used, including literature research, observations, interviews, and working group sessions with stakeholders.

**Setting and participants:** The interviews and working group sessions took place in the Dutch long-term home care context. Stakeholders invited to the individual interviews and working group sessions included care professionals, policymakers, client representatives, informal caregiver representatives, informal caregivers, and scientific experts.

**Results:** The co-creation process resulted in a 5-phase interdisciplinary primary care programme, called I-MANAGE. The programme focuses on improving the self-management and well-being of older adults by working towards their meaningful goals. During the programme, the person's physical and social environment will be put to optimal use, and sufficient support will be provided to informal caregivers to reduce their burden. Lastly, the programme aims for continuity of care and better communication and coordination.

**Conclusion:** The I-MANAGE programme can be tailored to the local practices and resources and is therefore suitable for the use in different settings, nationally and internationally. If the programme is implemented as described, it is important to closely monitor the process and results.

## Background

The number of older adults experiencing disabilities will increase over time and, while a large proportion of the older population remains independent, others will experience an increased need for support.<sup>1</sup> Moreover, 50% of people aged 85 years or older require care and/or support with daily activities.<sup>2</sup> As a result, it is expected that their demands for long-term care services will increase. When older adults live in an environment that is unsafe and does not meet their needs, the challenges they might face regarding independent living will increase further.<sup>3</sup> Previous research showed that a maladjusted environment negatively affects disability, which could lead to an accumulation of health risks, loss of independence, poor quality of life (QoL), and depression.<sup>4-6</sup> Care and service delivery in the community is often fragmented, with little coordination and poor communication amongst care providers, clients, and informal caregivers.<sup>3,7-9</sup> Furthermore, the focus of care is often on eliminating specific diseases and symptoms instead of supporting the remaining capacity to maintain QoL and independent living.<sup>10,11</sup> Rather than performing tasks *with* their clients, care professionals often tend to take over.<sup>11</sup> Failing to properly tackle these challenges could increase the use of health and social care and related costs.<sup>12</sup> In addition, this could lead to unnecessary (re)hospitalisations or permanent nursing home placement, which each have their own risks (e.g. increased mortality)<sup>13</sup> and at a time when financial and workforce resources are shrinking.<sup>7,12,14</sup> It is therefore essential to invest in sustainable solutions to promote independent living.<sup>15-17</sup>

A concept attracting growing interest in promoting independent living among older adults is reablement. This is a person-centred, holistic approach promoting active participation of older adults in daily activities through social, leisure, and physical activities chosen by the older adult in line with their preferences, either at home or in the community.<sup>18</sup> Instead of creating dependency by taking over tasks, care professionals identify the capabilities and opportunities of individuals to maximise their independence by supporting them to achieve their goals, through participation in daily activities, home modifications, assistive devices, and involvement of their social network.<sup>11,18-20</sup> Current evidence on the effectiveness of reablement interventions is inconclusive,<sup>11</sup> however several systematic reviews have indicated the positive results of reablement relating to activities of daily living (ADL) functioning and health-related QoL.<sup>21-23</sup> Due to the promising results, interest in implementing reablement into everyday care is growing internationally. In Denmark, New Zealand, and the United Kingdom, reablement has more-or-less been successfully implemented across the whole country.<sup>24</sup> For example, in Denmark reablement in long-term care for older adults was legally introduced in 2015, meaning

that all municipalities must offer reablement interventions and all applicants for home care are assessed for potential for reablement before being offered conventional home care.<sup>25</sup>

Despite the promising results and successful implementation abroad, contextual differences mean this is no indication that it would necessarily be effective in its current format in the Dutch home care setting.<sup>26</sup> Implementing reablement is a complex process and influenced by multiple factors, such as organisational factors, individual and social attitudes towards a new form of care, technological factors related to communication, and financial factors.<sup>27,28</sup> It is crucial to critically consider these factors in the design, delivery, and evaluation of reablement.<sup>29</sup> Moreover, to implement reablement in the Dutch home care setting, existing programmes need to be revised and adapted to suit the current context, which is crucial when developing and delivering complex health-care interventions.<sup>29</sup> However, the development and content of community care programmes, such as reablement programmes, are often insufficiently described in the scientific literature.<sup>19,30-32</sup> There are only limited articles available that describe either the development of the programme or its content in detail<sup>33-35</sup> and these descriptions are often included as part of a feasibility or pilot study.<sup>31</sup> This offers little guidance to replicate or build on the previous findings of such programmes, despite this being essential for the development and implementation of new and existing programmes in different settings.<sup>31,32,36</sup>

This paper therefore describes the development – using a co-creation process – and content of I-MANAGE, a reablement programme for community-dwelling older adults to improve older adults' self-management and participation in daily life, while also increasing QoL and decreasing informal caregivers' burden. By describing the development and content of the programme in detail, we increase the replicability and prevent other researchers from reinventing the wheel. The programme is specifically suitable for the Dutch community care setting, however, due to its extensive description, this manuscript may also provide a model for implementation in other countries.

## Methods

To describe the development process of the programme and ensure completeness of reporting, we used the guidance for reporting for intervention development studies in health research (GUIDED) (Appendix 1).<sup>31</sup> This checklist provides a clear and structured basis for the reporting of programme development, as well as the description of the content of the programme.

## Design

I-MANAGE was developed between September 2019 and June 2021 using a co-creation design. The programme was developed following the first phase (development) of the Medical Research Council (MRC) framework for the development and evaluation of complex interventions.<sup>37,38</sup>

## Patient and public involvement

Co-creation was initiated by the researchers as a response to the challenges that are caused by an ageing society (e.g. increasing care needs, decreasing staff). To deal with these challenges the Dutch government stimulates an ageing in place policy and promotes another way of (home) care delivery moving from 'doing for...' towards 'doing with...' clients, or in the best case to enable clients to do things by themselves again. These developments are also adopted by Dutch care organisations, which hope to improve the quality and sustainability of their care services.<sup>39</sup> All end users (care professionals who would be implementing and delivering the programme, as well as the target population) were represented and involved during the development process of the programme as members of the working groups and by participating in the individual interviews. However, they were not involved in the development of the study design of dissemination of the findings.

## Setting and participants

I-MANAGE is based on international evidence and tailored to the Dutch home care context. Home care in the Netherlands includes personal care (i.e. assistance with ADL), nursing care (i.e. medical assistance), and domestic support (i.e. assistance with instrumental activities of daily living (IADL)).<sup>40</sup> Usually home care is funded by two statutory forms of insurance cover care: the *Health Insurance Act* (ZVW) and the *Social Support Act* (WMO). Clients often use a combination of ZVW (e.g. general practitioner care, therapists, hospital care, or medication), and WMO (e.g. domestic support, home adaptations).<sup>40,41</sup> The programme was developed for community-dwelling older adults, irrespective of age or cognitive and functional status.

The programme was developed in co-creation with stakeholders who participated in observations, individual interviews and working groups. Appendix 2 provides an overview of all stakeholders involved and the research activities they participated in. Participants were

recruited from the professional network of the researchers. They were informed about the study and asked to participate via email. When participants agreed to participate, verbal or written informed consent was provided before the start of each interview or working group session.

### **Data collection**

First, a logic model was created. A logic model is a tool to illustrate how a programme will create change.<sup>42</sup> The logic model systematically visualises the aim and sub-aims of the programme, the programme components, and the intended outcomes.<sup>42</sup> The logic model was developed using six iterative programme development steps: 1) identifying the problem; 2) identifying the evidence; 3) identifying or developing a theory; 4) determining needs; 5) examining current practices and the context; and 6) modelling processes and outcomes.<sup>43</sup> The logic model was then translated to practice (step 7). Data collection was performed following a non-linear and iterative process as described by Bleijenberg et al,<sup>43</sup> and by using a variety of data collection methods, including literature research, observations, individual interviews, and working groups. Figure 1 illustrates the development process in detail.

#### ***Development of a logic model (steps 1 to 6)***

All steps were guided by literature research, especially steps 2 and 3 of the development process. To gain insight into current evidence-based practices (*step 2*), the relevant scientific literature on reablement programmes was reviewed. The methodology and results of this literature research is described elsewhere.<sup>44</sup> To identify a theoretical foundation for the programme (*step 3*), a literature review was performed on the concept of disability and its underlying causal mechanisms.<sup>45</sup>

Furthermore, a working group was composed and invited to three sessions (1.5 h each). Members of the working group included physiotherapists (PT), occupation therapists (OT), registered nurses (RN), a domestic support worker (DSW), a policymaker of the local municipality, a psychologist, a client representative, informal caregiver representatives, and a geriatric rehabilitation expert. The first session focused on the identification of the problem (*step 1*) and the examination of the current practice and context (*step 5*). Session two focused on the previously identified evidence, which participants could complement with practices from their own field of work (*step 2*), and the determination of needs (*step 4*), closely related to the previously identified problems. The third session focused on modelling the process and



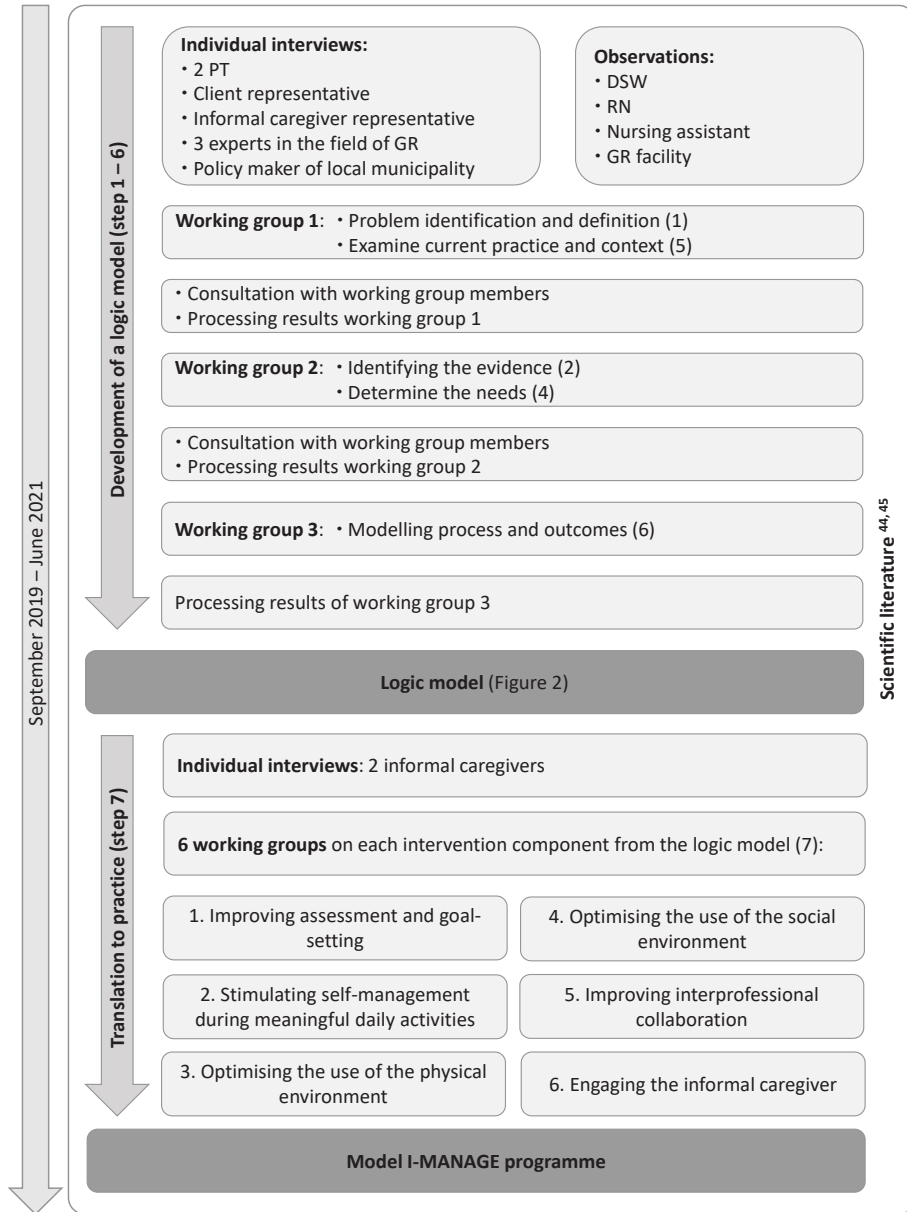
outcomes (*step 6*), during which a preliminary logic model was presented, on which participants could provide feedback. Between sessions, working group members were consulted for additional input and clarification if needed. The researchers processed the results from each session and the additional information in order to be used as a starting point for the next session. The working group sessions were led by the first and last author (IM and SM).

We then interviewed two PTs, a policy maker of the local municipality, a client and informal caregiver representative and three experts in the field of geriatric rehabilitation research. In total, eight interviews were conducted, all focusing on identifying the problem (*step 1*), determining the needs (*step 4*), and gaining insight into current practice and context (*step 5*). In addition, we interviewed two informal caregivers. Topics addressed during these interviews included their role as informal caregiver, how involved they were in the care process, how they were or felt supported and by whom and what they would like to change in the process.

Lastly, observations were performed by the researchers. Observations were conducted in the traditional community care setting to examine current practice and context of home care services (*step 5*) and to identify problems (*step 1*). Six observations, each lasting half a day, were conducted by shadowing a DSW, an RN, and a nursing assistant, and three days were spent with allied health professionals. Field notes were taken throughout the observation periods.

### ***Translation to practice (step 7)***

For each of the six programme components in the logic model, we invited members of the working group, a geriatrician, informal care consultant, reablement researcher, informal caregiver, and a community care teams' manager to a session to translate components into practice (*step 7*). Based on the programme component, the most relevant stakeholders were invited. For example, on informal caregiver support, we invited an informal care consultant, an informal caregiver, and a psychologist, resulting in three to four members per working group. Each working group attended one session lasting 1 hour. Each session began with an introduction to the goal of the programme, the logic model, and the results of steps 1 to 6 related to the programme component. Afterwards, participants were asked open-ended questions about the practical implementation as well as barriers and facilitators of the component. Lastly, results were summarised, and participants were asked for final feedback. Table 1 provides an overview of the different methodologies used in each development step.



**Figure 1.** The development process over time. This figure presents the development process over time from September 2019 until June 2021. The whole process is guided by scientific literature. The figure presents the two parts of the development process each with their related activities. The dark grey rectangles present the (intermediate) result of each part of the process. The numbers in between brackets represent the seven steps of the development phase as described by Bleijenberg et al.<sup>43</sup> PT = physiotherapist; GR = geriatric rehabilitation; DSW = domestic support worker; RN = registered nurse

**Table 1.** Overview of the different methodologies used in each development step defined by Bleijenberg et al.<sup>43</sup>

Programme development steps	Methodology			
	Literature research	Observations	Individual interviews	Working groups
Problem identification	•	•	•	•
Identifying the evidence	•			•
Identifying or developing theory	•			
Determine the needs	•		•	•
Examining current practice and context	•	•	•	•
Modelling process and outcomes	•	•	•	•
Translation to practice	•			•

*Note.* The full black dots • indicate a main source of information for the particular step, while the full grey dots ◐ indicate only a minor influence and guidance for the particular step.

## Data analysis

We used data triangulation to verify the results. Our main source of information was the working group sessions, as they provided the richest data on the perspectives of the different target groups. Individual interviews, observations, and literature research were used to complement and check the information obtained throughout the working group sessions. Working group sessions and individual interviews were recorded and transcribed non-verbatim. A thematic analysis was conducted based on the steps described by Braun and Clarke<sup>46</sup>. Common themes were identified within each step of the development process (e.g. lack of sufficient communication). Afterwards, the themes from all sessions were compared and associations were found between, for example, identified problems and determined needs, or current scientific evidence and best practices of the organisation. The results of each session provided input and structure for the next session. After each working group session or individual interview, a member check was conducted by summarising the most important findings. The results were discussed regularly within the research team. The research team consists of all authors involved. They work in the field of social gerontology, public health and primary and long-term care. A research logbook was kept by the researchers to keep track of all research activities and intermediate results, together with field notes from these activities.

## Results

The following section presents the final model of the I-MANAGE programme in detail, starting with the developed logic model, and eventually the translation to practice, which contains a detailed description of all programme components. A detailed description of the results from the first five programme development steps is provided in Appendix 3.

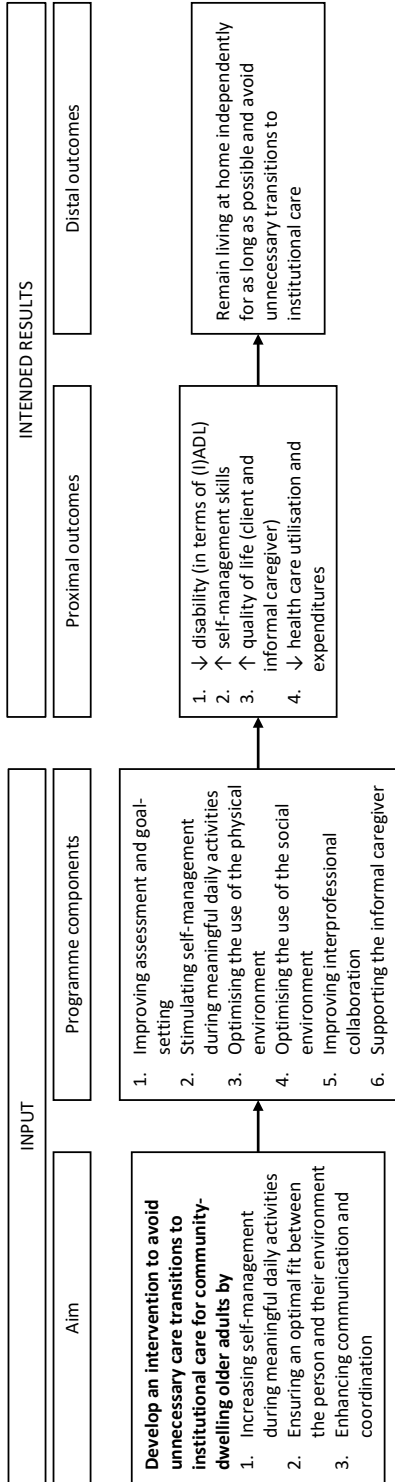
### Development of a logic model

The logic model starts with the aim and sub-aims of the programme based on identified problems and needs (*results from development steps 1 and 4*), which are derived mostly from the working group sessions and individual interviews. To fulfil these aims, six programme components were determined: 1) improving assessment and goal setting; 2) stimulating self-management during meaningful daily activities; 3) optimising the use of the physical environment; 4) optimising the use of the social environment; 5) improving interprofessional collaboration; and 6) supporting the informal caregiver. These originate from both the input from stakeholders (*result from development steps 2, 4, 5 and 6*) and evidence-based practices from the literature (*result from development step 2*). The intended client outcomes of the programme are reducing (I)ADL disability, improving self-management skills, increasing QoL of both the client and informal caregiver and reducing health-care utilisation and expenditures (proximal outcomes), which are common outcome measures in reablement programmes abroad. Eventually, improving these proximal outcomes would help the older adults to remain living at home independently and avoid unnecessary transitions to institutional care (distal outcomes). Figure 2 presents the logic model.

### Translation to practice: description of the I-MANAGE programme

The I-MANAGE programme, as described here, is the result of input from stakeholders and literature research during the last step of the development process (*step 7*).<sup>43</sup> The following sections describe the programme in detail. The programme, as described, may serve as a model for the use in different local settings and leaves room for tailoring to the specific needs and resources of the organisation.

To achieve the intended outcomes presented in the logic model, the programme should intend to apply a two-tiered approach: 1) focusing on the capabilities of the client and 2) paying



**Figure 2.** Logic model of the I-MANAGE programme. The logic model of the I-MANAGE programme presents the aim and associated sub-aims of the programme, the programme components, and proximal and distal outcomes

attention to environmental factors (i.e. physical, social, and organisational). I-MANAGE should be intended for community-dwelling older adults who are still able to (re)learn new skills and apply them in daily life without an indication of terminal illness or planned nursing home admission. The average duration of the programme is preferably 8 weeks according to the members of the working groups.

### ***Interdisciplinary collaboration***

I-MANAGE aims to facilitate interdisciplinary collaboration by encouraging intensive collaboration between the reablement team, client, informal caregiver and other care professionals delivering care and support to the client and informal caregiver. The programme should be delivered by an interdisciplinary reablement team, generally consisting of an RN, an OT, and, depending on the local context, supplemented with a PT, social worker, DSW, or other disciplines. The reablement team should initiate the programme and is responsible for the direct support of the client and informal caregiver. A care coordinator should be appointed, which in most cases, is the OT. Depending on the necessary care and goals set by the client, the reablement team may consult other care professionals (e.g. usual home care team, psychologist, or general practitioner); for example, during the intake phase for advice or while working on the client's goals. They should be informed and coached by the reablement team.

Furthermore, regular team meetings should be organised (e.g. (bi-)weekly to discuss the intake of new clients and informal caregivers, the progress made by clients, and the final evaluation of clients' personal goals. Additionally, team meetings could provide the opportunity to discuss specific cases with other team members and to organise training. All members of the reablement team should have access to access the care plan, report progress, and follow up on each other's work, preferably through a shared electronic care file (ECF) of the client. Lastly, when discharged from another care facility (e.g. hospital or rehabilitation facility), a smooth handover of client information should be initiated so no necessary details of the client's care process are lost.

### ***Practice-oriented training***

Preceding the programme, the reablement team should receive practice-oriented training focusing on adequately delivering I-MANAGE. Within this training, care professionals should receive a detailed manual beforehand, consisting of background information and a description of the programme, including the goal, key components, and I-MANAGE's care process. The manual was developed by the researchers and revised by working group members to make

sure it is suitable for practice. Additionally, a toolkit for achieving individual client goals should be provided (e.g. exercise booklet based on the OTAGO exercise programme,<sup>47</sup> social map including welfare initiatives, and tools to assess needs and wishes of the caregiver). The training should consist of multiple sessions, preferable in the following structure: the first is a kick-off meeting for the reablement team, focusing on the goal and content of I-MANAGE. Secondly, specific training sessions occur for OT and PT concerning the use of the Canadian Occupational Performance Measure (COPM)<sup>48</sup> to set personal goals with the client and the OTAGO exercise booklet respectively. Finally, the reablement team receives a booster session to practice and discuss challenging situations and focus on motivational and conversation skills. The kick-off and booster sessions each last two hours and the specific sessions for OT and PT last one hour. Additionally, the programme should stimulate training on the job, meaning that members of the reablement team can coach each other and external care professionals based on their own expertise.

### ***I-MANAGE care process***

The I-MANAGE care process consists of five consecutive phases: 1) initiation; 2) intake; 3) care plan; 4) care delivery; and 5) evaluation. Each phase is described in detail below and presented in Figure 3. The five phases are a result of the practical translation of the previously described logic model.

#### ***Phase 1: Initiation***

Programme referrals could be done through community nurses, general practitioners, or institutional care facilities. Community-dwelling older adults eligible for I-MANAGE should receive information about the programme. The care coordinator must plan a first visit to present the programme to the client and, if applicable, their informal caregiver to provide the opportunity to ask additional questions. The care coordinator should initiate an exploratory conversation based on the principles of positive health to gain insight into the client's needs and wishes.<sup>49</sup>

#### ***Phase 2: Intake***

Within the first week after the initiation phase, the OT should perform an environmental assessment, identifying necessary home modifications and assistive devices to ensure a safe environment. The environmental assessment is not limited to the inside environment but does also include the entrance and outside environment. Additionally, the care coordinator, or an assigned social worker, should perform an intake with the informal caregiver assessing their

needs and wishes. Furthermore, the OT must set meaningful goals with the client using COPM<sup>48</sup> (maximum of five goals). This instrument requires the clients to score both their performance and satisfaction when performing these activities.<sup>48</sup> Goal setting is guided by the exploratory conversation held in phase 1. The ultimate goal is to improve the client's participation and wellbeing; therefore, goals should not merely be (I)ADL-related (e.g. meeting friends at the local café, or painting in the hobby room on the first floor). Goals should be recorded in the client's ECF.

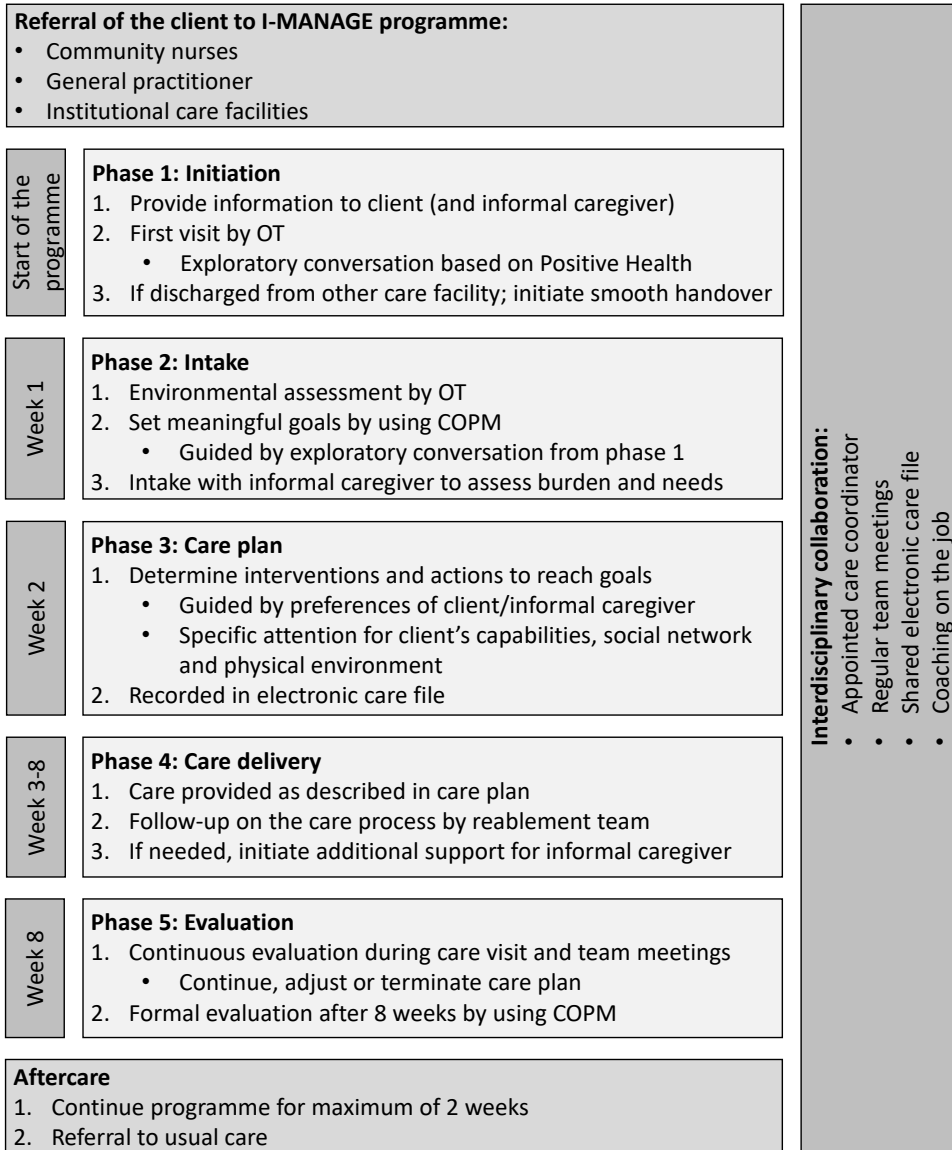
### *Phase 3: Care plan*

Possible interventions and actions to achieve the client's goals and provide the informal caregiver with the right support should be discussed within the reablement team. These interventions and actions are derived from the available toolkit. Afterwards, the care coordinator should determine the final interventions and actions with the client and informal caregiver, guided by their preferences and capabilities, possibilities of the social network and the physical environment. Subsequently, the care plan should be recorded in the client's ECF and shared with all members of the reablement team. The intensity of the programme depends on the care needs of the client and their pre-set goals, which may require a higher intensity in the beginning but less at the end when (sub-)goals are (partly) reached.

### *Phase 4: Care delivery*

The reablement team should deliver care and support as described in the care plan. Care delivery should be coordinated by the OT, who is also responsible for assisting with (re)learning and practicing meaningful daily activities. The RN is responsible for supporting managing the client's personal care needs. The PT, when part of the reablement team, is responsible for functional training and stimulating participation in daily life. The client's environment should be adapted (e.g. home modifications, assistive devices, and care technology), to support them in (re)learning activities. While supporting meaningful activities, the client's self-management should be stimulated by practicing activities and ensuring that tasks are not taken over by care professionals or informal caregivers. If necessary, a social worker should provide the informal caregiver with additional support to decrease their burden (e.g. respite care).





**Figure 3.** Detailed presentation of the I-MANAGE care process. I-MANAGE has a 5-phase care process (initiation, intake, care plan, care delivery, and evaluation), preceded with the referral of the client through different routes. After an average duration of 8 weeks, clients are referred to aftercare. Interdisciplinary collaboration is a continuous element of the programme. OT = occupational therapist; COPM = Canadian Occupational Performance Measure<sup>48</sup>

### ***Phase 5: Evaluation***

The evaluation of the care process should be structurally embedded in interdisciplinary team meetings. Based on conclusions drawn during these meetings, the care coordinator can decide whether the care plan is continued, adjusted or terminated. This must be discussed with the client and informal caregiver. At the end of the programme, a formal evaluation of the client's goals should take place using COPM,<sup>48</sup> including scoring the performance and satisfaction within activities. Afterwards, the care coordinator decides with the client and informal caregiver if the programme should be extended (max. two weeks) to ensure all goals are sufficiently reached or if the client needs referral to usual care.

## **Discussion**

This manuscript describes the development and content of I-MANAGE, a community-based reablement programme. The programme was developed for community-dwelling older adults to improve their self-management and participation in daily life and ensure that they can remain living at home independently as long as possible and avoid unnecessary transitions to institutional care, while also increasing QoL and decreasing informal caregiver burden.

The programme contains several key elements that are considered essential and should be present when implementing the programme in any care setting. Firstly, in line with the conceptual definition of reablement,<sup>18</sup> interdisciplinary collaboration is important in I-MANAGE. However, how this element is implemented in practice depends on the contextual circumstances of a country or region and the resources available. In this study it was recommended by Dutch stakeholder to appoint a care coordinator, schedule (bi-)weekly meetings, and implement a shared ECF. Recent literature indicates that investing in interdisciplinary collaboration stimulates patient-centred care by ensuring a holistic view of the client's situation and creates shared responsibility.<sup>50-52</sup> This is achieved by good communication and coordination within the team but also with the client and informal caregiver.<sup>53</sup> Moreover, delivery of the programme by an interdisciplinary team, including allied health, such as OTs, is deemed valuable because of their educational background.<sup>32,54</sup> It also stimulates continuous learning and is experienced as exciting and constructive by care professionals.<sup>52,53</sup> Additionally, the integrated practice-oriented and on the job training, where care professionals can learn from other disciplines, help to invest in the self-efficacy of care professionals. This is essential, because successfully changing behaviours remains a challenge. The training entails several key

topics as mentioned before, however, depending on the local context the extend of the training may vary, for example, due to previously received education or training. Secondly, at the start of the programme (phase 1 and 2), we implemented a standardised goal-setting tool, COPM,<sup>48</sup> preceded by an extensive intake based on the principles of positive health.<sup>49</sup> Previous research has indicated that using standardised assessment or goal-setting tools could increase the effectiveness of reablement interventions, and is therefore considered an essential element of the programme.<sup>32</sup> Additionally, it increased client involvement and helps professionals to identify meaningful activities with the client.<sup>55</sup> Thirdly, when delivering care (phase 4), the programme integrates several important aspects. Firstly, supporting informal caregivers is assumed to contribute to the effectiveness of I-MANAGE. Previous research found that providing informal caregivers with the right psychosocial and educational support strengthens their ability to cope with their new role.<sup>56,57</sup> This is an important addition to most reablement programmes because, although making use of the clients' social network is a strategy to reach their goals according to the internationally accepted definition,<sup>18</sup> this is often overlooked.<sup>58,59</sup> Additionally, I-MANAGE promotes optimal use of the social and physical environment, which is essential since a demanding environment can either stimulate or hinder a person's participation in meaningful activities.<sup>3,60</sup> Lastly, the programme stimulates self-management through participation in meaningful daily activities, which is a core element within reablement ('doing with...' rather than 'doing for...' the client).<sup>18,61</sup>

The described programme serves as a model and leaves room to tailor the intervention to a specific context and the needs of the organisation. For example, the programme leaves room for the organisation to choose which target group would benefit most. Additionally, delivering the programme by an interdisciplinary team is a prerequisite. However, depending on available resources, the organisation can decide on the composition of the reablement team. Moreover, I-MANAGE is a multi-component programme in which organisations can integrate their own innovative practices, especially when working towards and reaching clients' meaningful goals. Also, the duration and intensity of the programme may vary according to the needs of the local context and chosen target population. Moe and Brinchmann<sup>27</sup> confirmed the necessity of tailoring reablement services to local conditions by arguing that establishing reablement in an existing organisational structure is a complex process. Apart from available resources, during the co-creation process, some influencing factors for implementation were identified. For example, different IT systems, which make communication and information transfer less evident. Moe and Brinchmann<sup>27</sup> mentioned that – next to communication and IT systems – habitual ways of offering health services, a lack of knowledge about the rehabilitation potential

of older adults and active ageing benefits are also experienced as barriers. A recent scoping review identified several factors that act as barriers and facilitators during the implementation of care innovations, among which available resources and communication were listed as possible barriers to implementation.<sup>62</sup> It is critical to consider these factors when implementing I-MANAGE in practice. In order to overcome several barriers to the implementation of I-MANAGE, it could be useful to set up advisory boards and working groups to discuss the implementation process and adjust where needed. Additionally, investing in getting the management of care organisations on board to support the implementation within their organisation and setting up knowledge exchange between sites where reablement is being implemented to share experiences and best practices could be beneficial. Investing in a suitable organisational structure is essential because it remains a challenge to successfully change existing organisational structures.<sup>27,63,64</sup> Regarding future research, further knowledge is needed to explore feasibility and (cost-)effectiveness of I-MANAGE, as it has not yet been proven. Since the programme is very context specific and can be tailored according to the needs and resources of an organisation, it would be beneficial to investigate what works for which target group and under what circumstances – for example, by means of a realist evaluation.<sup>65</sup> The programme is currently being implemented and evaluated at different Dutch care providers. The systematic reporting of the development of the programme provides useful insight for future research looking to develop complex health interventions or to implement a similar programme.

A strength of I-MANAGE and its development is that it is both theory and evidence-based,<sup>44,45</sup> which has proven to be advantageous when developing effective interventions.<sup>66,67</sup> Moreover, Thuesen et al<sup>68</sup> highlight the demand for making theory explicit in reablement interventions and in addressing the physical, psychological, and sociocultural perspectives of ageing within these interventions. Another strength of the development process was the co-creation process, which gave a voice to multiple stakeholders and made the programme suitable for practice. We used the development approach described by Bleijenbergh et al,<sup>43</sup> which combined a range of published approaches to intervention development to enrich the MRC framework. This approach was chosen because using the MRC framework further assists us in evaluating and adapting the programme. However, we are aware that multiple approaches to intervention development exist as described by O’Cathain et al.<sup>69</sup> These different approaches share many similarities (e.g. stepwise approach or involvement of stakeholders), but there are also significant differences (e.g. the focus on implementation or theory). It is important to acknowledge these differences and always chose an approach best suited to the purpose of the

research. Additionally, most of these approaches are not set in stone and leave room for the researchers own interpretation. It must also fit the setting and timing of the development process. There are also some limitations related to this co-creation process. Firstly, during the process, we always informed management to obtain their support, but they were not included in the working groups, which could have blocked important insight. Secondly, we aimed to include all end users of the programme during the development process (care professionals, clients, and informal caregivers). However, we only included client and informal caregiver representatives in the working groups and interviewed only two informal caregivers between sessions. Additionally, care professionals were recruited from the professional network of researchers and were recruited in a convenient way. We therefore did not ensure variation among these participants in terms of, for example, gender, age, or years of experience. Lastly, we obtained data from many different sources (i.e. scientific literature, individual interviews, working groups, and observations), which made it difficult to find common ground throughout all the sources and forced compromise. However, this use of data triangulation is also a strength of the development of the programme as findings could be checked multiple times with different sources, increasing the validity of the results.

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## Appendices

### Appendix 1. GUIDED checklist. A guideline for reporting for intervention development studies

Item description	Explanation	Page in manuscript where item is located	Other*
Report the context for which the intervention was developed.	Understanding the context in which an intervention was developed informs readers about the suitability and transferability of the intervention to the context in which they are considering evaluating, adapting or using the intervention. Context here can include place, organisational and wider socio-political factors that may influence the development and/or delivery of the intervention.	p 69	
Report the purpose of the intervention development process.	Clearly describing the purpose of the intervention specifies what it sets out to achieve. The purpose may be informed by research priorities, for example those identified in systematic reviews, evidence gaps set out in practice guidance such as The National Institute for Health and Care Excellence or specific prioritisation exercises such as those undertaken with patients and practitioners through the James Lind Alliance.	p 68	
Report the target population for the intervention development process.	The target population is the population that will potentially benefit from the intervention – this may include patients, clinicians, and/or members of the public. If the target population is clearly described, then readers will be able to understand the relevance of the intervention to their own research or practice. Health inequalities, gender and ethnicity are features of the target population that may be relevant to intervention development processes.	p 69 – 70	
Report how any published intervention development approach contributed to the development process.	Many formal intervention development approaches exist and are used to guide the intervention development process (e.g. Squid or The Person Based Approach to Intervention Development). Where a formal intervention development approach is used, it is helpful to describe the process that was followed, including any deviations. More general approaches to intervention development also exist and have been categorised as follows: Target Population-centred intervention development; evidence and theory-based intervention development; partnership intervention development; implementation-based intervention development; efficacy-based intervention development; step or phased-based intervention development; and intervention-specific intervention development. These approaches do not always have specific guidance that describe their use. Nevertheless, it is helpful to give a rich description of how any published approach was operationalised	p 69	

Item description	Explanation	Page in manuscript where item is located	Other*
Report how evidence from different sources informed the intervention development process.	Intervention development is often based on published evidence and/or primary data that has been collected to inform the intervention development process. It is useful to describe and reference all forms of evidence and data that have informed the development of the intervention because evidence bases can change rapidly, and to explain the manner in which the evidence and/or data was used. Understanding what evidence was and was not available at the time of intervention development can help readers to assess transferability to their current situation.	p 70	Appendix 3 + Mouchaers et al <sup>44</sup>
Report how/if published theory informed the intervention development process.	Reporting whether and how theory informed the intervention development process aids the reader's understanding of the theoretical rationale that underpins the intervention. Though not mentioned in the e-Delphi or consensus meeting, it became increasingly apparent through the development of our guidance that this theory item could relate to either existing published theory or programme theory.	p 70	Appendix 3 + Mouchaers et al <sup>45</sup>
Report any use of components from existing interventions in the current intervention development process.	Some interventions are developed with components that have been adopted from existing interventions. Clearly identifying components that have been adopted or adapted and acknowledging their original source helps the reader to understand and distinguish between the novel and adopted components of the new intervention.	p 70	Appendix 3 + Mouchaers et al <sup>44</sup>
Report any guiding principles, people or factors that were prioritised when making decisions during the intervention development process.	Reporting any guiding principles that governed the development of the application helps the reader to understand the authors' reasoning behind the decisions that were made. These could include the examples of particular populations who views are being considered when designing the intervention, the modality that is viewed as being most appropriate, design features considered important for the target population, or the potential for the intervention to be scaled up.	p 69 – 73	Appendix 3
Report how stakeholders contributed to the intervention development process.	Potential stakeholders can include patient and community representatives, local and national policy makers, health care providers and those paying for or commissioning health care. Each of these groups may influence the intervention development process in different ways. Specifying how differing groups of stakeholders contributed to the intervention development process helps the reader to understand how stakeholders were involved and the degree of influence they had on the overall process. Further detail on how to integrate stakeholder contributions within intervention reporting are available.	p 69 – 73	

## Appendix 1. Continued

Item description	Explanation	Page in manuscript where item is located	Other*
Report how the intervention changed in content and format from the start of the intervention development process.	Intervention development is frequently an iterative process. The conclusion of the initial phase of intervention development does not necessarily mean that all uncertainties have been addressed. It is helpful to list remaining uncertainties such as the intervention intensity, mode of delivery, materials, procedures, or type of location that the intervention is most suitable for. This can guide other researchers to potential future areas of research and practitioners about uncertainties relevant to their health-care context.	p 74 – 80	
Report any changes to the intervention required or likely to be required for subgroups.	Specifying any changes that the intervention development team perceive are required for the intervention to be delivered or tailored to specific subgroups enables readers to understand the applicability of the intervention to their target population or context. These changes could include changes to personnel delivering the intervention, to the content of the intervention, or to the mode of delivery of the intervention.	p 81 – 82	
Report important uncertainties at the end of the development process.	Intervention development is frequently an iterative process. The conclusion of the initial phase of intervention development does not necessarily mean that all uncertainties have been addressed. It is helpful to list remaining uncertainties such as the intervention intensity, mode of delivery, materials, procedures, or type of location that the intervention is most suitable for. This can guide other researchers to potential future areas of research and practitioners about uncertainties relevant to their health-care context.	p 81 – 83	
Follow TIDieR guidance when describing the developed intervention.	Interventions have been poorly reported for a number of years. In response to this, internationally recognised guidance has been published to support the high-quality reporting of health care interventions and public health interventions. This guidance should therefore be followed when describing a developed intervention.		
Brief name.	Provide the name or a phrase that describes the intervention.	p 64	Title page
Rationale, theory and aim of the elements essential to the intervention.	Describe any rationale, theory, or goal of the elements essential to the intervention.	p 74	Appendix 3 + Mouchaers et al <sup>45</sup>
Materials used in the intervention delivery or in the training of intervention providers.	Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	p 74 – 79	

Item description	Explanation	Page in manuscript where item is located	Other*
Procedures, activities and/or processes used including enabling or support activities.	Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	p 74 – 79	
Expertise and background of intervention providers.	For each category of intervention provider (e.g. psychologist, nursing assistant), describe their expertise, background and any specific training given.	p 74 – 79	
How the intervention was provided.	Describe the modes of delivery (e.g. face-to-face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	p 74 – 79	
Location where the intervention occurred (incl. necessary infrastructure or relevant features).	Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	p 69	
When and how much the intervention was delivered.	Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose.	p 74 – 79	
Tailoring – what, why, when and how.	If the intervention was planned to be personalised, titrated or adapted, then describe what, why, when, and how.	p 81 – 82	
Modifications. †	If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).	N/A	
Strategies to improve or maintain fidelity.	If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	p 81 – 83	
Adherence and fidelity. †	If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	N/A	

**Appendix 1.** Continued

Item description	Explanation	Page in manuscript where item is located	Other*
Report the intervention development process in an open access format.	Unless reports of intervention development are available people considering using an intervention cannot understand the process that was undertaken and make a judgement about its appropriateness to their context. It also limits cumulative learning about intervention development methodology and observed consequences at later evaluation, translation and implementation stages. Reporting intervention development in an open access (Gold or Green) publishing format increases the accessibility and visibility of intervention development research and makes it more likely to be read and used. Potential platforms for open access publication of intervention development include open access journal publications, freely accessible funder reports or a study webpage that details the intervention development process.	N/A	Aim of this manuscript

*Note.* \* e.g. if item is reported elsewhere, then the location of this information can be stated here. † If completing the TIDieR checklist for a protocol, these items are not relevant to the protocol and cannot be described until the study is complete.



**Appendix 2.** Overview of the different stakeholders involved per research activity

Stakeholders <sup>a</sup> (n = 26)	Observations <sup>b</sup>	Individual interviews	Working groups								
			Development of a logic model <sup>c</sup>			Translation to practice <sup>d</sup>					
			1	2	3	1	2	3	4	5	6
Domestic support worker	•		•	•	•		•			•	
Registered nurse (n = 3)	•		•	•	•		•	•		•	•
Nursing assistant	•										
Physiotherapist (n = 4)		•	•	•	•		•				•
Expert in the field of GR research (n = 3)		•	•								
Informal caregiver (n = 3)		•									•
Policy maker of the local municipality (n = 2)		•		•	•				•	•	
Client representative		•	•	•						•	
Informal caregiver representative		•	•	•							
Occupational therapist (n = 2)			•	•	•		•	•	•		
Psychologist			•	•	•						•
Geriatrician							•				
Reablement researcher								•			
Manager community care team											•
Consultant informal care										•	•

Note. <sup>a</sup> if n > 1, not all stakeholders participated in every indicated research activity for that group; <sup>b</sup> observations were performed by the researchers; <sup>c</sup> indicates the three consecutive working group sessions throughout which the logic model was being developed following step 1 to 6 as described by Bleijenberg et al<sup>43</sup>; <sup>d</sup> indicated the 6 working groups related to each programme component described in the logic model (1 = improving assessment and goal setting, 2 = stimulating self-management during meaningful daily activities, 3 = optimising the use of the physical environment, 4 = optimising the use of the social environment, 5 = improving interprofessional collaboration, and 6 = engaging the informal caregiver). GR = geriatric rehabilitation

### Appendix 3. Overview of the intermediate results of the first five steps of the development phase

Programme development step	Results
1. Problem identification	<p>The identified problems were situated in three main areas:</p> <ol style="list-style-type: none"> <li>1. A lack of attention to meaningful daily activities. According to the working group, older persons were mainly focused on functional goals related to (I)ADL tasks rather than meaningful daily activities that increase their well-being. Additionally, the focus of care is often on eliminating diseases and symptoms instead of maintaining quality of life<sup>10,11</sup>;</li> <li>2. There appeared a gap between the person's abilities, needs, and wishes, and the environment they reside in. When older adults experience a deterioration in health status, their environment is often not adapted, i.e. the necessary home modifications and assistive devices are not always in place<sup>3,70</sup>;</li> <li>3. Communication and coordination within the care trajectory of an older person. There is insufficient communication amongst different care professionals but also with older persons and informal caregivers.<sup>3,71-73</sup></li> </ol>
2. Identifying the evidence	<p>The identification of the evidence-based practices was mainly based on literature research. A literature review was performed to gain insight into current evidence on effective reablement programmes aimed at improving the independent living of older persons.<sup>44</sup> We specifically sought to gain a general understanding of different reablement programmes, their characteristics (e.g. duration), content, outcome measures, and effectiveness. Thirteen programmes were identified, all intended for (I)ADL-impaired community-dwelling older adults. The most common features were: 1) delivery by a trained and coordinated multidisciplinary team and 2) implementation of an intake assessment and goal-setting tool. The applied interventions focused on supporting (I)ADL and physical functioning and improving home safety. Nine programmes showed a statistically significant improvement on at least one of the outcome measures (e.g. (I)ADL functioning).</p>
3. Identifying or developing theory	<p>A literature review was performed on the concept of disability and its working mechanisms<sup>45</sup> to identify a solid theoretical foundation for our programme (<i>step 3</i>). We concluded that by optimising the use of personal, as well as environmental, resources and focusing on health and functioning, rather than disability, an older person's independence and wellbeing could be improved, especially while performing meaningful daily activities in accordance with the person's needs and preferences.</p>
4. Determine the needs	<p>The determined needs are closely related to the identified problems. Stakeholders expressed the need for:</p> <ol style="list-style-type: none"> <li>1. Standardised goal setting at the beginning of the care process. Goals should be meaningful, embedded in the older person's own environment, and not solely focused on (I)ADL;</li> <li>2. Timely assessment and, if necessary, adaptations to the home environment of the older person. This concerns adaptations to the built environment, as well as the availability of assistive devices. Additionally, the social environment of the older person needs to be assessed in order to make optimal use of it or provide additional support if the social network is rather weak;</li> <li>3. Improved communication and coordination within the care trajectory of the older person. For example, a smooth handover of information between care professionals and organisations, involvement of the informal caregiver when discussing a client's care needs, multidisciplinary collaboration with clear roles for each provider, and the appointment of a care coordinator.</li> </ol>

Programme development step	Results
5. Examining current practice and context	When examining the current practice and context we focused on positive aspects and possible barriers for implementation. Possible barriers could be different financial arrangements and different communication systems within a multidisciplinary team. Positive aspects include the comprehensive assessment by community nurses at the start of receiving community care, a signalling role for domestic support workers, and the presence of various welfare initiatives in the Netherlands. A suggestion was made to include the principles of positive health <sup>49</sup> in the programme, a best practice that is already known and applied by some care professionals.

*Note.* (I)ADL = (instrumental) activities of daily living



# Chapter 5

## Exploring the support and involvement of family caregivers for reablement programs: a qualitative study

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## **Abstract**

**Background:** Reablement is a person-centred, holistic approach promoting older adults' participation through social, leisure, and physical activities. Family caregivers are seldom involved in reablement services despite their wish to be an active member of the care team and expressing a need for more support and recognition. The voice of family caregivers is often forgotten when evaluating services such as reablement. Little is known how family caregivers can be involved and supported more effectively in reablement services; therefore, the aim of our research is to investigate the perceived support and involvement of family caregivers.

**Methods:** As part of the TRANS-SENIOR project, we studied perceived support and involvement of family caregivers during and after geriatric rehabilitation, a setting in which principles of reablement, like goal setting and training of daily activities, are applied. In total, fourteen semi-structured interviews were conducted with family caregivers of people admitted to a geriatric rehabilitation facility. Thematic analysis was used.

**Results:** Results reflected four themes: 1) support for family caregivers, 2) involvement in care, 3) trusting care professionals, and 4) asking for and accepting support. Family caregivers' experiences with support from care professionals were mainly ambivalent. While caregivers expressing a lack of support and information whilst also indicating that they do not expect to be supported by care professionals. Regarding involvement, caregivers wanted to be involved, i.e. express their opinion and be involved in decision-making. However, more involvement could also lead to a higher burden.

**Conclusion:** There is a discrepancy between the perceived support and involvement of family caregivers, their expressed needs, and their expectations of care professionals. A personalised approach is needed to create room for the family caregiver to be an active participant in the care process while also providing the right amount of support, when preferred by the caregiver.

## Introduction

The majority of older adults prefer to remain living at home for as long as possible and as independently as possible, even those with frail health and challenging social situations.<sup>1,2</sup> An approach to promote independent living among older adults is reablement. Reablement is a person-centred, holistic approach that promotes older adults' active participation in daily activities through social, leisure, and physical activities chosen by the older person in line with their preferences, either at home or in the community.<sup>3</sup> Within reablement, care professionals identify the older person's capabilities and opportunities to maximise their independence by supporting them in achieving their goals, through participation in daily activities, home modifications and assistive devices, and involvement of their social network.<sup>3-6</sup> Although the evidence on the effectiveness of reablement remains mixed,<sup>7-9</sup> the approach has shown promising results related to activities of daily living (ADL) functioning, quality of life (QoL), and well-being of older adults.<sup>9-12</sup>

According to the internationally accepted definition of reablement,<sup>3</sup> making use of clients' social network is a strategy to reach their goals. However, previous studies have shown that family caregivers are seldom involved in reablement or are insufficiently supported throughout the process, often resulting in a higher experienced burden.<sup>13-16</sup> When involved, they often lack the right information and advice while providing care for their relative.<sup>13,14</sup> Moreover, family caregivers expressed a wish for more support and recognition of their needs (e.g. a break from providing care).<sup>13,14</sup> They also indicated that they wanted to be involved and participate in the decision-making regarding care and to be a contributor to the care process of their relative.<sup>13,17,18</sup> Insufficient preparation, lack of information and education, poor communication and collaboration with care professionals, and lack of involvement of the family caregivers,<sup>19-21</sup> often results in increased anxiety and stress, social isolation, decreased quality of life, financial difficulties, and worse perceived health of the caregiver.<sup>21-25</sup>

Reablement is not common practice yet in the Netherlands, however, principles of reablement, such as the goal-setting aspect, being delivered by an interdisciplinary team of care professionals, and the shared goal of enabling older adults to return or remain at home after regaining their independence, are integrated in geriatric rehabilitation.<sup>3,26</sup> Moreover, introducing reablement after geriatric rehabilitation could contribute to maintaining the progress made by the older adult; it could bridge the gap between the regulated rehabilitation environment and clients' own home environment by focusing on relearning daily skills in that unregulated home environment. Compared to reablement, support for family caregivers seems

more developed in geriatric rehabilitation; for example, some geriatric rehabilitation facilities in the Netherlands took on board a consultant on informal care to provide the right support to the caregiver.<sup>27</sup> Since little is known about how family caregivers can be involved and supported more effectively during reablement services, we aimed to understand the lived experiences regarding support throughout and involvement in care of family caregivers who care for someone who has been admitted to a geriatric rehabilitation facility. This setting was chosen because of its similarities with reablement and since reablement is not common practice yet in the Netherlands. Getting insight into their experiences is valuable to improve reablement services and to understand how adequate support for family caregivers should be integrated. The aim of this study is to gain insight into the perceived support and involvement of family caregivers during the care process in geriatric rehabilitation and to explore how this support and involvement can be optimised in their opinion.

## **Materials and Methods**

### **Design**

The current study has a qualitative exploratory research design and is based on a phenomenological approach from Heideggerian's hermeneutic perspective. This approach allows researchers to understand a phenomenon (i.e. support throughout and involvement in care) as experienced by family caregivers through their stories.<sup>28,29</sup> The COREQ guideline was used for the reporting of this study.<sup>30</sup>

### **Setting**

The study was conducted at the geriatric rehabilitation facility of two large health-care providers that offer long-term care services in the south of the Netherlands. Geriatric rehabilitation is defined as *"a multidimensional approach of diagnostic and therapeutic interventions, the purpose of which is to optimise functional capacity, promote activity and preserve functional reserve and social participation in older people with disabling impairments."*<sup>26</sup> The goal of geriatric rehabilitation is to enable older adults to return home after successfully completing their rehabilitation trajectory.<sup>26</sup> In the Netherlands, a care physician, who is specialised in the care of older persons, leads a multidisciplinary team which supports the older adult to work on their rehabilitation goals and regain independence.<sup>31</sup> The



average length of stay is about 39 days, after which the majority of patients return home.<sup>32</sup> The geriatric rehabilitation facilities in this study pay specific attention to involving and supporting family caregivers throughout the rehabilitation process and the care transition afterwards (e.g. organised information sessions or employing a consultant on informal care, who offers guidance and support for family caregivers and helps arrange specific types of support, such as respite care).<sup>27</sup> These facilities also have the ambition to optimise the support and involvement of family caregivers at their facility.

### **Participants and recruitment**

A convenience sample of family caregivers was recruited between May 2022 and December 2022.<sup>33</sup> Family caregivers closest to the patient, who were providing care and support throughout the institutionalisation, were invited to participate while their relative was admitted to the geriatric rehabilitation facility. Additionally, participants needed to be able to participate in the interviews (i.e. understand and speak the Dutch language). We aimed to include different family caregiver profiles based on, for example, relation type (e.g. spouse, child, neighbour, etc.), living situation (living with the patient in the same house or not), or working status (e.g. working, unemployed, retired, etc.). Eligible family caregivers were asked by staff of the health-care organisation whether they were interested in participating in the research and if they could share their contact information with the research team. When interested, researcher IM contacted the participants by telephone to provide additional information about the aim and purpose of the research. Afterwards the interview was planned. Before the start of the interview, the researcher conducting the interview introduced herself as well as her role in the research project. Subsequently, participants received information about the study on paper and orally and were asked to provide written informed consent. Participants were included until data saturation was reached. There was no relationship established between the participants and the researcher conducting the interviews prior to the start of the study.

### **Data collection**

Background information was collected through a questionnaire, including date of birth, gender, marital status, number of children, educational level, work status, relationship to the patient, reason for the patient's admission, if and how long they provided care to their relative before admission, hours (per week) of informal care before admission, and if there were other

caregivers involved. Semi-structured interviews were conducted between May 2022 and December 2022 in a serial manner either in the rehabilitation facility or at their home. Preferably, participants were the only person present at the interview, however, it was not prohibited that their partner was present in the room. Interviews were conducted by first author IM (MSc, female). At the time of the interviews IM was employed as a PhD candidate with basic experience and training in qualitative research methods. We aimed to interview family caregivers twice at different time points of the care process with a minimum of 4 weeks between both interviews, preferably one interview during inpatient geriatric rehabilitation of their relative and one after discharge, to get a comprehensive view of their experience. A semi-structured interview guide was used, focusing on two overarching topics: 1) their perceived support and involvement during the care process in geriatric rehabilitation and 2) their needs and wishes regarding support and involvement and how support and involvement can be optimised. No field notes were made during or after the interview. Table 1 provides an overview of example questions per overarching topic. All interviews were audio recorded. In order to increase the credibility and confirmability of the data, a member check was conducted after each interview by summarising the findings and asking if the participant agreed or wanted something to be added. Interviews were planned for approximately one hour each.

### **Data analysis**

Data were anonymised, transcribed verbatim, and analysed with support from qualitative data analysis software ATLAS.ti Windows (Version 22.2.5.0). A thematic analysis approach was used, following the steps identified by Braun and Clarke.<sup>34,35</sup> A combination of open and axial coding was used. First, the researcher (IM) read the transcripts several times and made notes to familiarise herself with the data. Subsequently, open coding was used to analyse the data. Relationships between codes were identified by means of axial coding. Keeping the research questions in mind, axial coding led to the final themes. The analysis was an iterative process during which initial codes were recoded and relationships and themes were revised. The interviews were coded by the first author and summarised, and subsequently discussed with the second and last author throughout the analysis process. Disagreements were discussed within the research team.

## Ethics

Ethical approval for this study was obtained from the FHML Research Ethics Committee (FHML-REC/2022/041). Informal caregivers voluntarily signed informed consent after they were fully informed about the purpose and procedures of the study and had the opportunity to ask additional questions or raise any concerns. The informed consent stated that participation in this study is completely voluntary and withdrawal from the study is possible at any moment, with or without providing a reason, by contacting one of the researchers. Additionally, the informed consent included publication of anonymised responses.

**Table 1.** Overarching topics and example questions for the semi-structured interviews

Overarching topic	Example questions
Perceived support and involvement	How would you describe the relationship with others involved in the care for your relative? How do these people involve you in the care process of your relative? In what way do you feel heard by these people?
Needs and wishes	In terms of support, what would you like to have for yourself? What would you need to achieve this? What could be improved in terms of support?

## Results

Nine informal caregivers agreed to be interviewed. A more detailed description of the background information is presented in Table 2. Reasons for not participating in more than one interview were unavailability during admission of relative ( $n = 1$ ) or not being willing to further participate after the first interview ( $n = 3$ ). The interviews lasted 52 minutes and 50 seconds on average.

The results reflect four overall themes highlighting the family caregivers' experiences: 1) support for family caregivers, 2) involvement in care, 3) trusting care professionals, and 4) asking for and accepting support (see Table 3). Themes and experiences were relatively similar for the first and the second interviews. Even when their relative lived at home, the family still reflected a lot on the time involved in geriatric rehabilitation.

**Table 2.** Participants' profiles of family caregivers (n = 9)

Participant* (age, gender)	Caregiver/care receiver relationship	Reason for admission of care receiver	Marital status	Work status	Other caregivers involved	Caregiver for others
Anne (57, F) <sup>a</sup>	Daughter	Broken hip after fall incident	Divorced	Employed	Y, brother	N
Tom (49, M)	Son	Pneumonia after Covid-19 infection	Single	Employed	Y, mother	N
Marie (64, F)	Wife	Abscess	Married	Employed	Y, friend	N
Laura (57, F) <sup>a</sup>	Daughter-in- law	Stroke	Married	Unemployed	Y, mother-in- law, children	Y, mother-in- law, mother
Emma (26, F) <sup>a</sup>	Granddaughter	Crisis admission	Single	Unemployed	Y, parents, grandfather	Y, grandfather
Sophie (48, F) <sup>a</sup>	Wife	Motorcycle accident	Married	Employed	N	N
Mark (71, M)	Husband	Multiple health problems	Married	Retired	N	N
Sarah (58, F) <sup>a</sup>	Daughter	Dementia	Married	Employed	N	N
Eva (74, F)	Wife	Cerebral infarction and haemorrhage	Married	Retired	Y, children	Y, friend

Note. \* Pseudonyms; <sup>a</sup> Interviewed twice; Y = yes; N = no; F = female; M = male

**Table 3.** Themes, content, and description

Theme	Content	Description
Support for family caregivers	Support by care professionals, social network, and work environment	How family caregivers were supported by different parties and how they experienced this, and also what their expectations were, and what they wished for
Involvement in care	Informing and consulting about the care process and participating in the care process	How family caregivers were involved in the care process of their relative, and what they wished for
Trusting care professionals	(Un)satisfied with care provided, (no) trust in care professionals	The nature of the relationship between family caregivers and the care providers, the extent to which they trust them with their relative's care
Asking for and accepting support	(Struggle to) ask for help, reasons to not ask for help	When and if family caregivers asked for help, and if they did not, why not

## Support for family caregivers

Participants mentioned three different parties as important sources of support, namely care professionals involved in the care process of their relative, their social network, and their working environment.

### **Support from care professionals**

The experiences with support from care professionals were mixed. Some family caregivers stated that they were very well supported by care professionals, whilst most others indicated that they did not receive a lot of support from the care professionals involved in their relative's care. For example, multiple caregivers pointed out that they experienced a lack of guidance during the admission or discharge of their relative and concerning how they could handle their new role as caregiver. Additionally, some participants indicated that they were never or seldom asked how they were doing and pointed out that the contact with care professionals was mostly about their relative:

*“My mother got discharged from the hospital and transferred to the rehabilitation facility, I knew that [...] They brought her up to the second floor, but I didn't know anything. So, I'm at the facility, there was no one at the reception, and I thought 'where is my mother?' [...] I do think it's a shame [...] I missed that bit of support here.” (Anne)*

*“Also, we were not asked, 'how are you guys doing?' or anything like that [...] we're not even asked, 'are you all right?' [...] So yeah, in terms of informal care, there's not really...” (Emma)*

*“No that [contact with doctor] is all about my mother. So, I – I don't think about that at all, now for once I want someone who – who listens to me.” (Sarah)*

Despite expressing experiencing a lack of support, caregivers also indicated that they did not expect care professionals to support them because that is not their job; their job is to look after their relative. Moreover, they could not see how care staff would be able to support them:

*“I don't know if they can contribute to that [getting more time for himself]. I assume they are here to take care of my father, and not me.” (Tom)*

*“I think that as a partner – I don't know if you can get a lot of support in that either – because every situation is different, of course.” (Sophie)*

However, when looking into the expressed needs of family caregivers, they were ambivalent with respect to their previous expectations regarding not receiving any support from care professionals. When asked about their needs and wishes, participants often indicated that

informal care is a challenge and obligation. They wish to hand over most care tasks and just be a relative, which would indicate the need for more support from care professionals to take over basic care needs:

*“I just want to be able to live my own life again and not actually be at the service of my grandparents, as much as I love doing it for them. [...] Yeah, I just want to have that peace of mind that she’s really in the right place [regarding received care] and that we’re not her caregivers anymore but can just go and visit grandma again. Just the way it used to be.” (Emma)*

Moreover, as mentioned before, family caregivers indicated that they experienced a lack of guidance during specific stages of the care process and more guidance is therefore desirable so that they do not have to figure everything out themselves:

*“When your relative is admitted then you [as care professionals] can’t say, ‘oh yeah, figure it out for yourself. That’s something for the informal caregiver and the family.’ I think that task is also yours [as care professionals], a bit of guidance. Not just for me, but that it’s also clear to the rest of the people [who care for someone who is admitted] [...] There is still a lot to gain there.” (Laura)*

There is also a need to share their experiences with either professionals or peers. Participants mentioned that having a care professional who opened the door for them to ask questions or share concerns was highly appreciated. Especially the consultant on informal care was praised by family caregivers; they mentioned the consultant was *“a relief”* (Laura), *“an open door”* (Anne), *“an eye opener”* (Sarah):

*“There are, of course, several sons and daughters who are caregivers for their father and mother, and they are in the same situation as me or that you have, what do you call it, a peer group. [...] Then those informal caregivers can sit together, and you get tips and ideas. [...] That would provide recognition and acknowledgement.” (Sarah)*

*“I really liked the fact that she [the consultant on informal care] called me herself. I also really liked the fact that she says, ‘do you have an hour so we can really talk in person?’ I really like that you can tell her anything you like to say.” (Sarah)*

### **Support from social network**

The perceived support from their social network (i.e. family members, friends, or neighbours) varied. When participants had a strong social network from which they got a lot of support, they experienced this as very helpful, and they were generally grateful for all the support provided. It also offered a form of relief. When participants mentioned being supported by their social network, it mostly related to offering emotional support – for example, by showing

interest and compassion. However, in a few cases, the social network of the caregiver also offered more structural support – for example, by sharing responsibilities or taking over care tasks:

*“The love I get from the people around me. There’s a bunch of friends who say very often, sometimes twice a week: don’t you feel like coming over, having a coffee, or a glass of wine or something. And those are nice and such important things.”* (Eva)

*“Yes, my parents do try to be careful not to overburden me. [...] They really look after me. [...] I just really didn’t have any more energy to go through that discussion [about the right type of care for grandmother] again. So, then my mother was like ‘I’ll go, and I’ll arrange what I can and we’ll see how it goes from there.’”* (Emma)

However, not being supported by their network led to frustration because family caregivers were unable to share their story or experiences, or they felt alone in carrying out all tasks related to informal care:

*“That’s frustrating, frustrating that you hope your husband supports you in that or goes with you [to the rehabilitation facility] or says, ‘What can I do for you Sarah?’ [...] That bit [of support], I missed that too. [...] That also makes it exhausting that I do everything on my own again.”* (Sarah)

Although participants highly appreciated the support offered by their social network, it was often pointed out that this could also be overwhelming (e.g. too many texts or phone calls, which only cost time and energy); therefore, some people indicated that they did not look for this support:

*“However well intentioned, but when people are constantly texting and calling, ‘How is your mother? And how are you?’ That takes up way too much of my time; those are way too many stimuli.”* (Sarah)

### **Support from working environment**

Participants who were still employed expressed that support from the employer and colleagues was much needed and appreciated – for example, being given time off to visit their relative and arrange things. Additionally, being able to vent to colleagues relieved stress, and it was comforting when colleagues showed interest and compassion. However, when the employer was not supportive, it only added to the burden and stress of family caregivers:

*“I have a good employer. They said, ‘Take your time, and then after that, if you can, come back to work.’ So, I was lucky with that. [...] They have been very accommodating.”*

*They also took those two weeks [during intensive care] very – I hardly had to take any leave.” (Sophie)*

*“If he [partner] comes home, then I just need that care leave. They were very difficult about that at work, which I found very unpleasant. [...] Because I thought if it goes on like this, I’ll just drop out. I can’t handle all that, it’s just not possible.” (Marie)*

### **Involvement in care**

Involving family caregivers in care was discussed in three ways: by informing family caregivers, by consulting family caregivers, or by the participation of family caregivers. Most participants indicated that the involvement was mainly related to informing family caregivers, and included being able to consult care reports, meetings with family and care professionals, information evenings for relatives, or the possibility of attending therapy sessions.

With regard to informing, the experiences varied strongly among family caregivers; it was remarkable that it was often either a very negative or a very positive experience. Family caregivers mentioned that being updated about the status of their relative, receiving a call when something happened, or getting advice contributed to a positive experience. They expressed that they appreciated the amount of information they received, and they indicated that good communication also created a good relationship between them and care professionals. It was noticeable that these people were often the family caregivers who also felt well supported either by care professionals or their social network, who were satisfied with the care delivered, and who generally experienced a lower burden:

*“That information was incredibly good, and on the ward everything went perfectly. Yes, and in the rehabilitation institution likewise. We were always updated on what was going to happen and how the wound looked [...]. Yes, that was really nice. You were very much involved.” (Marie)*

Contrary to the aforementioned positive experiences, most family caregivers indicated that they were insufficiently and/or incorrectly informed. This often led to frustration, could possibly affect their experienced burden, and had an influence on their relationship with care professionals. Being insufficiently and/or incorrectly informed was reflected in, for example, not being contacted when something happened to their relative (e.g. a fall incident) or expecting activities and certain services for their relative based on information folders, which in the end were not provided. Ultimately, these family caregivers expressed a high need for more (accurate) information and better communication with care professionals. Again, we see



a possible relationship between the perceived support of family caregivers and their experienced burden; often the people who expressed a high burden and did not feel supported were also the people who felt they were insufficiently informed:

*“You just don’t know [...] how things work there, you never get to speak to anyone, or you have to call, but.... It’s not like you can just, when you’re there, just ask, ‘How do you guys think it’s going?’ It’s just... Yeah, you just have to hear it from her [grandmother], while that’s what she’s there [the rehabilitation facility] for, that we can’t believe what she says [because of her condition].” (Emma)*

Family caregivers reported rarely being consulted when it came to the care process of their relative and the choices that needed to be made, although this was a strong desire across most of them. It was often mentioned that they wished they were asked more about their opinion because they felt that they knew their relative best and could be of added value when certain decisions had to be made by the care team:

*“That they listen actually. Listen better to you after all. [...] Yes, you know him very well too. That they do listen, like, ‘Okay, it’s... It’s maybe not such a good idea what we’re doing now after all.’ Yes... I know they are the doctors of course, that first of all. But do listen to what – whatever the family thinks. I would have preferred that to be different.” (Marie)*

Being heard was an important aspect for family caregivers, and the majority of participants felt heard by the care professionals – for example, when they were given the opportunity to express their opinion, ask questions, or express their concerns. This was experienced as pleasant and was also appreciated by most family caregivers:

*“Knowing that time is taken for you and that even yesterday they said, ‘Do you have any questions?’ That I think, ‘Yes, indeed I have all kinds of questions written down.’ Just the fact that you know there will be a conversation.” (Sarah)*

Only one family caregiver mentioned something about being an active participant in their relative’s care process, rather than merely being informed or consulted like most other participants. She, for example, wanted to be involved in the decisions that were being made and have a say in this as an equal partner in the care process:

*“That’s just irritating, and I just want to be able to spar with someone: ‘What do you think?’ That I can help think about the care process. I would just really like that. Because I’ve obviously cared for her at home for so many months [...] then if they [care professionals] don’t believe you [...] Yeah, that’s just irritating.” (Emma)*

When asked if family caregivers wanted to be more involved in their relative's care, many stated that, apart from more adequate information, they did not wish to be more involved because this could add to their perceived burden:

*"No, I'm fine like this and I think that's also a bit because I – my head is so full."* (Eva)

### **Trusting care professionals**

Trust was pointed out as an important determinant of how family caregivers experienced the care process and their role as informal caregiver. Whether or not they trusted the care professionals involved in their relative's care, contributed to their perceived burden and stress. Both a trusting and non-trusting relationship with the care providers was mentioned by participants. Having trust in the care professionals often seemed related to the satisfaction of family caregivers with the care provided and vice versa. For example, one caregiver mentioned that when they noticed that their relative was not washed in the morning, they had the feeling that they constantly had to oversee the care professionals and what they were doing. When they knew their relative was taken care of well, they could let go of their concerns more easily, indicating a trusting relationship with the care professionals:

*"Because it just kept going wrong in the rehabilitation facility and so much has gone wrong during the whole process, you have to keep trying to trust that things will go right there [nursing home]. But yes, it's a bit of a balance between 'Is it going well, and can we trust them?'"* (Emma)

Trusting care professionals was not only related to the care provided. It also became apparent that family caregivers who expressed that they trusted the care professionals involved in the care for their relative were the ones who overall had a positive experience with being supported by those care professionals.

### **Asking for and accepting support**

It was noticeable that asking for help is not easy for family caregivers. This might be related to the fact that family caregivers do not feel that they should be supported because it is about their relative, as mentioned before. Additionally, when offered help from their social network, they often did not accept this. There are two apparent reasons for not asking and accepting

support. On the one hand, participants did not want to burden others, such as family members or even care professionals.

*“You have to go and ask if you want something. It’s as simple as that. And that’s not such a strong point of mine. No, that’s me – that’s not me. Rather, I’m someone who does it myself.” (Tom)*

On the other hand, participants indicated that they do not want to hand over their responsibilities to others, mostly because they were used to doing everything on their own but also because they were afraid of other people’s opinions, which might possibly conflict with their own or the wishes of their relative:

*“I do it for my mother, and I am happy to do it, and maybe I don’t want to hand it over to anyone else either. [...] My mother used to be there for me, and now we are going to turn the tables, and now I am there for her.” (Anne)*

## Discussion

The aim of this study was to gain insight into the perceived support and involvement of family caregivers during the care process in geriatric rehabilitation and to explore how this support and involvement can be optimised in their opinion. The results of this study can be used to improve reablement services and provide insight into how to integrate adequate support for family caregivers. The results of this study reflected four main themes: 1) support for family caregivers, 2) involvement in care, 3) trusting care professionals, and 4) asking for and accepting support. Our findings highlight the variation in family caregivers’ perceived support and involvement.

Family caregivers’ experiences with support from care professionals were often ambivalent, expressing a lack of support and information whilst also indicating that they do not expect to be supported by care professionals. This is supported by Weisser et al,<sup>36</sup> who also found that family caregivers experience ambivalent feelings between proactively seeking help and feeling disturbed by increasing numbers of meetings. Additionally, how family caregivers experienced the support they received and how they were involved often related to their perceived burden. This was also found by Boots et al,<sup>37</sup> who discovered that family caregivers have a hard time identifying and expressing their needs, which is due to their high subjective burden experienced. When focusing on the needs that caregivers did express, we noticed a need for more guidance and better communication and information. Previous research also concluded

that there is a need for more inclusion in the care process (e.g. being aware of the decisions made or being involved in the discharge planning) and both good communication and accurate information when caring for an admitted relative or during the transition back home.<sup>19,38,39</sup> Especially in the beginning when family caregivers are new to their role, it is important that care professionals help them navigate this new role.<sup>40</sup> Our results showed that trust between the family caregiver and the care professional is an important element throughout the care process. It is important to build a relationship of trust at the beginning of the process; this facilitates the acceptance of support and will ultimately reduce the burden.<sup>41</sup> Besides support, involvement was also an important aspect of our findings. It became apparent that family caregivers wanted to be involved, i.e. wanting to be able to express their opinion and to be involved in decision-making. However, it is important to be cautious because more involvement could also lead to a higher burden. Previous research also stated that once a person becomes more dependent on care, family caregivers spent more time on care-related activities (i.e. become more involved), which was associated with a higher burden.<sup>42-44</sup>

Besides knowing what support needs to be provided to meet the needs of family caregivers, it is also important to reflect on how this support should be offered to family caregivers. Our results clearly indicated that family caregivers have difficulty asking for and accepting help, either because they did not want to burden others, or they did not want to hand over responsibilities. Previous research found that family members often take on the role of caregiver as a sense of moral commitment based on family obligations and solidarity.<sup>45</sup> Willemse et al<sup>46</sup> also found that informal caregivers seldom look for professional support. Moreover, previous research states that family caregivers are reluctant to seek external support because they do not want to disclose family-related problems due to a sense of pride,<sup>47,48</sup> but are also reluctant to accept help from other family members.<sup>49</sup> Additionally, Willemse et al<sup>46</sup> found that information on the possibilities was often lacking, and they stressed the necessity of proactively informing caregivers.<sup>46</sup> Over the past years, multiple interventions have been described to support family caregivers in their role as a caregiver and to eventually reduce their perceived burden. These interventions use different approaches, such as respite care, psychosocial support (either in group or individual), education/skill-based interventions, assistive technology, or multicomponent interventions.<sup>50-55</sup> However, often the family caregivers have to take the initiative themselves, while our findings clearly show that informal caregivers will rarely act proactive in this. Therefore, it is important to, as a care professional, proactively inform the informal caregiver about their options for support and offer a tailor-

made, personal approach with enough room to participate in the care process when this is preferred by the informal caregiver.<sup>49</sup>

The aim of this research was also to inform reablement programmes on how to integrate adequate support for family caregivers and how to involve them in reablement services. The previous section has already provided some implications for future practice. First, addressing the need for more guidance and information throughout their relative's care process is an important element that should be integrated. This is also supported by Hjelle et al,<sup>13</sup> who emphasise the importance of family caregivers' need to receive but also give information. Additionally, making the family caregiver an equal member of the reablement team would make them feel heard and is an important strength of reablement interventions,<sup>13,56</sup> but it could also relieve some of the burden by decreasing the feeling of being alone in the process.<sup>57</sup> However, informal caregivers need to have a choice in the amount of involvement during the care process. Our study clearly indicated that this wish was not the same for every family caregiver. This finding is in line with previous research showing that family caregivers experience more burden, if they do not have a choice in the amount of involvement.<sup>58,59</sup> It is also important that caregivers have someone they can turn to; however, this is often overlooked, so it would be beneficial to appoint a team member as single point of contact for the family caregiver for emotional support.<sup>14</sup> To build a family–staff relationship, it is important that care professionals possess the right competencies and skills, e.g. being empathic, showing interest, etc.<sup>60</sup> Last, since reablement focuses on improving well-being, knowing that their relative is supported in activities they value, could add to the caregiver's trust, which was indicated in previous research to be a benefit of reablement services.<sup>57</sup>

Some methodological considerations have to be made. First, since we used convenience sampling at two sites, it could be possible that family caregivers who were much overburdened did not participate in our study, although their experiences could be of added value. However, we did manage to include a varied sample in terms of relation type, living situation, or working status, thus providing us with broad insight into the experiences of different family caregivers. Second, we gathered the experiences of family caregivers through (sequential) interviews. However, it could be argued whether this is the most suitable method to get an in-depth perception of participants' experiences and whether other research methods in which a trusting bond is created between the participant and the reviewer (e.g. ethnographic research or patient journey method) would be more suitable. Last, we did not interview family caregivers

who were involved in reablement because it is not common practice yet in the Netherlands. We did, however, try to match the population and setting by choosing geriatric rehabilitation.

## **Conclusion**

To our knowledge this is the first study investigating the perceived support and involvement of family caregivers for reablement programmes and shedding light on their needs and wishes for future programmes. This study shows that there is a discrepancy between the perceived support and involvement of family caregivers, their expressed needs, and the expectations they have of care professionals. Our findings build upon and reinforce previous research performed on the support and involvement of family caregivers. However, we also demonstrate new insights. Family caregivers say that they lack support and information, whilst also indicating that they do not expect more support or to be supported by care professionals. Additionally, regarding involvement, their experiences were either very positive or very negative. Family caregivers wished that they were consulted more often but did not have a high need for participation. Trust is an important determinant of how family caregivers experienced the care process and their role as informal caregiver. Whether or not they trusted the care professionals involved in their relative's care, contributed to their perceived burden and stress. Family caregivers have trouble asking for and accepting help, because they do not want to burden others, or they do not want to hand over responsibilities. To respond to family caregivers' needs, a personalised approach is needed to create room for the family caregiver to be an active participant in their relative's care process, if preferred, while also providing the right amount of support. Although our findings give a good indication of what the support and involvement of family caregivers should look like, more research is needed to gain additional insight into the experiences of family caregivers who are involved in reablement services. Additionally, this paper makes suggestions on how to integrate adequate support for family caregivers and how to involve them in reablement services. However, these should be pilot tested in practice to make sure they are feasible and lead to an improvement in care.

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## Chapter 6

What matters to you? A mixed-method evaluation of  
goal setting and attainment within reablement from  
clients' perspectives

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## **Abstract**

**Background:** Goal setting is an essential component of reablement programmes. At the same time, it is also an important aspect in the evaluation of reablement from the perspective of clients.

**Objectives:** As part of the TRANS-SENIOR project, this research aims to get an in-depth insight of goal setting and goal attainment within reablement services from the perspective of the older person.

**Material and Methods:** A convergent mixed methods design was used, combining data from electronic care files and completed Canadian Occupational Performance Measure (COPM) forms with individual interviews.

**Results:** In total, 17 clients participated. Participants' meaningful goals mainly focused on self-care, rather than leisure or productivity. This mattered most to them, since being independent in performing self-care tasks increased clients' confidence and perseverance. Regarding goal attainment, a statistically significant and clinically relevant increase in self-perceived performance and satisfaction scores were observed.

**Conclusion:** Although most goals focused on self-care, it became apparent that these tasks matter to participants, especially because these often precede fundamental life goals.

**Significance:** This study shows that reablement can positively contribute to goal setting and attainment of clients and may contribute to increased independence. However, effectiveness, and subsequently long-term effects, are not yet accomplished and should be evaluated in future research.

## Introduction

Many countries encourage ageing in place, which means promoting older adults to remain living at home for as long as possible.<sup>1-3</sup> Moreover, most older adults prefer to remain living at home despite increasing care needs.<sup>2,4-6</sup> This is in line with the Healthy Ageing framework; the goal of the framework is to enable older adults to continue to remain in their usual place of residence and avoid or delay transitions to institutional care.<sup>1,7</sup> The framework also emphasises the importance of maintaining functional ability, preserving intrinsic capacity, and creating a supportive environment to meet a person's needs.<sup>8-10</sup> Being able to perform meaningful daily activities creates a sense of purpose, especially when these activities take place in the community and result in social connectedness.<sup>4,5</sup> Both the physical and social environment of older adults play an important role in their health and well-being, thus investing in a supportive environment, and devoting attention to how people engage with their environment becomes all the more important.<sup>10,11</sup>

Reablement is a strategy to stimulate independence in an older person's own environment. It is a person-centred, holistic approach that promotes older adults' active participation in daily activities through social, leisure, and physical activities chosen by the older person in line with their preferences, either at home or in the community. It is delivered by an interdisciplinary team often led by an occupational therapist and/or registered nurse.<sup>12,13</sup> An important element of reablement is that individuals define their own meaningful goals together with care professionals.<sup>11,14</sup> Care professionals assist individuals in identifying their capabilities and opportunities to maximise their independence and support them in achieving their goals, through participation in daily activities, home modifications, assistive devices, and the involvement of their social network.<sup>12,13,15-17</sup> Finally, it is important to monitor and evaluate the achievement of goals.<sup>12,18</sup>

The evidence on the effectiveness of reablement compared with traditional home care is mixed and limited.<sup>16</sup> While some literature reviews highlight promising results,<sup>19-22</sup> especially in terms of daily functioning, health-related quality of life, and health-care utilisation, others report significant ambiguity regarding its effects, costs, and cost-effectiveness.<sup>13,23-25</sup> The mixed results are mostly due to the fact that different outcome measures are used, making it hard to compare findings.<sup>26</sup> Moreover, a lot of these outcome measures are generic. However, reablement is a tailored approach guided by personal goals, needs, and resources. This means that the less sensitive generic measures are not the most suitable to detect improvements in independence.<sup>13</sup>

A core component of reablement is setting personal goals and the engagement of people therein; when participants are not fully consulted regarding their reablement goals this could lead to a lack of engagement of the older person (e.g. ignored need for social connectedness during goal setting).<sup>27</sup> More insight is needed into what meaningful goals are and whether these goals are achieved while using reablement programmes. Despite the importance of goal setting and goal attainment in reablement services, they are often overlooked as outcome measures when evaluating reablement.<sup>11,28</sup> For example, the Canadian Occupational Performance Measure (COPM)<sup>29</sup> has been found to be sensitive to measuring improvements in older adult's participation in chosen daily activities.<sup>30</sup> However, only three reablement studies have included this outcome measure in their evaluation.<sup>28</sup> Moreover, despite conflicting evidence regarding the effectiveness of reablement, participants' and their carers' experiences are mostly positive.<sup>27,31,32</sup> Therefore, in a person-centred approach, it is recommended to evaluate changes and gains experienced by older adults by using qualitative research methods.

Despite its critical role, goal setting and goal attainment are often neglected as outcome measures. Moreover, combining and integrating both the quantifiable effects regarding goal attainment and the person's experiences regarding both goal setting and attainment, comprehensively captures clients' progress and perceptions, shedding light on the effects of reablement services beyond mere quantitative metrics. Therefore, this research aims to get an in-depth insight of goal setting and goal attainment within reablement services from the perspective of the older person.

## **Material and methods**

### **Study design**

This study entails a convergent mixed-methods design,<sup>33</sup> meaning that both qualitative data (individual interviews to gain an in-depth insight into clients' experiences with the goal-oriented approach) and quantitative data (regarding goal setting and goal attainment scores) were collected and analysed simultaneously. Subsequently, both analyses were compared, and results were integrated. The integration involved merging the results from the quantitative and qualitative data so that a comparison could be made, and a more complete understanding is obtained than that provided by the quantitative or the qualitative results alone.<sup>33</sup> Data collection and analysis took place during the period March 2022 and May 2023.



## Setting

The study took place in the Netherlands, more specifically the 'Longer Vital at Home' (LVaH) reablement programme was evaluated at one care provider in the province of North Holland in cooperation with the local municipality. The long-term care organisation provides home care (i.e. district nursing and domestic care), primary care (i.e. allied health), social care, inpatient geriatric rehabilitation and residential care.

## Intervention: Longer Vital at Home

LVaH is a community-based interdisciplinary reablement programme to promote self-management and self-reliance of community-dwelling older adults. LVaH is based on the principles of I-MANAGE, a model for a reablement approach tailored to the Dutch home care setting. The model provides guidance and structure for implementation in different local care contexts and leaves room for tailoring to the specific needs and resources of the organisation and the needs of care receivers.<sup>18</sup> LVaH is intended for community-dwelling older adults with care needs regarding self-care, mobility, household activities and/or well-being. Exclusion criteria are lack of motivation, terminal illness or receiving end-of-life care, planned nursing home admission, complex cognitive problems, or a care need which only requires technical nursing skills (e.g. complex wound care). An interdisciplinary team consisting of occupational therapists (OTs), district nurses, registered nurses, certified nursing assistants, physiotherapists (PTs), domestic support workers and community consultants from the municipality join forces to promote the self-management and self-reliance of participants. This may entail activities of daily living (e.g. self-care activities, household chores) as well as mobility and well-being activities either at home or in the community, depending on the older adult's personal goals. The programme lasts up to 12 weeks and has 5 phases. After programme referral by district nurses, community consultants from the municipality, or the general practitioner (GP) (Phase 1), the OT visits the participant together with the community consultant or district nurse for a comprehensive assessment (Phase 2). Based on the principles of positive health,<sup>34</sup> both the current level of self-management and self-reliance is examined, as well as gaining insight into what the older adult's wishes are and what they value in life. If necessary, additional assessments (e.g. environmental assessment) or a conversation with the family caregiver may take place. Next, the OT conducts the Canadian Occupational Performance Measure (COPM)<sup>29</sup> to identify the older adult's personal goals and draws up a tailored support plan together with

the older adult and the reablement team (Phase 3). The LVaH team then delivers care and support according to the support plan (Phase 4). Interventions that could be deployed include training of daily activities, using helping aids, home modification and health-care technology (e.g. telemedicine) or informal caregiver support. Depending on the goals of the older adult, other disciplines may be involved, for instance welfare staff, social workers, or dieticians. Family caregivers and the older adult's social network are also closely involved in the process. The core team (OT, district nurse, community consultant, domestic support planner) have weekly interdisciplinary meetings to discuss progress. Based on these meetings, the team determines whether the care plan should be continued or adjusted, which is then discussed with the participant. A final evaluation takes place at the end of the programme, including the reassessment of the COPM<sup>29</sup> by the OT to see whether clients achieved their goals or need referral to follow-up care (Phase 5). Three months after the end of the programme, there is a follow-up with the older adult.

## **Participants**

All LVaH participants who enrolled in the programme between March 2023 and December 2023 were eligible to participate in the study. To participate in the interviews, they had to be able to communicate in Dutch. Participants were approached by one of the OTs of the LVaH team. The OT explained the purpose and method of the study and asked clients if they were interested in participating. Interested clients additionally received a patient information letter and signed a consent form to participate in the study. Participants' contact details were then shared with the researcher (IM). It was anticipated that 30 clients would enrol in the LVaH programme. Eventually, 17 clients participated in the study of whom nine were interviewed at the end (Table 1).

## **Data collection**

Data were collected using three data collection methods: electronic care files (ECFs) of participants; COPM<sup>29</sup> forms completed by care professionals together with participants and semi-structured interviews with a subsample of participants. Socio-demographic characteristics (i.e. age, sex, living situation, and marital status) from participants were collected through their ECFs. Additionally, the route of referral to the programme (i.e. through

the general practitioner (GP), district nurse, or community consultant from the municipality) was tracked in a logbook by care professionals.

Quantitative data on goal setting and goal attainment was gathered through the completed COPM<sup>29</sup> forms, i.e. the number of goals, type of goals, and clients' perceived performance and satisfaction scores. The COPM<sup>29</sup> was structurally embedded in the LVaH programme and conducted by the occupational therapist at baseline and after approximately 12 weeks (i.e. at the end of the programme). The COPM<sup>29</sup> consists of a semi-structured interview, in which the participant is encouraged to identify problems they experience during daily activities, categorised into self-care, productivity and leisure. Self-care consists of personal care (e.g. dressing, bathing), functional mobility (e.g. transfers indoor or outdoor), and community management (e.g. transportation, shopping). Productivity consists of (un)paid work (e.g. volunteering), household management (e.g. cleaning, laundry), and play or school (e.g. homework). Leisure consists of quiet recreation (e.g. hobbies, crafts), active recreation (e.g. sports, travel), and socialisation (e.g. visiting, phone calls). The client scores the five most important problems on a scale of 1 to 10 in terms of performance and satisfaction. Subsequently, the total score is calculated by summing up all performance or satisfaction scores and dividing the sum by the number of problems. After the reassessment, the change in both the performance and the satisfaction scores was calculated by subtracting the score from the reassessment from the score from the initial assessment.

Simultaneously, the project leader (SvH) conducted semi-structured interviews with a subsample of the participants. Participants did not know the project leader beforehand. The subsample was selected based on whether the participants completed the programme and agreed to participate in the interview. Participants were approached to participate in the interviews and included until data saturation was reached. Data saturation was considered achieved when no new themes or codes were identified. The interviews followed a semi-structured interview guide, which included topics such as the care they received during the programme, how they experienced receiving the programme and more specifically the goal-setting aspect of the programme (i.e. how they perceived the process on working towards reaching these goals). The interviews took place at the place of participant's residence. The duration of the interviews ranged from 14 to 45 minutes and lasted 24 minutes on average. The full interview guide is available in Appendix 1. All interviews were audio-recorded. Furthermore, the reablement process of one participant was explored and described more in detail (Box 1). We wanted to describe the process and results from start to finish. Therefore,

we collected data on the background of this participant, the goals that were set, the actions that were performed to achieve these goals, the progress of this participant, and their end result. These data were gathered through the ECF of this participant, the completed COPM<sup>29</sup> form, and an individual interview with the participant.

### **Data analysis**

Quantitative data were analysed using IBM SPSS Statistics (Version 25). Firstly, descriptive statistics (mean, standard deviation, and percentages) were used to describe the background characteristics of participants. Secondly, change scores regarding performance and satisfaction were calculated to assess whether a client has achieved his or her goals. A Wilcoxon signed-rank test was conducted to compare both the COPM<sup>29</sup> performance and satisfaction score at the start of the programme and the end of the programme, and to test the statistical significance of change scores. A change score of 2 points on satisfaction or performance was deemed a clinically relevant difference as it is a widely used cut-off in literature and no other cut-off points have yet been defined.<sup>35,36</sup>

Data regarding the type of goals that were set by participants were collected and classified according to the predefined (sub-)categories as described in the COPM<sup>29</sup> manual by researcher IM. This classification was discussed within the research team and adapted when needed, for example, when there was any doubt to which (sub-)category a goal belonged.

Qualitative data derived from the interviews were anonymised, transcribed verbatim, and analysed with support from the qualitative data analysis software ATLAS.ti Windows (Version 23.0.8). A thematic analysis approach was used, following the steps identified by Braun and Clarke.<sup>37</sup> A combination of open and axial coding was used. First, two researchers (IM & SM) read the transcripts several times to familiarise themselves with the data. They also made notes to mark sections of the transcripts that could be relevant to answer the research question, for example, parts of the interview that contributed to understanding goal setting and goal attainment from the perspective of the participant. Subsequently, open coding was used to analyse the data. Both researchers (IM & SM) independently coded the first transcript by creating open codes which were close to the original transcript text. The codes were compared for similarity and differences were discussed. Afterwards, researcher IM coded the other transcripts in a similar manner. Relationships between codes were identified by means of axial coding; initial codes were organized under potential themes and similar codes were collated.

These themes were reviewed within the research team and, keeping the research questions in mind, axial coding led to the final themes. The analysis was an iterative process during which initial codes were recoded and relationships and themes were revised. Disagreements were discussed within the research team.

After analysing both quantitative and qualitative data, we triangulated out findings to create cohesive results. We started with the quantitative findings and complemented these with relevant parts of our qualitative analysis to fit the main focus of the research aim, being goal setting and goal attainment. Therefore, we opted to include the qualitative analysis as an Appendix (Appendix 2), which presents the code tree, so more insight into the qualitative analysis and the (sub-)themes derived can be found here.

## **Ethics**

The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of Maastricht University, Faculty of Health, Medicine and Life Sciences (approval number FHML-REC/2022/054). Participants voluntarily signed informed consent after they were fully informed about the purpose and procedures of the study and had the opportunity to ask additional questions or raise any concerns. The informed consent stated that participation in this study was completely voluntary and withdrawal from the study was possible at any moment, with or without providing a reason, by contacting one of the researchers. The informed consent also stated explicitly that their participation in or withdrawal from the study would not affect the service they received by any means.

## **Results**

In total, 17 clients participated in the study. The socio-demographic characteristics of the participants are displayed in Table 1. Thirteen participants finished the full reablement programme during the study period; one was still in the programme at the end of data collection with no perspective on when this would be finished. Three participants dropped out of the programme. Reasons for dropout were not being able to formulate goals (n=2) and deterioration of health status (n=1). Nine participants agreed to be interviewed.

The following sections first presents the findings related to goal setting and subsequently the findings related to goal attainment. Both sections start with a presentation of the quantitative

results, which are then complemented by qualitative findings that were relevant and related to the quantitative results, meaning that not all (sub-)themes are described in detail in the result section. More insight into the qualitative analysis and the themes derived can be found in Appendix 2. Additionally, an example case is presented at the end of the result section (Box 1).

**Table 1.** Socio-demographic characteristics of the participants

<b>N</b>	<b>17</b>
Age (years), mean (SD)	79.3 (7.6)
Sex (male), n (%)	5 (29.4)
Marital status, n (%)	
Divorced	2 (11.8)
Married	6 (35.3)
Widowed	9 (52.9)
Living situation, n (%)	
Living alone	11 (64.7)
Living together	6 (35.3)
Route of referral, n (%)	
District nurse	8 (47.1)
Community consultant	6 (35.3)
General practitioner	3 (17.6)

### Goal setting

In total, 15 out of 17 participants were able to set goals at the start of the programme. In total, these participants formulated 62 goals. On average, 4.2 (SD = 1.15) goals per participant were formulated. An overview of the goals that were set by participants classified according to the (sub-)categories of the COPM<sup>29</sup> are listed in Table 2. Overall, most goals were related to self-care (n = 39), followed by leisure (n = 14), and productivity (n = 9) (Figure 1).

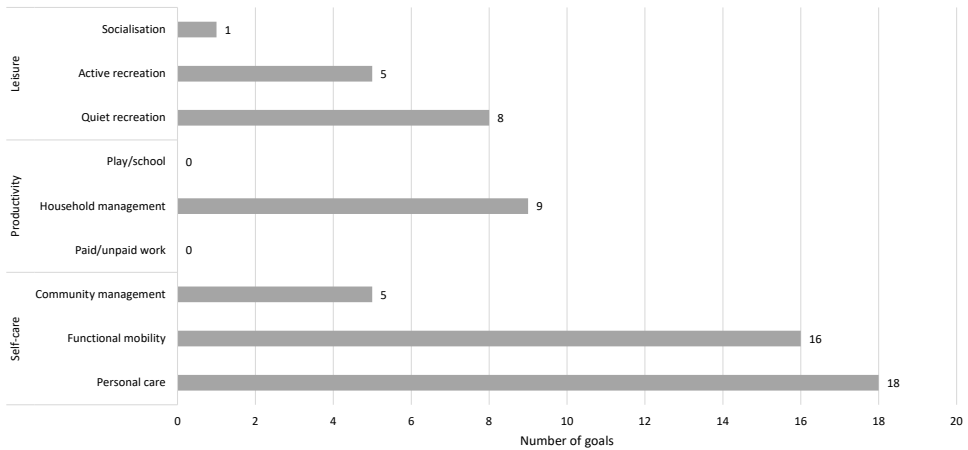
Regarding setting goals, participants mentioned that they felt heard and could express all their needs. Additionally, they felt that the care professionals supported them throughout this process and helped them to focus on their possibilities and what they were still able to do. Participants indicated that the goals that were set were in line with their wishes. So despite of the holistic nature of reablement, most goals were focused on self-care. In the interviews participants mentioned that these activities were important to them, as they contributed to

their well-being and quality of life. Being less dependent during self-care meant that they were able to remain living at home for as long as possible, and that they did not have to rely on others. These were also the motivations for participants to enrol in the programme and were therefore reflected in the goals that were set. Other reasons for participating were being able to (re-)do the things they loved, staying active, and receiving the right care. These reasons reflect the underlying principles of reablement and may indicate how participants were convinced of the benefits of the programme.

*“And if it’s too much for you, you can say no. But yes, [the occupational therapist] also listened so well, [...] She picked up things between the lines anyway.”* (Participant, 73, F)

*“For a very long time, I couldn’t do what I always wanted to do. [...] Couldn’t cut my own nails and peel an apple anymore, my husband had to do these things for me... All that fell away, then you only have a small world left. [...] Having my nails cut by someone else is terrible to me, those are things I really wanted to do again, those were very important things to me.”* (Participant, 72, F)

*“Well look, if I sit in a chair all day and nurses take care of me, then I myself suffer. I then only deteriorate because I sit all day.”* (Participant, 91, M)



**Figure 1.** Bar chart presenting the classification of goals set by participants. The bar chart displays the number of goals set within each category of the COPM<sup>29</sup> (i.e. leisure, productivity, and self-care). All categories are divided into sub-categories each presented with the number of goals set

**Table 2.** Overview of the goals that were set by participants classified according to the (sub-)categories of the COPM<sup>29</sup>

<b>(Sub-)categories of the COPM<sup>29</sup></b>	<b>Goals set by participants</b>
<b>Leisure</b>	
Socialisation	Communicate in a group.
Active recreation	Gardening, taking a walk, walking the dog, walking with wife.
Quiet recreation	Crafting, reading, writing, embroidery, painting, having an appropriate daily structure, playing the clarinet, reading a book.
<b>Productivity</b>	
Household management	Doing household chores (while standing), clearing the table, changing the bed, vacuuming, dusting, straightening and tucking in the duvet, taking laundry out of the dryer.
<b>Self-care</b>	
Community management	Driving a car, grocery shopping, cycling.
Functional mobility	Standing for long periods, walking long distances, getting in and out of bed, moving indoors, moving to the common room on the ground floor, walking around on the balcony, walking around in the village, sleeping in bed, going out independently, walking outside the house.
Personal care	Opening packages, clipping toenails, cooking, handling cutlery, putting on (compression) socks, showering and bathing, toilet hygiene, taking a meal out of the microwave, zip-fastening, washing and dressing, drinking.

### Goal attainment

Regarding goal attainment, 13 out of 15 COPM<sup>29</sup> reassessments were completed. Three (re-) assessments were missing scores for some goals. There was a significant increase in the performance score after completing the programme (Mdn = 6.25) compared to at the start of the programme (Mdn = 4.2);  $Z = -3.11$ ,  $p = 0.002$ . Additionally, there was a significant increase in the satisfaction score after completing the programme (Mdn = 6.67) compared to at the start of the programme (Mdn = 4.33);  $Z = -3.18$ ,  $p < 0.001$ . When looking at the individual change scores, nine participants had a change score greater than two on both performance and satisfaction, indicating a clinically relevant difference. Figure 2 presents the individual change scores on performance as well as satisfaction.

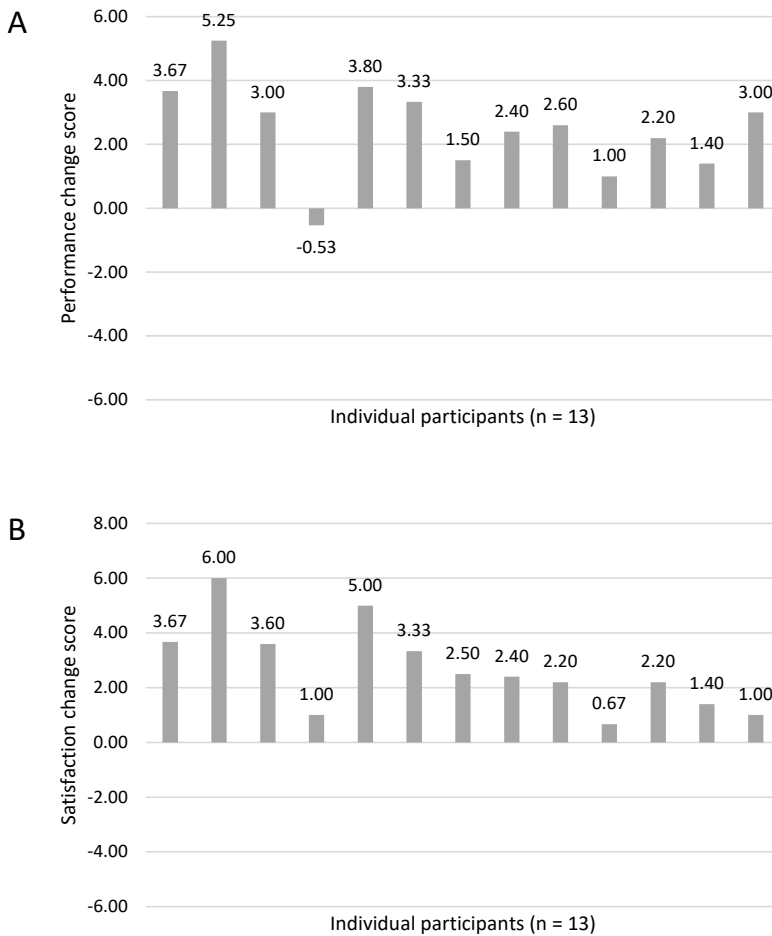
These results are in line with the experiences of participants regarding goal attainment. Most participants mentioned that they did reach (some of) their goals and that they were also able to maintain this. They expressed that by participating they gained in confidence, perseverance, and independence. They also mentioned that they had become more self-reliant, that it made



their life easier and that it gave them more freedom. This related to the clinically relevant change score of 2 or higher and was also reflected in the individual interviews. This may indicate that working towards and achieving personal goals has a lasting impact on participants.

*“I always say it gives me a lot of freedom. That may sound very strange, but it really gives a lot of freedom.”* (Participant, 72, F)

*“Well, I no longer have that many goals at 91. But at least now I can get by in the household and with the grandchildren. And you may smell it, I am making a nice bowl of soup again. [...] I am convinced I will keep doing what I have learnt.”* (Participant, 91, M)



**Figure 2.** Column chart presenting the individual change scores of participants (n = 13) for both performance (A) and satisfaction (B)

Several strategies and interventions were used by the reablement team to reach goals; mostly participants mentioned the use of assistive devices. Other strategies were providing information and advice, for example how to order food online or which financial aid options are available to them through the municipality.

*“They found out that my walker was actually not good at all. Now I have one of those walkers with elbow rests. [...] With the other one, I really had to sit down after a while. Pain in my shoulders, my elbows, my wrists. Had to sit. I can really walk for hours now without having to sit. She [the occupational therapist] helped me tremendously with that.”* (Participant, 66, F)

Additionally, some clients received help from a physiotherapist, providing them with exercises and helping them to regain their functional mobility and staying active so that they, for example, will be able to walk their dog. The involvement of the social network to work towards goals was mixed. Some participants mentioned that their children and neighbours were involved, whilst others mentioned there was no specific attention for family caregivers, which was also not desired by these participants.

Moreover, participants indicated they appreciated the personal attention and practical help they received. They clearly felt well-supported by care professionals in reaching their goals. For example, they mentioned it was pleasant that they did not have to reinvent the wheel and care professionals proactively looked for the right solutions. The participants appreciated the type and amount of support, which resulted in a feeling of trust in the team’s professionalism and put participants at ease. They felt that the reablement team had everything under control.

*“I liked it so much that I didn’t always have to invent the wheel myself, but that the occupational therapist was there. [...] She knew all the ways and also arranged it for you. It saved me so much energy. Yes, I loved that so much.”* (Participant, 72, F)

**Box 1.** Description of a real-life 'Longer Vital at Home' trajectory. This box provides an example (Marie, a pseudonym) and detailed description of a completed 'Longer Vital at Home' trajectory from start to finish by means of a specific case

#### Background information

Marie is a 72-year-old woman living in a ground floor apartment with her husband. Due to a recent hand operation, she feels limited in performing daily activities. At the moment, Marie receives home care twice a week for showers and daily help with compression socks. Once a week, she also gets assistance with heavier tasks like vacuuming. She can manage light chores like folding laundry and uses a walker indoors, while her mobility scooter allows her to do light grocery shopping. Marie is a very social person. She was a taxi driver for over 30 years and served as a volunteer afterwards. She is also a member of the residents committee of the community she resides in. She is an active community member, participating in activities like cards, coffee chats, and crafting, although her recent hand operation has made crafting challenging.

#### Setting personal goals

During their initial conversation, Marie expressed her desire to assist her husband more with household tasks, resume driving, and return to crafting. She also mentioned her wish to participate in community activities on foot instead of using her mobility scooter. Following this conversation, the OT conducted the COPM<sup>29</sup> and set five personal goals with Marie: 1) crafting; 2) (un-)loading the dishwasher; 3) clearing the table; 4) driving her car; and 5) clipping her own nails. She mentioned she really missed the crafting activities that were organised in the community, but due to the pain she experiences in her hand she is unable to do this anymore. Additionally, she wanted to ease her husband's burden by (un-)loading the dishwasher by herself. Lastly, she mentioned that she hates it when other people have to clip her nails and would like to be able to do this by herself again.

#### Working towards her goals

Marie worked on her goals with the reablement team, receiving advice from the OT, like placing her cup in the sink while pouring boiling water instead of on the countertop. The OT also recommended assistive devices such as a custom nail clipper, suitable clothes pegs, and a vegetable peeler. After training and using these devices for a few weeks, Marie showed visible improvement in several tasks. The home care team also assisted her in relearning to dress herself, and the OT found ways to support her in returning to crafting, such as applying a thickening on the crochet hook which made it easier for Marie to hold it.

#### Achieving goals

After three months, the OT conducted a final assessment of Marie's goals using the COPM.<sup>29</sup> She had made significant progress, with an average change score of 5.25 for performance and 6 for satisfaction. Marie found the thickening of the crochet hook very helpful. She felt more independent, especially with loading the dishwasher, but on her doctor's advice couldn't resume driving. Marie was thankful that she had participated in the programme and said, '*I can manage myself, I matter again.*' At the three month follow-up, Marie mentioned that she still experiences a lot of pain in her right hand, making it harder to perform some of the activities trained before. However, she still very grateful for the things that she has learned during the programme. She is still able to perform most of the activities and is happy with the devices and advice that she received.

## Discussion

This research aimed to get an in-depth insight of goal setting and goal attainment within reablement services from the perspective of the older person. Participants appreciated the programme and its personalised and practical approach. It helped them to set clear goals that were in line with their preferences, which were mainly self-care related. Most participants reached their goals and indicated several personal gains they had obtained from participating in the programme (e.g. self-reliance, confidence, independence).

With regard to setting goals, our findings show that the majority of the goals set were on self-care level, more specifically, personal care and functional mobility, which is in line with previous research.<sup>30,32</sup> Several authors claim that more attention should be paid to social needs, social connectivity and leisure activities in reablement programmes, as it is assumed that these are the most meaningful activities for older adults.<sup>15,32,38</sup> It has been argued that the lack of focus on social needs may be in line with governmental priorities since investing in those needs does not necessarily reduce dependency on ongoing care and support services.<sup>27,39</sup> However, our research underlines that the setting of self-care goals aligned with the wishes and preferences of older adults. Despite reablement's broader focus on meaningful activities and well-being, participants emphasised that self-care tasks were crucial to their well-being and quality of life. Self-care is associated with staying at home longer without relying on others. Performing self-care activities in one's own home is important for people to view themselves as an independent person.<sup>40</sup> Previous research argues that goals set by older adults do not necessarily need to be 'big', meaning that independence in 'simple' activities, such as self-care, increases the participant's self-confidence.<sup>40,41</sup> It is more than merely the task of showering, for example, but also about their subjective experience; they want to remain autonomous and being able to manage their everyday life, which contributes to their quality of life.<sup>31,42</sup> This is also reflected in the WHO's Healthy Ageing framework, which defines Healthy Ageing as "*the process of developing and maintaining the functional ability that enables well-being in older age*",<sup>31</sup> and is seen as fostering an individual's functional ability to be and do what they value.<sup>8</sup> Often people have multiple types of goals (i.e. care or medical-related goals, and fundamental or life goals), which all contribute to a person's well-being and quality of life.<sup>44,45</sup> However, smaller, more specific, targeted care goals are a necessity to achieve fundamental goals and cannot be neglected when providing person-centred care.<sup>45,46</sup>

Our findings indicated that most participants at the end of the programme achieved the goals that were set at the beginning and that they believe they will be able to maintain performing

these activities. This was reflected in both statistically significant and clinically relevant change scores in self-assessed performance and satisfaction of valued activities in everyday life. Moreover, interviews with participants showed that they gained in confidence, perseverance, freedom, and independence, and became more self-reliant. Within reablement, it is important that participants formulate their goals themselves in line with their own preferences, with the necessary support of the reablement team. Moe and Brinchmann<sup>41</sup> emphasize the importance of service users setting their own goals at their own pace to maintain motivation. Similarly, Hjelle et al<sup>47</sup> found that allowing users to define goals without restrictions boosts intrinsic motivation. Involving service users in goal setting, as noted by Rose et al,<sup>48</sup> enhances confidence and a sense of ownership. Mulquiny and Oakman<sup>27</sup> highlight the significance of setting goals that were in line with their meaning of independence for the success of reablement. Our findings regarding self-assessed performance and satisfaction of meaningful activities in everyday life are in line with previous research,<sup>36,49</sup> which were both larger trials (i.e. n = 61 and n = 828 respectively) and used the COPM<sup>29</sup> as the primary outcome measure. Both studies found significant improvements in self-perceived performance and satisfaction scores, although it is unclear whether these effects were sustained long-term.<sup>26,36,49</sup> Nevertheless, these promising findings could be an indication that reablement may offer a solution to address the needs of an ageing population, such as increasingly complex care needs, the shift from inpatient to home-based care, and the growing pressure on financial and workforce resources in long-term care.<sup>1,50-52</sup>

Some methodological considerations have to be made. First, the sample for this study only entails 17 participants of which not all completed the full programme. It is therefore important to interpret the quantitative findings with the necessary caution, since small sample sizes tend to overestimate effect sizes.<sup>53</sup> Second, it is possible that only highly motivated and enthusiastic people were included in our study, leaving out the more critical voices, because these people will likely not enrol in a reablement programme in the first place (e.g. lack of willingness or motivation), which could lead to more positive experiences and effects.<sup>42</sup> Moreover, participants were approached by the OT member of the reablement team, which could also lead to selection bias. However, an information session took place with the OTs before the start of the study to explain the process in detail to make sure they did not select participants beforehand based on their assessment of whether clients would want or be able to participate. Additionally, we asked the participants about their experiences retrospectively, which may induce recall bias. Previous research has also shown that reflecting on their trajectory and personal gains after they have experienced improvement in functioning and daily life could lead

to a more positive view of their perceived trajectory.<sup>42</sup> We used the COPM<sup>29</sup> as a measurement for goal attainment (i.e. self-assessed performance and satisfaction scores). There is, however, insufficient evidence for the cut-off value of 2 points being a clinically relevant change, despite this being used in multiple studies.<sup>35,36</sup> However, because of the triangulation and mixed-methods design, the statements from participants formed an additional validation for our findings regarding clinical relevance. Additionally, the COPM<sup>29</sup> is preceded with an extensive intake conversation exploring what is meaningful to the participant. Performing this initial conversation could have a therapeutic effect and could motivate and convince participants to look for and work towards suitable solutions for their problems themselves,<sup>36,49</sup> which could diminish the effects of the reablement programme as a whole.

This study has some implications for future research and practice. Our research showed positive experiences and promising results regarding goal setting and goal attainment in reablement. However, it is still necessary to conduct more robust trials to investigate its effectiveness. Additionally, previous research has shown that participants may experience the end of reablement services as abrupt and often fall back into the care-dependent model afterwards, losing all gains previously achieved.<sup>27,41</sup> Therefore, more research needs to be conducted to investigate the long-term effects of reablement. For practice, it would be beneficial to invest in the sustainability and maintenance of the achieved gains in the shape of long-term follow-up. Additionally, where people are referred back to usual care after the reablement services, it is important to invest in the training of these care professionals so that the obtained gains are not lost. Second, an important finding both in our study as well as in previous literature is the lack of focus on social needs and wishes, especially in the light of fundamental life goals succeeding the necessary care goals. More attention needs to be provided on both these aspects within reablement services, and care professionals need to be trained and supported herein.

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## Appendices

### Appendix 1. Semi-structured interview guide

1. Could you tell us a little more about yourself (age, children ...)?

Recently, you have received a new form of care, namely the 'Longer Vital at Home' programme.

During this programme, the team worked with you on your personal goals;

2. Can you tell me a bit more about the care you received during this period?

a. What was it like for you to set goals together with the occupational therapist?

b. How did the team work towards these goals with you?

3. How did you experience this goal-oriented care?

a. What did you find positive?

b. What did you find negative?

4. What helped you work on your personal goals?

a. Can you elaborate a little more about that?

5. What prevented you from working on your personal goals?

a. Can you elaborate a little more about that?

6. Looking back on the past period, what do you think could be improved?

## Appendix 2. Code tree

Data extract	Code	Sub-theme	Theme
<p>I: We are actually very curious about why did you participate in longer vital at home programme?</p> <p>C: For a very long time, I couldn't do what I always wanted to do. I'm really a handyman. I couldn't do that anymore. Couldn't cut my own nails anymore and peel an apple. I had surgery on my hand, so all that actually fell away. And yes, then you only have a small world left actually.</p>	Wanted to do again what she used to do	Personal benefit as a motivation	
<p>I: Can you tell us why you think it is so important that you can still do things yourself?</p> <p>C: Because ... There are several reasons. We live very nicely here in this house, and although it's way too big for two people at this time of course, yes, this is where you feel at home.</p>	Wants to continue living at home		Incentive and motivation to participate
<p>I: Could you tell me why you joined the programme?</p> <p>C: Well, anything that can benefit care in general, I am in favour of.</p>	Participated because of benefits for care in general		
<p>I: What was your first thought when they told you about the programme?</p> <p>C: Well, yes, nice to be able to participate in that.</p> <p>I: What makes it nice for you to participate?</p> <p>C: Well, if it's in the context of a study that might ultimately benefit the whole community, I would be happy to participate in that.</p>	Participation because of benefit to community	Societal benefit as an incentive	
<p>C: And then I was offered that to join this trial I call it. And we were incredibly pleased with that. I'm so glad I did it. It has brought me a lot, yes.</p>	Glad she participated		
<p>I: Okay. Did you have any ... Were there any ... Do you have any tips, say, for us? Things that maybe went less well, areas for improvement?</p> <p>C: No, I was just raving. I liked it so much that I didn't have to invent the wheel myself everywhere 'how do I get ... how do I arrange this, or how do I arrange that', but that there was a ... The occupational therapist was always sitting there. You asked and she delivered. It saved so much energy. Yes, I loved that so much. And I wouldn't ... I have no areas for improvement.</p>	Enthusiastic about programme	Appreciated the programme and their participation	Overall impression of the programme
<p>C: Well, and [the community consultant] who also came regularly to check on things and with questions or who appended or called; we were also kept up to date by that just fine. So yes, I thought it was really great.</p>	Well informed	Adequate communication and information	
<p>I: Let's see. What did you appreciate most during the programme?</p> <p>C: The adequacy. Just good agreements made and right away what was said of: I'm going to take care of that tomorrow right away.</p>	Values adequacy and clear agreements		

Data extract	Code	Sub-theme	Theme
C: And because of her, I also started making my bed all by myself. In my way the way I like it. But you can look at it how my made up is. And so yes, that's actually the biggest advantage I have. And then cooking myself. Or at least, cooking myself that's what I do.	Became self-reliant again	Functional gains	
C: Well, I no longer have that many goals at 91. But to be in the household and my children well-Yes, at least can help and help out. And you may smell it. I am now making another nice bowl of soup.	Can fend for himself again		Personal gains from reablement
I: Ok. And how did you experience that? C: Favourable, yes. I: Yes. C: I also got more or less more perseverance through her efforts actually. Which I now benefit from.	Gained perseverance	Psychological gains	
C: Yes, I really felt-Yes, you just couldn't do anything. Just sitting around. Then I think yes, that doesn't work. I: No. C: No-and now you just feel much more confident yourself again.	Became more confident		
I: Can you tell a bit more about the first conversation you had with them, how did it go? C: Oh dear, the short-term memory is waning a bit. Well, it was all very positive and pleasant, and yes, while talking we came up with all sorts of things that could be improved here in the house. I had a whole laundry list and we ended up choosing five topics that we then didn't stick to, because other new things came up, and I think our situation is a bit less average than normal. We're actually carers for each other and the request for help came from me, so it's been totally focused on me, but my husband has just as much. He just broke his hand as well.	More and more needs and wishes surface during conversation	Intake and assessment to determine needs and wishes	The process of setting and reaching goals
I: Did you fill it in yourself? C: Together we did it. I: Together, yes. C: Yes, I really liked it. Then you can do it-you're a bit more careful yourself and they explain it so well that you really fill in the right thing. Yes, I found that very important	Goals were set together		

## Appendix 2. Continued

Data extract	Code	Sub-theme	Theme
<p>I: If it is good, there are ... have you had a conversation about goals you would like to work on, say, the things you would like to pick up with the occupational therapist within the programme. Can you tell us anything about that?</p> <p>C: Yes, the occupational therapist, in response to I'll just call it 'complaints' of mine - but you have to put that complaints in brackets - but reduction of strength in terms of opening jars and, well, all that sort of thing more, she showed me away. Well, what attributes you can use for that, what tools you can use for that.</p>	Offering assistive devices	Strategies and interventions applied by team to reach goals	
<p>C: My wife has been given a transport budget.</p> <p>I: Yes.</p> <p>C: That someone can just drive her back and forth.</p> <p>I: Yes.</p> <p>C: So in that way, that is totally supported from the municipality.</p>	Transport budget from municipality		The process of setting and reaching goals (continued)
<p>I: And do you manage to keep up what you have learned?</p> <p>C: Oh yes. What I've learnt I'm confident I'll stick to that.</p>	Can sustain achieved goals		
<p>I: Are there any other things that have helped you work on and achieve your personal goals?</p> <p>C: Wouldn't know that way, no. I wouldn't know. No. Because they are so enthusiastic you also start doing more things yourself.</p> <p>I: Yes.</p> <p>C: That's what really helped me though. Their enthusiasm is fantastic. Yes.</p>	Enthusiasm of care professionals helps	Being able to attain goals	

Note. I = interviewer; C = client







# Chapter 7

## A qualitative exploration of professionals' perspectives on the implementation of reablement programmes in community care

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## **Abstract**

Reablement is considered a complex intervention due to its multicomponent, person-centred, holistic approach promoting older adults' active participation in daily activities. It is important to consider the unique context in which complex interventions are implemented, as contextual factors may interact and influence implementation outcomes. As part of the European TRANS-SENIOR project, this qualitative study aimed to gain insight into professionals' experiences with reablement implementation in Dutch community care. Using the Consolidated Framework for Implementation Research, four focus groups were conducted comprising 32 professionals. Two groups were formed: one at operational level, including therapists, nursing staff, social workers, and domestic support; and one at organisational/strategic level, including project leaders, managers, directors, municipality representatives and health insurers. Participating care organisations had at least 6 months of experience with deploying and implementing reablement. The findings reflected three themes: 1) strength of interdisciplinary collaboration; highlighting the significance of sharing goals and beliefs; 2) integrating the reablement philosophy into the organisation, underscoring management's role in fostering support across all organisational layers; and 3) achieving a culture change in the health-care system, emphasising current funding models impeding value-based care tailored to the individual's goals and needs. The results offer valuable insights for the implementation of complex interventions, like reablement.

## Introduction

Many countries stimulate ageing in place, promoting older adults to remain living at home independently for as long as possible.<sup>1-3</sup> Aging in place provides a stable foundation during times of significant change in the lives of older adults, promoting not only autonomy but also contributing to the preservation of their own identity.<sup>4,5</sup> It refers to the ability of older adults to live independently and comfortably their own homes or communities as they grow older. The concept encompasses not only the physical residence but also the community and social networks they are a part of.<sup>6,7</sup> Moreover, ageing in place is often the preferred goal of older adults, despite increasing care needs.<sup>2,6,8,9</sup> Therefore, there is a need for sustainable, cost-effective, and patient-centred initiatives, focusing on improving quality of life and preventing or postponing institutionalisation and inpatient care.<sup>10</sup> Reablement is considered an appropriate response to these needs.<sup>10</sup> It is a person-centred, holistic approach that promotes older adults' active participation in daily life through social, leisure, and physical activities chosen by the older person in line with their preferences, either at home or in the community.<sup>11</sup> Reablement had some core principles and common features – for example, goal setting, an interdisciplinary approach, and a practice-oriented staff training.<sup>12-14</sup> A reablement trajectory is often time-limited and consists of several phases (i.e. initiation, intake, care plan, care delivery, and evaluation).<sup>12</sup> Instead of taking over tasks, care professionals identify the capabilities and opportunities of individuals to maximise their independence by supporting them to achieve their goals, through training in daily activities, home modifications, assistive devices, and involvement of their social network.<sup>11,15-17</sup> Reablement is not a 'one size fits all' approach, meaning it is tailored to both the individual (i.e. their needs, preferences, and capabilities) and their environment.<sup>13,18</sup>

As the ageing population continues to grow and individuals continue to live longer, the complexity of care needs and health issues also increases, often involving multiple health conditions.<sup>19</sup> To continue to meet these changing needs and adhere to the wish of older adults to age in place, care provision and health care interventions also become more complex. Reablement can be considered a complex intervention, which is typically difficult to implement in everyday practice.<sup>20</sup> Complex interventions generally include many interrelated components and factors and are provided and evaluated at different levels.<sup>20,21</sup> The complexity is more than the sum of all components, as other factors – for example, the implementation process, context, and participants – also have a major influence on achieving desired outcomes.<sup>21-23</sup> Much research has been done to unravel the barriers and facilitators influencing the

implementation of complex interventions in health care (e.g. availability of resources, communication, culture, motivation and knowledge, etc.).<sup>24-28</sup> Previous research has revealed important aspects related to the implementation of reablement, such as the engagement of all parties involved, flexibility and professional autonomy, and shared vision and commitment.<sup>18,29-32</sup> However, some of these results were mainly based on researchers' responses,<sup>29,31</sup> drawn from multilevel analyses,<sup>30</sup> or only based on the experiences of care staff.<sup>18,32</sup> Therefore, this needs to be further explored, especially from the perspective of multiple professionals involved in the implementation of reablement, since this has not been investigated previously. Moreover, it cannot be assumed that these factors are also applicable to the implementation of all reablement programmes, across all settings. As complex interventions, like reablement services, are context-dependent,<sup>30,33,34</sup> it is important to consider the unique context in which they are implemented, as contextual factors such as organisational culture, networks and communication, and resources, may interact and influence implementation outcomes.<sup>35</sup> Therefore although reablement has been successfully implemented into usual care in, for example, Denmark and Australia,<sup>14</sup> it cannot be assumed that this applies to every context.

This study aims to gain insight into the experiences of care professionals, management, and funders with the implementation of reablement in Dutch community care. By understanding and advancing reablement implementation, health-care providers and policymakers are better equipped to successfully implement reablement both nationally and internationally. This study aims to address the following research question: how do professionals (i.e. operational, strategic, and organisational) experience the implementation of reablement in community care?

## **Methods**

### **Design**

The current study used a qualitative descriptive research design to closely align interpretation and data analysis with participants' responses. The study was guided by the Consolidated Framework for Implementation Research (CFIR), i.e. preparation of the interview guide and data analysis.<sup>36</sup> The CFIR is a meta-theoretical framework consolidating 19 previous implementation theories. The framework can be used to prepare for innovation implementation and/or evaluative purposes to better understand factors influencing implementation outcomes, making the CFIR both dynamic and valuable.<sup>37</sup> Moreover, the

framework provides useful tools and aids to guide data collection, analysis, and reporting.<sup>38</sup> The Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist was used to strengthen the reporting of this study.<sup>39</sup>

### **Setting and participants**

The study was conducted at three large care organisations that can be considered early adopters of reablement in the Netherlands (i.e. they started the implementation of a reablement programme at least six months prior to the start of the study). All organisations provide a range of services: from home care and (medical) treatment, to clinical rehabilitation and inpatient long-term care.

Criterion sampling was used to select professionals.<sup>40</sup> Eligible professionals had to be involved during the development, deployment, and/or implementation of reablement ensuring a well-rounded representation of professionals (i.e. a variety of disciplines on operational, strategic, and organisational levels). Two groups of professionals were formed: 1) at the operational level – from here on referred to as care professionals – including occupational therapists, nursing-care staff, physiotherapists, social workers, and domestic support workers; and 2) at the organisational or strategic level – from here on referred to as management – including project leaders, managers, directors, and policymakers, as well as representatives from the municipality and health insurance companies, who played essential roles in the programme's implementation. Care organisations were contacted via email, stating the study's background, objectives, and participation information. The project leaders within each organisation were responsible for distributing the invitation to eligible professionals. Eligible participants received study details, including an information letter and informed consent form. Participants were requested to provide their written informed consent at the beginning of each interview.

### **Data collection**

Participant demographics (i.e. age, sex, and educational level, organisation of employment, occupation, years of experience in the field, and years of experience with reablement) were collected through a questionnaire.

At each care organisation, an on-site focus group was conducted with care professionals. Additionally, one overall online focus group was conducted with management. The separation

of care professionals and management was maintained to create a safe environment when sharing their experiences. All focus group interviews were planned between December 2022 and February 2023 for a duration of one and a half or two hours. No repeat interviews were conducted. All researchers conducting interviews were female and had prior experience with conducting interviews. Authors IM or LEB (doctoral students) led the interviews and were assisted by one observer IM, LEB, or SFM (assistant professor). Interviews were guided using a semi-structured interview guide (Appendix 1) based on the five domains of the CFIR,<sup>36</sup> namely Intervention Characteristics, Outer Setting, Inner Setting, Characteristics of Individuals, and Process. The interview guide started with an open question about experiences with the implementation of reablement and what hindered or facilitated them therein. This first question was answered using sticky notes on which participants could write down hindering and facilitating factors. Subsequently, the sticky notes were clustered into themes and were discussed with the group. Follow-up questions were based on the five CFIR domains<sup>36</sup> to obtain participants' views on each domain. Field notes were taken during and after each interview and all interviews were audio-recorded to capture the intricate and nuanced data that characterise this type of research.

### **Data analysis**

Descriptive analyses of the background characteristics were performed using IBM SPSS Statistics (Version 25). Qualitative data were coded and analysed using the qualitative data analysis software ATLAS.ti Windows (Version 23.0.8). All interviews were pseudo-anonymised and transcribed verbatim. For exploration and refining purposes, the data was first coded using inductive content analysis, the initial themes and categories were developed through iterative coding and discussions among IM, LEB, and SFM. Afterward, the data was analysed and structured according to the CFIR domains using deductive content analysis<sup>41</sup> with guidance from the CFIR information site<sup>42</sup> while following the steps of the Framework Method as described by Gale et al<sup>43</sup> IM and LEB conducted the analysis collaboratively. The authors familiarised themselves with the data by reading the transcripts and taking notes. All coding was done independently, reviewed and compared, and discrepancies were discussed and resolved. The deductive coding was supplemented with the prior inductive coding for comprehensive analysis, ensuring no data was missed. Summarised data were organised into a matrix using Microsoft Excel 2016 (Microsoft Corporation, Redmond, WA, USA). This was reviewed and adapted by authors IM, LEB, and SFM.

## **Rigour and reflexivity**

Multiple strategies were used to increase rigour in terms of credibility, dependability, and conformability.<sup>44</sup> Member checking was done during and at the end of each focus group using interpretation checks, and afterwards with summaries of key findings providing participants with the opportunity to respond, which was used by one participant. Investigator triangulation was applied in both data collection and data analysis. The iterative process allowed for re-examining initial findings using insights that emerged during analysis. Results were discussed within the research team until consensus was reached. To reflect on the process, choices made and intermediate results, a research diary was used by IM and LEB. During data collection, objectivity was ensured by consciously formulating the posed questions and prompts. However, knowledge of the subject matter and close involvement in practice may have influenced the decisions during data analysis and thematic selections. These decisions were discussed within the research team on a regular basis to prevent such influences, involving members less directly involved in practice.

## **Ethics**

The study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the Ethics Committee of Maastricht University, Faculty of Health, Medicine and Life Sciences (approval number FHML-REC/2022/126). Participants voluntarily signed informed consent after they were fully informed about the purpose and procedures of the study and had the opportunity to ask additional questions or raise any concerns. The written informed consent stated that participation was completely voluntary and withdrawal from the study was possible at any moment, without providing a reason, by contacting one of the researchers (IM/LEB/SFM).

## **Results**

In total, 32 professionals participated in the study. Eighteen professionals were involved in the three focus group interviews with care professionals. The care professionals included: occupational therapists (n=4); physiotherapists (n=4); district nurses (n=3); certified nursing assistants (n=2); a nurse practitioner (n=1); elderly care physician (n=1); community consultant (n=1); consultant informal care (n=1); and a work planner domestic support services (n=1).

Twelve professionals were involved in the online focus group with management. Management included: directors (n=3); managers (n=3); project leaders (n=3); an implementation coach (n=1); a policymaker from the municipality (n=1); and a team leader (n=1). Additionally, two health-care insurer representatives participated in the online focus group at organisational and strategic levels, from here on referred to as ‘funders’. Table 1 provides an overview of all participants involved, including information about their age, sex, educational level, discipline or professional role within the organisation, and years of experience within their discipline and reablement.

**Table 1.** Background information of participants (n = 32)

	Care professionals (n = 18)	Management (n = 12)	Funder (n = 2)
Age (years), mean (SD)	41.7 (11.0)	48.1 (9.6)	37 (0.0)
Sex, n (%)			
Male	2 (11.1)	2 (16.7)	1 (50.0)
Female	16 (88.9)	10 (83.3)	1 (50.0)
Educational level*, n (%)			
Intermediate	3 (16.7)		
High	15 (83.3)	12 (100.0)	2 (100.0)
Organisation, n (%)			
Care Organisation A	8 (44.4)	3 (25.0)	
Care Organisation B	5 (27.8)	5 (41.7)	
Care Organisation C	5 (27.8)	3 (25.0)	
Municipality		1 (8.3)	
Health-care insurer			2 (100.0)
Years of experience, mean (SD)			
Professional role	10.3 (8.0)	7.5 (8.9)	3.5 (0.7)
Reablement	1 (0)	1.6 (0.7)	2.0 (1.4)

Note. \* Intermediate: Intermediate vocational or higher secondary education; High: Higher vocational education, university

The results reflected three overarching themes: 1) strength of interdisciplinary collaboration; 2) integrating the reablement philosophy into the organisation; and 3) achieving a culture change in the health-care system. The data corresponding to the domains and constructs of the CFIR are presented as ‘(Domain: Construct)’.



## **Strength of interdisciplinary collaboration**

This theme describes how aspects related to the architecture and application of the programmes impacted implementation. However, the key focus was on collaboration, both internal and external, and was mainly related to the CFIR domains: Inner setting; Outer setting; and Intervention Characteristics.

### ***Internal collaboration***

All care professionals perceived reablement's interdisciplinary character as facilitating (*Inner Setting: Networks & Communications*). They mentioned a more intensive collaboration due to increased insight into each other's profession and capabilities, which was also noticeable beyond the programme. In addition, care professionals indicated that, together with the client, they gave more consideration to which professionals should be involved. In their view, the structured team meetings improved communication, and the shared set of goals created shared ownership. These facilitating factors were endorsed by management.

*"That [collaboration] really has improved. You also know what everyone does, what you can find each other for. [...] It's as if the threshold has somehow disappeared. They know who you are, they know what you do and they also come to you with different questions about very different things, not just reablement."* (Occupational therapist, Care Organisation C)

However, most care professionals also indicated hindrances, such as scheduling meetings and intake assessments, limited access to others' reports, and lack of overview of the care professionals involved (*Inner Setting: Structural Characteristics*). Furthermore, management indicated unclear task distribution among professionals with coordinating roles sometimes caused tension. For example, when the occupational therapist took on a coordinating role, this sometimes felt threatening to district nurses or case managers.

*"But, where the friction often arises is in the coordinating role [...] that has nothing to do with professionals feeling more or less than another. But, that they [...] don't quite understand what their [...] role looks like within that reablement programme, and that the coordination might temporarily lie with the occupational therapist [...], or temporarily with the district nurse. If those agreements are unclear, that's the feeling you get."* (Director, Care Organisation A)

### ***External collaboration***

Participants indicated a lack of structural collaboration with external professionals, including domestic support workers, general practitioners, case managers, and municipalities (*Outer*

*Setting: Cosmopolitanism*). In particular, the lack of collaboration and involvement with general practitioners was experienced as hindering due to a lack of background information and was reported to hinder clients' independence. This was also the case when external care professionals were involved who did not follow reablement principles.

*"We also get regular referrals of clients saying, 'Go take a shower twice a week and pretend to be worse than you are, because then you might get a long-term care indication and then you can move [to a nursing home].' Because there are care professionals [outside the organisation] who think they should move."* (Physiotherapist, Care Organisation B)

### **Integrating the reablement philosophy into the organisation**

This theme reflects on the role management played in integrating the reablement philosophy throughout all actors involved. Their efforts to establish a strong foundation were considered crucial for successful implementation. Additionally, this theme reflects on what influenced the necessary readiness for change, both for professionals as well as clients and their informal caregivers. These findings were mainly related to the domains: Inner setting, Outer setting, Characteristics of the individual, and Process from the CFIR framework.

### ***Role of management in programme integration***

Care professionals felt both facilitated and hindered by management; while they experienced freedom to experiment with reablement, they also expressed a need for clearer boundaries (*Inner Setting: Implementation Climate – Learning Climate*). Additionally, home-care teams experienced change fatigue due to the simultaneous implementation of numerous projects during the time reablement was implemented (*Inner Setting: Implementation Climate – Relative Priority*). Most care professionals expressed that they felt unheard by management when raising issues and missed feedback and follow-up (*Inner Setting: Networks & Communications, Readiness for Implementation – Leadership Engagement*). They also mentioned a lack of clarity in terms of the programme's purpose, which resulted in mismatched expectations of care professionals (*Inner Setting: Implementation Climate – Goals & Feedback*). Management endorsed the need for a communication strategy beyond just providing information. Lastly, care professionals felt pressure to deliver positive results due to high expectations from both management and researchers.

*“Policy, management, ministry and so on all come up with plans. We have to implement it, but there is no connection. We have to pass on signals all the time. It takes an awful lot of time. Moreover, it is very incomplete, because we have to put it into words, [...] then you have to meet with your quality officer again. [...] I just don't have time for this.”* (Community consultant, Care Organisation C)

However, participants also emphasised the vital role that management played to sustain the reablement philosophy within their organisations and acknowledged management's successful efforts. For example, hiring an implementation coach, conducting regular evaluations and project group meetings (*Process: Planning, Engaging, Reflecting & Evaluating*), sharing success stories, and establishing low-threshold communication with care professionals and clients (*Process: Engaging*) were mentioned as facilitators for the implementation of reablement to resonate both inside and outside the organisation (*Inner Setting: Readiness for Implementation, Leadership Engagement*).

*“What has also helped us a lot is the success stories [...] that are there, and to celebrate and share them. And collaboration [...] also very beneficial. Because then they will have achieved something together which they can be proud of. And well that totally contributes to the whole process of getting [...] the change going, and to be especially mindful of that.”* (Manager, Care Organisation B)

### **Readiness for change**

Nearly all participants indicated that the implementation of reablement programmes led to a change in perspective among care professionals, facilitating interdisciplinary collaboration and promoting equality and sustainability. (*Characteristics of the Individual: Knowledge & Beliefs about the Innovation, Individual Stage of Change*). However, a lack of mutual beliefs (e.g. external professionals) was perceived as hindering (*Outer Setting: Cosmopolitanism, Characteristics of the Individual: Knowledge & Beliefs about the Innovation*). Care professionals' readiness for change was said to be influenced by personal factors, such as years of experience, educational level, and motivation (*Characteristics of the Individual: Individual Stage of Change, Other Personal Attributes*).

*“You notice that the people who were already working in home care [...] find it much more difficult [to change]. Because then it's like, ‘Oh, I'll just do that quickly and then I'll finish earlier and I can move on to the next one quicker, so no one has to wait’. But with the younger generation, you notice that it really is easier [to change].”* (District nurse, Care Organisation A)

Care professionals indicated that it was mainly personal factors among clients and informal caregivers that influenced their readiness for change. For example, their motivation, expectations, whether they had been receiving care for a long time, perceptions of care among the older generation, knowledge, and health literacy (*Characteristics of the Individual: Individual Stage of Change, Other Personal Attributes*). To facilitate change, and consequently the success of the programme, care professionals stressed the importance of conducting the intake and goal setting in a way that helps clients and informal caregivers become aware of the necessary steps to achieve their goals and creates a sense of ownership (*Characteristics of the Individual: Knowledge & Beliefs about the Innovation*).

*“We really ‘do with’ and most people are really still ‘doing for’ [...] that does clash regularly. Clients also feel, and I think this is especially true for wealthier people, that they are entitled to a lot of things. Because they have worked hard all their lives and paid a lot and now we will have to [care for them]. [...] I am often told, ‘Yes, you could just come anyway, because we have been paying health insurance all our lives, so we are entitled to this, so you should do it.’”* (District nurse, Care Organisation A)

### **Achieving a culture change in the health-care system**

This theme reflects on the shift towards a ‘doing with’ rather than ‘doing for’ approach, which means that instead of taking over tasks from clients, self-management is stimulated. This empowers clients to actively participate and take ownership, with a focus on prevention, which matches the ongoing care transformation in the Netherlands. It also explores the societal responsibility that health-care organisations bear in this transformation. Participants discussed funding issues and the prerequisites for successfully navigating this transition. These findings were related to the domains: Inner setting, Outer setting, Characteristics of Individuals, and Intervention Characteristics from the CFIR framework.

### **Funding**

All participants perceived current funding of reablement as hindering the desired deployment of the reablement programmes. Current insurance reimbursement in the Netherlands falls short for some aspects of reablement – for example, team meetings, physiotherapy, and a sufficient amount of occupational therapy (*Outer Setting: Needs & Resources of Those Served by the Organisation*). Subsequently, care professionals mentioned that clients were reluctant to pay for additional non-reimbursed costs and therefore possibly would not participate in the programme (*Inner Setting: Readiness for Implementation – Available Resources*). Moreover,

management indicated that the possibility of implementing reablement more preventatively is also hampered by the financial and administrative rules of the current reimbursement system in primary care. Both management and care professionals therefore expressed a need for a form of funding that is not project-based and facilitates integral reimbursement (*Outer Setting: Needs & Resources of those Served by the Organisation*).

*“We also hope that eventually there will be an integral reimbursement for this issue so that you can really look specifically at the client: ‘Hey, what do they need now?’ And that you don’t have to weigh up every time, like: ‘They can get a bit more occupational therapy [reimbursed] now, so we use that a little bit more, because physiotherapy is not in the [reimbursement] package.’ You don’t want to look at it that way. You really want to look at: ‘Hey, what are the goals and [...] what can we deliver to reach that?’”* (Project leader, Care Organisation C)

From management’s perspective, the current project-based approach to implementing and funding reablement is hindering its permanent positioning within the health-care system (*Inner Setting: Implementation Climate – Relative Priority*). They felt this approach leads to perceptions that reablement is merely an add-on, lacks commitment, and may not replace or supplement existing care services effectively. One of the funders endorsed that not having integral funding is hindering, but emphasised that they need to know what the added benefits of reablement are compared to usual care (*Intervention Characteristics: Trialability*).

*“We are really not looking to know it all. We don’t need huge thick files to back it up, but we do want to be able to compare it. [...] What is the difference with usual care, except, that clients are more in the lead and have more autonomy. I’m all in favour of that, but can we also make it clear what it means? What the other way of working entails, compared to the old way?”* (Funder, Care Organisation C)

### **Care transformation and prerequisites**

Management mentioned that they felt external pressure due to the societal mission set by the Dutch government, which emphasises the need for affordable and accessible health care (*Outer Setting: Peer Pressure, External Policy & Incentives*). Care professionals and management consider reablement an essential change to address the growing demand for care (*Inner Setting: Tension for Change*). They see it as a way to offer more preventative care, reducing clients’ dependency on services, and possibly delaying more complex care (*Inner Setting: Implementation Climate – Relative Priority*).

*“What I sincerely believe is that reablement will very much contribute on prevention. That this will ultimately keep people out of long-term care facilities, or at least not until*

*a later stage. We also see now – certainly the group that is currently applying through the municipality – we see that when on time... Being involved much earlier, that's really going to result in needing less hospital care and other expensive forms of care.”* (Project leader, Care Organisation C)

To implement reablement on a larger scale, management believes that maintaining a dialogue with professionals and expanding collaboration with other organisations is crucial (*Inner Setting: Implementation Climate – Relative Priority*). However, they also mentioned that the time and effort required to establish behavioural change among care professionals may be a hindrance. They also felt this transformation was insufficiently supported by national policies. In their view, prerequisites, laws, and regulations needed to implement reablement in the Dutch context are largely absent (*Outer Setting: External Policy & Incentives*). Additionally, management believes that, besides staff shortages, they have a responsibility to facilitate a new professional standard, as current standards are lacking and missing the necessary skillset needed for effective reablement delivery (*Characteristics of Individuals: Individual Stage of Change*).

*“We need to move towards a new professional standard, especially for district nursing. And you don't achieve that by quickly scaling up. I personally believe that in the long run, once you have it implemented correctly, you can enable many clients to take care of themselves in the community with district nursing, reablement, and potentially other aids. [...] The entire programme must be delivered by occupational therapists. And we don't have 10.000 of them either. So [...] I think we shouldn't think it [upscaling] is just done like that. Because, in my view [...] it's moving too fast. It's too complicated for that.”* (Manager, Care Organisation B)

## **Discussion**

This study aimed to gain insight into professionals' experiences with the implementation of reablement, a complex interdisciplinary intervention in Dutch community care. The findings reflected three overarching themes: 1) strength of interdisciplinary collaboration; 2) integrating the reablement philosophy into the organisation; and 3) achieving a culture change in the health-care system. Through the perspective of multiple professionals on different levels (i.e. operational, strategic, and organisational), the findings reflect the characteristic interrelations of different components and influences associated with the implementation of complex interventions.

Care professionals experienced improved interdisciplinary collaboration, enhanced understanding of each other's roles, and shared ownership, which was mainly facilitated by structured team meetings and shared goals. Interdisciplinary collaboration is experienced as positive and essential amongst care professionals working with reablement,<sup>45-47</sup> for example, in getting perspectives from different angles.<sup>48,49</sup> However, other studies endorsed the hindering factors (i.e. scheduling conflicts and lack of accessible reports) found in our study.<sup>47,50</sup> The most important finding relates to the challenges encountered due to a lack of mutual beliefs, structural collaboration and alignment with external parties, and consequently, the extent to which all involved care professionals adhered to the reablement principles, thus, causing ambiguity and possibly leading to suboptimal contributions of some team members.<sup>45</sup> However, competing logics among involved parties should not hinder implementation.<sup>51</sup> This can be strengthened when all parties work towards a shared goal, align their beliefs, and establish more structured forms of collaboration.<sup>52</sup> In addition, it is essential to enable care professionals to learn from each other's perspectives thereby complementing and enhancing their skills.<sup>49</sup>

The success of the implementation seems to depend on the integration and upkeep of the reablement philosophy throughout all professionals involved. In accordance with prior research,<sup>49</sup> the most important finding was management's pivotal role in sustaining the reablement philosophy within the organisations. Especially in these contexts, where the collective shift of mindset and professional role identity depends on the expectations of multiple professionals, achieving cultural change relies on rethinking institutional logics (i.e. shared beliefs and values determining behaviour, shaping actions and decisions) and interrelationships.<sup>52</sup> Management's initiatives were seen as facilitating the implementation and have proven to be effective when applied within all layers of the organisation.<sup>47,53</sup> However, Fakha et al<sup>27</sup> confirm that the lack of continuity indicated by the participants (i.e. disrupted information flow, communication, etc.) can impede the implementation of innovations. Establishing strong external networks and clear communication is essential to foster implementation.<sup>27</sup> Therefore, it is recommended to maintain open communication across all organisational layers and provide time, space, and resources necessary to reconsider institutional logics.<sup>49,52,54</sup> This engagement can be further enhanced when staff are given the opportunity to provide input and feedback (e.g. during interactive sessions with management), through which they can voice their opinions and concerns, ask questions, offer suggestions, and feel heard.<sup>49,54,55</sup>

It became evident that funding and supporting regulations in the Netherlands were perceived as impeding for nationwide implementation of reablement. Current funding and reimbursement schemes fall short of covering all costs related to reablement programmes and their accompanying interdisciplinary collaboration.<sup>56</sup> Consequently, this hampers care professionals from delivering care based on the client's goals and needs, as the care provided is dictated by reimbursement criteria. This is in line with Parsons et al,<sup>34</sup> who emphasise the need for a funding model that facilitates goal-oriented, holistic, and person-centred home care. Both management and care professionals expressed a need for a more integrated form of funding as the current fee-for-service model does not encourage value-based care, fosters fragmented health care, and encourages volume-based incentives.<sup>14,57</sup> In addition, the current model does not incentivise preventive care and early interventions.<sup>57,58</sup> Moreover, a strong and shared national vision regarding a new way of delivering home care is needed (i.e. supporting organisational procedures and national policies).<sup>17</sup> An integrated funding model could potentially provide a solution providing high-quality care tailored to the client's needs, ultimately reducing health-care costs by promoting preventive care and early interventions.<sup>59,60</sup>

Some methodological considerations have to be made. First, we used a criterion sample of professionals based on the personal judgement of the research team and previous collaboration with the professionals, which could lead to a selection bias of more motivated participants. However, it allowed us to obtain insight from the professionals who were closest to the implementation process. Second, to minimise time investment and effort required from organisations and professionals, the decision was made to conduct four focus groups instead of pursuing data saturation. In addition, the uneven distribution of participants raised a concern, especially since one of the interviews involved 14 participants, potentially limiting the representation of some participants in our combined analysis. Nevertheless, our study presents a methodologically sound and comprehensive understanding of the factors influencing a nationwide implementation of reablement from an implementation science perspective – for example, by using a well-known framework (i.e. CFIR)<sup>36</sup> to guide our study. It is important to note that the CFIR framework was updated during the preparation of this research.<sup>61</sup> The revised version highlights the importance of including the end-users' perspective which ensures care meets their needs, enhancing person-centred and effective health care.<sup>62</sup> As a consequence, our study only reflects clients' experiences from the perspective of professionals.

Notwithstanding these limitations, this study offers valuable insights for the implementation of reablement across diverse (international) settings and offers lessons applicable when



implementing complex interventions. It can serve as a starting point to determine suitable and effective strategies to address the identified influences on implementation. Linking our findings to the CFIR provides sufficient guidance to choose appropriate strategies for implementation.<sup>63</sup> Future research could quantify a mix of key influences and explore their impact due to reablement's context-specific character, further tailoring the chosen strategies. For practical application, care organisations should foster an innovation climate promoting open communication throughout all layers of the organisation, as well as with service users. Policies should prioritise adopting an integrated funding model, which offers structure when implementing complex, interdisciplinary interventions such as reablement, especially early on in the care process.

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## Appendices

### Appendix 1. Semi-structured interview guide

#### A. Overall experiences with implementing reablement

1. Which factors did you experience as facilitating when implementing reablement?
  - a. Why was this a facilitating factor?
2. Which factors did you experience as hindering when implementing reablement?
  - a. Why was this a hindering factor?

#### B. Domain 1: Intervention characteristics

3. What challenges did you face during the implementation of reablement?
4. How can these problems be solved?
5. What do you think are the advantages and disadvantages of reablement compared to conventional home care?

#### C. Domain 2: Outer setting

6. To what extent has current legislation and regulations influenced the implementation of reablement?
7. To what extent have other factors outside the organization influenced the implementation of reablement?

#### D. Domain 3: Inner setting

8. To what extent has the organization facilitated or hindered the implementation of reablement?
9. In what way has communication within the organization and within the reablement team influenced the implementation of reablement?
10. To what extent does reablement fit within the organization's current policy and how did this affect the implementation of reablement?

#### E. Domain 4: Characteristics of the individual

11. Which people supported you in the implementation of reablement?
  - a. How did they support you?
12. Which people hindered you in the implementation of reablement?
  - a. How did they hinder you?

#### F. Domain 5: Process of implementation

13. Was the reablement program implemented as intended?
  - a. If not, why not?
14. What strategies were used to implement the reablement program as planned?





# Chapter 8

## General discussion

Due to the growing interest in reablement worldwide, it is vital to gain insight into the essential components of community-based reablement and user experiences. These insights provide valuable information for future policy and practice. Therefore, the objectives of this thesis were 1) to investigate community-based reablement and its essential components for future intervention programmes and 2) to explore the experiences of clients, their family caregivers and professionals with reablement programmes to inform and advance future implementation.

This chapter discusses the main findings of these studies, followed by methodological and theoretical considerations. Furthermore, implications for research, practice, policy, and education are presented.

## **Main findings**

With regard to the first objective, a literature review (*Chapter 2*) identified that optimising both personal and environmental resources, as well as prioritising health and functioning rather than disability can enhance the independence and well-being of older adults during meaningful daily activities. Additionally, recent literature on the evaluation of international reablement interventions (*Chapter 3*) showed that these were often multicomponent, with some common features (a multidisciplinary approach coordinated by a case manager, goal setting, and staff training). The results of these interventions were often promising regarding health-related quality of life and health-care utilisation. In addition to these findings, a co-creation study (*Chapter 4*) – involving care professionals, policymakers, clients, informal caregivers, and scientific experts – identified six essential components for (future) reablement programmes, namely: 1) improving assessment and goal setting; 2) stimulating self-management during meaningful daily activities; 3) optimising the use of the physical environment; 4) optimising the use of the social environment; 5) improving interprofessional collaboration; and 6) supporting the informal caregiver (*Chapter 4*). These components are essential in order to improve older adults' self-management and quality of life, while also improving the quality of life of their informal caregivers, and to support older adults to remain living at home independently for as long as possible. Eventually, the six identified components were translated into a 5-phase care process, including a practice-oriented training, suitable for various settings and organisations.

Regarding the second objective, experiences with reablement programmes were primarily positive. Clients expressed that they (re-)gained confidence, perseverance, and independence in their everyday life (*Chapter 6*). With regard to goal setting and goal attainment, two key elements of reablement, clients had overall positive experiences and were pleased with the personalised approach. Moreover, a clinically relevant and statistically significant change was visible regarding clients' goal attainment, meaning that they achieved their personal goals. Moreover, participants mentioned that they regained freedom and self-confidence. Despite the overall positive experiences, family caregivers often mentioned ambivalence about support from care professionals (*Chapter 5*). They expressed a lack of guidance and information, but also do not expect support from them. A trusting relationship is essential, and they want to be involved in decision-making, but care professionals should be cautious not to overburden them with information or tasks. Family caregivers rarely sought help from their social network or professionals. They preferred professionals to be proactive, meaning that they did not have to take the initiative themselves. Additionally, an approach tailored to their needs is also preferred. Furthermore, when reflecting on the implementation of reablement on a national level, professionals pointed out three main aspects (*Chapter 7*). First, the interdisciplinary collaboration created a shared goal and mindset, and was perceived as facilitative and should be extended to people outside their own organisation. Second, the involvement of management and other strategic stakeholders was found crucial to accomplish a cultural shift through all layers of the organisation. There was often a substantial difference between the perception of management and health-care providers when it came to whether and how reablement was implemented in practice. Third, the financial and organisational structure of health care hindered the implementation of reablement; it falls short in covering costs related to reablement programmes and their accompanying interdisciplinary collaboration, and hampers care delivery based on the client's goals and needs, as the care provided is dictated by reimbursement criteria.

## Methodological considerations

The specific methodological considerations of all studies in this thesis have been discussed in the previous chapters. This section focuses on some general considerations made in this thesis regarding the importance of a logic model of complex interventions, the involvement of older adults and their informal caregivers, including frontrunner organisations as research partners, and choosing explorative and qualitative designs.

### **The importance of a logic model for complex interventions**

The development of I-MANAGE was conducted using a systematic approach based on an extended version of the development phase of the MRC framework<sup>1</sup> as described by Bleijenberg et al<sup>2</sup> (*Chapter 4*). This approach suggests developing a logic model to illustrate how a programme will create change.<sup>3</sup> A logic model is a systematic approach to shed light on the aim and sub-aims of the programme, the programme components, and the intended outcomes.<sup>3</sup> Our logic model was developed in collaboration with stakeholders from the field through observations, individual interviews, and working group sessions to obtain a thorough understanding of the context and current practice, the experienced problems and the needs of stakeholders, creating a holistic 360-degree view. However, due to the ongoing Covid-19 pandemic, it became challenging to collaborate with health-care organisations and professionals because their priorities were shifting, and we had to frequently pause our research activities. Additionally, we had limited access to our target population (i.e. older adults and their informal caregivers) due to infection prevention guidelines and regulations, hindering the planned interviews and observations. Ideally, we would have conducted a more extensive contextual analysis.<sup>4,5</sup> This would have provided us with insights into the environment in which the programme will be implemented and which external factors (e.g. politics or socioeconomic factors) would interact with and influence the implementation and achievement of intended outcomes.<sup>3,5</sup> Despite our best efforts, we were restricted to a limited number of digital meetings. Ideally, approaches such as participatory action research, where stakeholders are equal partners in the process and build on the model together, would be more appropriate.<sup>6,7</sup> Furthermore, due to limited access to the field, we were unable to test elements of the model throughout the development process. This would have allowed us to identify any practical challenges or adjustments needed before full-scale implementation.<sup>5</sup>

In addition to the collaboration with stakeholders from the field, we used existing literature on international reablement programmes, thereby strengthening the evidence base of I-MANAGE (*Chapter 3*). However, studies often lack detailed descriptions of programme content. Without a thorough explanation of these components in the literature, there is a risk that our logic model may overlook key components essential for change, compromising its completeness. It would have been beneficial to consult an expert panel (e.g. developers of international programmes) to ask for additional information that may be lacking from the literature and why certain choices were made. Given the contextual variations in reablement programmes, understanding the factors influencing the selection of components and

outcomes is crucial. Insights into the underlying mechanisms could enhance the success of I-MANAGE. Understanding the link between causal mechanisms and how context affects their operationalisation and outcomes is important since causal mechanisms are always embedded in specific contexts and social processes, meaning that a programme does not necessarily work in every context, in every circumstance, for every individual.<sup>8,9</sup> The absence of robust evaluations assessing the effectiveness of reablement programmes prompts the question of whether the components integrated into our logic model – derived from existing literature – suffice to achieve the intended outcomes. A study on the effectiveness of I-MANAGE components is needed to understand which elements are essential, for whom, and their impact on older adults.

Furthermore, the scarcity of empirical evidence on reablement effectiveness raises the question of whether the identified outcomes – both in the literature and our logic model – are really the right outcomes to focus on.<sup>10</sup> Current research often focuses on physical functioning or service outcomes, whilst measures such as participation, engagement and well-being are more in line with the principles of reablement and the essential components identified in *Chapter 4*.<sup>10,11</sup> Therefore, in *Chapter 6* we included goal attainment as an outcome measure, which monitors outcomes that older adults themselves prioritise.<sup>12</sup>

### **Involving older adults and their informal caregivers**

In *Chapter 5* and *Chapter 6* we captured older adults' and family caregivers' experiences with community-based reablement. However, during the development of I-MANAGE (*Chapter 4*), our primary focus was the professional perspective of scientific experts, organisations, and care professionals; which is often the case in intervention design.<sup>13</sup> The perspective of older adults and their informal caregivers could only be given limited consideration. Yet, their involvement is crucial in health research and intervention development since it could enhance feasibility, efficacy, and effectiveness.<sup>2,14,15</sup> Though it is recommended, it remains challenging to involve them and to involve them in a correct way. We opted for individual interviews when capturing older adults' and family caregivers' experiences, as well as during the development process. However, these retrospective, one-off, in-depth interviews – while having provided us with valuable insights – present certain pitfalls. One notable limitation is the potential for recall bias, as participants may struggle to accurately remember and report events, experiences, or details from the past; which could compromise reliability of the

obtained data.<sup>16</sup> Another concern is the lack of ongoing engagement, as a single interview may not capture the evolving perspectives and experiences of participants.<sup>17</sup> In *Chapter 5* we attempted to interview participants twice in order to get a comprehensive view of their experience and possibly capture variations over time. Furthermore, the researcher's presence and the interview format itself can influence responses, potentially leading to social desirability bias or respondents providing what they perceive as expected answers.<sup>18</sup> To mitigate these pitfalls in the future, we should consider other methodologies that capture lived experiences and emotions in real time, during the interactions they have with the care service, and the influences of their social and physical environment, such as patient journey mapping.<sup>19</sup>

Furthermore, during the development, it would have been beneficial to involve clients and informal caregivers on an equal footing as professionals to increase success of the final product and adhere to the needs and wishes of both parties.<sup>2,14</sup> Rather than consulting them through individual interviews, involving them more actively is necessary in working group sessions, possibly together with professionals. However, this may also present itself with some challenges. For example, care staff – and other professionals – often have different priorities or views on what is important for the patient than the patients and their informal caregivers themselves, which may lead to divergent focuses during discussions.<sup>20,21</sup> Additionally, power dynamics and communication barriers (i.e. use of technical language) may lead to hesitancy among older adults or informal caregivers to express their opinions openly, as they may feel intimidated. The potential for groupthink poses a risk as participants may conform to prevailing opinions, limiting the diversity of ideas. Therefore, it is important to explore how active participation by all relevant stakeholders can be achieved and how all perspectives can be considered in a balanced manner.<sup>22</sup> Involving both perspectives requires a safe and receptive environment, space for creating trusting relationships, an open dialogue, and a 'reset' of power relationships.<sup>13,14,23</sup> This can be achieved by establishing ground rules that emphasise equal participation and mutual respect at the start of each session. Furthermore, it may be helpful to allow participants to provide feedback anonymously if they feel uncomfortable about sharing openly. Additionally, prompting participants to share diverse opinions and experiences may help to avoid groupthink. Lastly, to handle different perspectives, it could be helpful to set up a structured agenda of both patient-centred and professional-focused discussion topics.

### **Frontrunner organisations as research partners**

The research presented in this thesis was performed in collaboration with care organisations who were already acquainted with reablement rather than organisations unfamiliar with the concept. For example, the care organisation involved in the development of I-MANAGE (*Chapter 4*) was previously involved in research on a reablement training programme for home-care workers.<sup>24</sup> Furthermore, the organisations involved in *Chapter 7* are considered frontrunners in reablement,<sup>25</sup> since they were one of the first organisations in the Netherlands to start with the implementation and deployment of reablement in their daily practice. While the collaboration with frontrunners offers valuable insights, it introduces a potential source of selection bias.<sup>26</sup> By exclusively focusing on these frontrunners, we may have inadvertently overlooked the perspectives and challenges faced by organisations whose vision is not yet fully aligned with reablement principles. The discrepancy in vision among organisations, especially those less familiar with reablement, could mean that our findings might not adequately capture the barriers and facilitators to implementation in contexts where the concept is still gaining traction. Organisations less familiar with reablement may face unique barriers, including a lack of awareness and understanding, cultural resistance to change, resource constraints, and challenges in staff training and skill development.<sup>27</sup> Including a more diverse range of organisations in various stages of aligning their vision with reablement practices would provide a more comprehensive understanding of the challenges and opportunities associated with the implementation of reablement nationwide.

### **Choosing explorative and qualitative designs**

The research presented in this thesis mostly used an explorative and predominantly qualitative research design – for example, using a co-creation approach and literature research to investigate the essential components of reablement (*Chapter 2, 3 and 4*) or to explore the experiences of different user groups with reablement programmes (*Chapter 5, 6 and 7*). There is much uncertainty regarding the content of the programmes in the literature, so before conducting a large-scale trial, it is necessary to gain more insight into the hypothesized essential components, hence the logic model. While these methods provided rich insights into the experiences of different user groups and allowed for a nuanced understanding of reablement practices in a real-world setting, they also present limitations, especially in light of the scarcity of evidence regarding the effectiveness of reablement.<sup>28</sup>

However, more insights into effects of reablement programmes and their components is highly warranted.

One key critique is the absence of quantitative studies to complement our qualitative findings. This limitation hampers our ability to solidify the essential components of reablement we found and how they contribute to achieving desired outcomes, such as remaining to live at home and reducing health-care utilisation. Without quantitative data, we face a challenge in providing empirical evidence to support broader recommendations for further implementation of reablement. While exploration is essential for generating hypotheses and understanding complex phenomena, it also poses challenges in terms of establishing causal relationships and generalising findings beyond the studied context. Furthermore, when exploring the essential components of reablement, it would be helpful to identify which elements are effective for whom and under what circumstances in relation to the desired outcomes.<sup>9,29,30</sup> Understanding the underlying mechanisms is needed to guide well-informed decisions about further implementation of reablement both on a policy (e.g. what circumstances need to be created) and practice level (e.g. what implementation strategy and resources are needed).

## **Theoretical considerations**

### **The social environment as invaluable link**

The findings of this thesis emphasise that the social environment plays a crucial role in reablement, although, in current reablement practices, the focus primarily revolves around the client and the professional, overlooking the optimal utilisation of informal caregivers and the broader social network as valuable sources of support. These findings are in misalignment with the central principles of the 'convoys of care' model described by Kemp et al,<sup>31</sup> highlighting the pivotal role of the social environment in care processes and ageing in place.<sup>32</sup> In this model, convoys of care are defined as

*“the evolving collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring, and advocacy.”<sup>31</sup>*

As frequently highlighted throughout this thesis, the model highlights the importance of good collaboration between formal and informal care, which relies on negotiations to determine



roles, expectations, and preferences.<sup>31</sup> This may present as challenging since everyone involved in these convoys has different perspectives and expectations<sup>20</sup> regarding the appropriate course of care, decision-making authority, and the division of responsibilities.<sup>33,34</sup> Furthermore, not all convoy members have equal power; it would be assumed that clients have the most power, however they are often dependent on others for care and are vulnerable.<sup>31</sup> This power differential may contribute to tensions, potentially impacting the quality of communication and collaboration.<sup>35</sup> However, the social network may possess unique insight into the older adult's preferences and context, which may present a valuable contribution alongside care professionals' clinical expertise. Therefore, the underutilisation of the social environment in reablement can be considered a missed opportunity to make use of the full potential of the convoy, and consequently hindering the reablement process. Investing in care convoy structures, functions, and adequacy may positively influence outcomes for care recipients (e.g. sense of self, well-being, ability to age in place), informal caregivers (e.g. sense of fulfilling responsibility, level of care burden), and formal caregivers (e.g. job satisfaction).<sup>31,32</sup> Furthermore, integrating the social environment into a care convoy calls for a shift within health-care systems to actively involve and recognise them. This shift involves acknowledging their expertise, valuing their contributions, and integrating them into decision-making processes throughout the reablement journey.

### **From novelty to routine**

This thesis demonstrated a discrepancy between the perception of management and care staff regarding the adoption of reablement principles. Furthermore, our findings highlighted that care organisations and professionals often believe they are already applying the principles of reablement into their everyday practices, while in reality they are not. This discrepancy aligns with the Theory of Planned Behaviour in understanding the intentions and actions of care providers. The Theory of Planned Behaviour states that a person's intention for a certain behaviour is shaped by three attributes: attitude; subjective norms; and perceived behavioural control.<sup>36</sup> While there appears to be a positive attitude of care organisations and professionals towards reablement, the observed reality indicates a gap between attitudes and actions, or between intentions and actual performed behaviour. The results of this thesis underscore that this change does not happen overnight. After all, the Theory of Planned Behaviour states that the intention to perform a certain behaviour is not equal to the actual performance.<sup>36,37</sup> The gap between intentional and actual behaviour

indicates the presence of barriers to the implementation of reablement. For instance, our findings suggest that perceived behavioural control may be overestimated, potentially due to organisational constraints or lack of resources.<sup>36-38</sup> These insights highlight the importance of addressing barriers to effective implementation of reablement within care settings. Moreover, the disparity in perception between management and care staff underscores the influence of subjective norms and social pressures within organizational contexts.<sup>36-38</sup> Our findings also highlight that recognizing these influences is crucial for developing targeted interventions and policies that foster a more consistent and effective application of reablement principles in practice. In essence, bridging the gap between attitudes and actions necessitates a comprehensive approach that addresses organizational culture, resource allocation, and staff training to promote genuine integration of reablement principles into everyday care practices.

Our findings resonate with both the 'Diffusion of Innovations Theory' and the 'Transtheoretical Model of Change', providing valuable insights into the dissemination and adoption of innovative practices within home care settings. The Diffusion of Innovations Theory explains the complexities involved in the spread of new innovations within society over time, categorising individuals into distinct adopter categories based on their readiness for change: innovators; early adopters; early majority; late majority; and laggards.<sup>27</sup> Reablement can be seen as an innovative approach to home care and a potential solution to longstanding challenges in the field.<sup>39-41</sup> However, the results of this thesis found that its adoption may face several challenges as it navigates through the different stages of the diffusion curve. Despite the presence of champions and early adopters among managers and certain care staff, the transition to widespread acceptance is gradual and comes with barriers – including resistance, lack of perceived relative advantage, or organisational constraints as highlighted throughout this thesis. These barriers mirror the stages individuals undergo when contemplating and enacting behavioural changes outlined in the Transtheoretical Model of Change (i.e. precontemplation, contemplation, preparation, action, maintenance, and termination).<sup>42,43</sup> This underscores the interplay between individual readiness for change and organisational dynamics, shedding light on the challenges impeding the seamless integration of reablement into routine home care practices. Moreover, the diffusion process is influenced by various factors, including the characteristics of the innovation, the adopter, the social system, communication channels, and the perceived attributes of the innovation itself.<sup>27,44</sup> These factors were also presented throughout the findings of this thesis when reflecting on the implementation of reablement, emphasising the essence of addressing these factors to

foster widespread acceptance and integration of reablement into routine care practices. For example, effective communication, supportive organisational structures, and recognition of varying attitudes towards reablement and its core principles were often stated essential for promoting successful adoption of reablement principles across care organisations.

## Future directions

Despite the lack of conclusive evidence on long-term effects, the positive and promising experiences reported during our research have served as a catalyst for both policy and practice decisions regarding the further exploration and implementation of reablement in the Netherlands.<sup>25,45</sup> Therefore, with this thesis we also aimed to provide guidance on how to proceed with the monitoring and simultaneous implementation of reablement by forming clear implications for future research, practice, policy and education.

## Research

The research presented in this thesis provides insight into key components of reablement. Understanding the specific elements that potentially make reablement successful is essential for optimising care practices, considering the large differences regarding settings and populations.<sup>46</sup> While there is no stopping in the further spread of reablement in the Netherlands, conclusive evidence for the effectiveness of reablement programmes is still lacking, certainly, in the long-term.<sup>28</sup> It is needed to conduct robust trials with long follow-up periods evaluating the effectiveness of reablement interventions. Insights into the effectiveness of components and impact of reablement on both staff, older adult and informal caregiver levels, as well as on the organisational level (e.g. health-care costs) would be of added value for future practice and policy.

Additionally, future research should prioritise a more thorough examination of appropriate outcome measures. It is necessary to look into less generic outcome measures, which reflect the purpose of reablement and are able to measure variations regarding well-being and participation in meaningful daily and social activities.<sup>47</sup> Furthermore, previous research does not focus on *how* reablement works. Nonetheless, it is plausible – given its diverse and tailor-made nature and the mixed results – that how reablement is designed, for whom, and under what circumstances, has a large impact on the outcomes achieved.<sup>48,49</sup> Only by linking

outcomes to insights into how it works and what contextual and personal influences play a role can well-informed decisions about successful implementation and dissemination of reablement be made, both on a policy (e.g. what circumstances need to be created) and practice level (e.g. what implementation strategy and resources are needed).

Moreover, the findings of this thesis underscore the importance of the social environment within reablement. Currently, reablement is focused on the client and the professional. Recognising the pivotal role of the social environment offers an opportunity for researchers to delve deeper into the role and optimal utilisation of the social environment and to integrate this more intentionally into reablement programmes. By doing so, there is potential to enhance the effectiveness of reablement interventions, fostering a more comprehensive and holistic approach that takes into account the dynamic interplay between individuals and their social surroundings.<sup>50-52</sup>

## **Practice**

This thesis clearly highlighted the importance of the involvement of and support for informal caregivers in the reablement care and support process of their relatives. When implementing reablement in practice, it is highly recommended to actively involve and support informal caregivers as integral partners in the care process.<sup>50,51</sup> Care professionals need to recognise the essential role informal caregivers play in the well-being of their relatives.<sup>52</sup> Additionally, care professionals should foster a collaborative, supportive, and trusting relationship with informal caregivers, encouraging open communication, and addressing any concerns or questions they may have.<sup>50,51</sup> Nevertheless, care professionals should maintain a healthy balance between involving and supporting informal caregivers in a way that matches their needs and does not add to their experienced burden.<sup>53,54</sup>

Second, the findings of this thesis emphasise the role of organisations and management in implementing and sustaining the reablement philosophy within organisations. Organisations should invest in a culture that embraces innovation – for example, through encouraging continuous learning and risk taking. Organisations should provide sufficient training opportunities for their staff to create a change in mindset (i.e. ‘doing with ...’ rather than ‘doing for ...’)<sup>55,56</sup> – for example, by stimulating coaching on the job and offering training programmes. However, previous research has shown that training home-care workers in the philosophy of reablement alone has been insufficient to create a change in staff’s behaviour

and improved outcomes,<sup>57-59</sup> indicating that there was a need for a more structured and defined approach – for example, clear roles and responsibilities and working with a structured implementation plan – to integrate the philosophy into practice.<sup>24</sup> Therefore, organisational leaders and board members should articulate a clear strategic vision, embracing reablement principles.<sup>60</sup> This should be communicated effectively throughout the organisation and become embedded in the organisational structure, while emphasising the importance of adopting this new, innovative way of providing care.<sup>61</sup> This will support care professionals to change their everyday routines, however, it is also important to translate this vision into practice and give tools to employees by making the strategy concrete (e.g. through an intervention programme). Ultimately, care needs to be organised and delivered differently, and staff need to be supported and trained in delivering these alternative ways of working.

## **Policy**

This thesis highlights that current funding models are perceived as a barrier for successful implementation, hindering the immediate effectiveness of reablement and the long-term perspectives of organisations.<sup>62</sup> Given these challenges, it is suggested that policymakers reconsider current funding models, dedicating resources to support the implementation of reablement programmes. By restructuring funding models to align with the core values of reablement, it becomes possible to foster interdisciplinary collaboration among care professionals (e.g. through integral funding) and to provide adequate support for informal caregivers.<sup>46</sup> Alternatively, by considering a shift from fee-for-service to case-mix funding, which provides the right incentives adhere to a preventive approach to care provision and promote independence.<sup>63</sup> Furthermore, considering client characteristics (e.g. social network and ADL independence) in allocating funding, can not only enhance the well-being and quality of life for older adults but also potentially lead to a reduction in health-care utilisation and related costs.<sup>64-67</sup>

## **Education**

In preparing care professionals of the future or professionals wishing to further develop their knowledge and skills, it is highly recommended to integrate reablement principles into health-care educational curricula (e.g. occupational therapy, physiotherapy, nursing, and health sciences). This thesis highlights that reablement is a new approach to delivering care, focusing

on appropriate care in line with the person's abilities and wishes. Therefore, it is important that (future) care professionals are trained in and made aware of this new approach to care. It is recommended to use hand-on, practical teaching methods for this, providing practical experiences and simulations to enhance proficiency in applying reablement principles in real-world cases, or through coaching on the job. These real-world cases are also an approach to emphasise interdisciplinary training, ensuring that students learn from and appreciate each other's professional expertise. Changing the perspective of (future) care professionals from 'doing for...' towards 'doing with...' may also require a different set of skills. Education should therefore focus on developing adequate communication and motivational skills tailored to interacting with older adults, informal caregivers, and fellow professionals. By embedding these principles into the education of care professionals, we can better equip them with the necessary skills to embrace and implement reablement practices, ultimately fostering professionals who will be trained to provide person-centred and holistic care.

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# Addenda

Summary

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Impact

Dankwoord

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Living Lab in Ageing and Long-Term Care



# Summary

The concept of ‘ageing in place’ is becoming increasingly popular, both in policy and research. This is defined as enabling older adults to remain living at home independently for as long as possible. To successfully age in place, sustainable initiatives are needed. One of these initiatives is reablement, a person-centred, holistic approach that promotes older adults’ active participation in daily activities through social, leisure, and physical activities chosen by the older adult in line with their preferences. Reablement is attracting growing interest worldwide, as well as in the Netherlands, and was therefore, the focus of this thesis. The aim of this thesis was to study its essential components, as well as the experiences of professionals, clients, and family caregivers with reablement, to inform and advance reablement programmes and their future implementation. The research presented in this thesis is part of the European Union’s Horizon 2020 TRANS-SENIOR research and innovation programme, focusing on avoiding unnecessary care transitions and optimising care transitions that are actually needed.

**Chapter 1** provides insight into the challenges associated with ageing and the ageing population. Following these challenges, the chapter highlights the importance of ageing in place and that home is more than just a physical space to older adults, it is also about autonomy, meaningfulness, and social connections. Furthermore, the chapter sheds light on the principles, current evidence, and international evolution of reablement. To conclude, the chapter describes reablement as a complex intervention and highlights the current research gaps that will be addressed in this thesis.

**Chapter 2** presents a literature review on the evolution of models describing disability and elaborates on their causal mechanisms. Ageing with a disability increases the risk of hospitalisation and nursing home admission. Ageing in place interventions aiming to reduce disability, such as reablement programmes, are often not sufficiently effective and inadequately theory-based. Overall, 29 publications were included in the final sample. All described models arisen from three original models and could be divided into two types: linear models and models on the interaction between the person and the environment. Results indicated that disability is not a static concept but a dynamic and interactive process that may fluctuate over a life course. Disability is not seen as an end stage and might be reversible when receiving the right support. Moreover, it is important to view disability from a social and integrated perspective, which reflects the individual as part of an environmental context or community. Obtaining an optimal fit between the individual and their environment is key to functioning adequately in this environment and can contribute to the individual’s wellbeing.



Lastly, the focus is more on health and functioning, rather than disability. Not only does this emphasise what an individual is able to do, it also reflects the opportunity to focus on what they would like to do in their own social and physical environment. When aiming to support the individual to age in place, it is necessary to consider their capabilities and emphasise these, rather than only focusing on their limitations in daily life.

In **Chapter 3**, a second literature review is presented, which aims to gain insight into the content (e.g. target group, duration, goal setting, etc.) and effectiveness of international reablement programmes. Thirteen programmes were identified, originating from six countries. All programmes were intended for (I)ADL-impaired community-dwelling older adults. Several common features were identified throughout the different programmes, such as delivery by a trained and coordinated multidisciplinary team and implementation of an intake assessment and goal-setting tool. Furthermore, the main interventions applied in order to reach older adults' personal goals focused on supporting (I)ADL and physical functioning, and improving home safety. Of the 13 programmes included, five showed a statistically significant improvement in (I)ADL functioning, two in physical functioning, three in quality of life of the older adult, and three showed a statistically significant decrease in health-care utilisation. To conclude, reablement programmes have the potential to improve health-related quality of life and reduce health-care utilisation. Therefore, the input of these international programmes in terms of content and common features can be used for the development of future interventions, based on the principles of reablement, although contextual differences should be considered because there is no indication that they would necessarily be effective in their current format elsewhere.

**Chapter 4** presents the development and content of the I-MANAGE model. The model was developed using a co-creation design, including literature research, observations, individual interviews, and working group sessions involving care professionals, policymakers, clients, informal caregivers, and scientific experts. I-MANAGE is a reablement programme for community-dwelling older adults to improve their self-management and participation in daily life, while also increasing quality of life and decreasing informal caregivers' burden. The programme consists of six components: 1) improving assessment and goal setting; 2) stimulating self-management during meaningful daily activities; 3) optimising the use of the physical environment; 4) optimising the use of the social environment; 5) improving interprofessional collaboration; and 6) supporting the informal caregiver. These components

are translated into a 5-phase care process, which also includes a practice-oriented training. The programme may serve as a model for use in different local settings and leaves room for tailoring to the specific needs and resources of organisations.

In **Chapter 5**, a qualitative study provides insight into the perceived support and involvement of family caregivers in a setting applying the principles of reablement (i.e. goal setting, interdisciplinary team), and explored how this support and involvement can be optimised in their opinion. In total, nine family caregivers were interviewed, of whom five were interviewed twice to gain a comprehensive view of their experience over time. Family caregivers' experiences with support from care professionals were often ambivalent, expressing a lack of support and information whilst also indicating that they do not expect to be supported by care professionals. There was a need for more guidance and better communication and information. Additionally, a trusting relationship between the family caregiver and care professionals is essential. Family caregivers want to be involved, i.e. they want to be able to express their opinion and to be involved in decision-making. However, it is important to be cautious because more involvement might also lead to a higher burden. Lastly, family caregivers seldom ask for or accept help either from their social network or from professionals, meaning a proactive and tailor-made personal approach with enough room to participate in the care process is preferred.

**Chapter 6** presents the evaluation of the 'Longer Vital at Home' programme, which is based on the I-MANAGE model. The aim was to investigate the overall experiences of clients regarding reablement, and more specifically how they perceived goal setting and goal attainment in relationship to the effect of reablement on their self-assessed performance and satisfaction of valued activities in everyday life. A convergent mixed methods design was used, combining individual interviews with data from electronic care files and completed Canadian Occupational Performance Measure (COPM) forms. In total, 17 clients participated. The personal goals set by clients mainly focused on self-care, rather than leisure or productivity. These goals often precede fundamental life goals and being able to perform these activities contributes to their independence and consequently to their confidence and perseverance. Regarding goal attainment, a statistically significant and clinically relevant increase in self-perceived performance and satisfaction scores were observed. This chapter highlights that reablement can positively contribute to increased independence by focusing on setting and attaining personal, meaningful goals.

In **Chapter 7**, a qualitative study investigates how professionals (i.e. operational, strategic, and organisational) experience the implementation of reablement in community care. The experiences of professionals were obtained using focus group interviews involving 32 participants in total. The results reflected three main themes. First, interdisciplinary collaboration was experienced as a strength and facilitator of the implementation. It enhances the understanding of each other's roles and creates a sense of shared ownership. When there is a lack of mutual beliefs, this may hinder the deployment of reablement into community care. Second, the success of the implementation depends on the integration and upkeep of the reablement philosophy throughout all the professionals involved, in which management plays a pivotal role. For example, through effective and continuous communication and providing time, space, and resources. Last, in order to effectively implement reablement in community care, a cultural change is needed within the health-care system. This emphasises that current funding and reimbursement schemes impede the desired deployment of reablement principles – for example, they do not facilitate goal-oriented, holistic, and person-centred home care – as well as interdisciplinary collaboration.

To conclude, **Chapter 8** summarises the main findings of all studies included in this thesis, followed by methodological and theoretical considerations. Regarding the methodological considerations, the chapter reflects on the importance of a logic model for complex interventions and how this is developed. Second, it reflects on the inclusion of older adults and informal caregivers in development and evaluation research. The third methodological consideration provides insight into the inclusion of frontrunner organisations as research partners and the risk of selection bias. The last methodological consideration reflects on the predominantly explorative and qualitative nature of our research. With regard to the theoretical considerations, the chapter sheds light on the invaluable role of the informal caregiver within reablement, as well as the integration of reablement, a new and innovative approach, into daily practice and routines. Furthermore, the chapter presents several implications for future research, practice, policy, and education.



# Samenvatting

Het concept 'thuis ouder worden' wordt steeds populairder, zowel in beleid als in onderzoek. Hiermee wordt bedoeld dat ouderen zo lang mogelijk zelfstandig thuis kunnen blijven wonen. Om succesvol thuis ouder te worden, zijn duurzame initiatieven nodig. Eén van deze initiatieven is reablement, een persoonsgerichte, holistische benadering die de deelname van ouderen aan dagelijkse activiteiten bevordert door middel van sociale, vrijetijds- en fysieke activiteiten die door de ouderen worden gekozen in lijn met zijn of haar voorkeuren. Reablement staat wereldwijd, maar ook in Nederland, steeds meer in de belangstelling en was daarom de focus van dit proefschrift. Het doel van dit proefschrift was om de essentiële componenten ervan te bestuderen, evenals de ervaringen van professionals, cliënten en mantelzorgers met reablement, om zo de reablement programma's en hun toekomstige implementatie te informeren en te bevorderen. Het onderzoek in dit proefschrift maakt deel uit van het Horizon 2020 onderzoeks- en innovatieprogramma TRANS-SENIOR van de Europese Unie, dat zich richt op het vermijden van onnodige zorgtransities en het optimaliseren van zorgtransities die daadwerkelijk nodig zijn.

**Hoofdstuk 1** geeft inzicht in de uitdagingen die gepaard gaan met het ouder worden en de vergrijzing. Vervolgens belicht het hoofdstuk het belang van thuis ouder worden en dat een thuis voor ouderen meer is dan alleen een fysieke plaats; het gaat ook over autonomie, zingeving en sociale connecties. Verder gaat het hoofdstuk in op de principes, het huidige bewijs en de internationale evolutie van reablement. Tot slot, beschrijft het hoofdstuk reablement als een complexe interventie en benadrukt het de huidige hiaten in het onderzoek die in dit proefschrift aan bod zullen komen.

**Hoofdstuk 2** geeft een literatuuroverzicht over de evolutie van modellen die beperkingen beschrijven en gaat dieper in op hun oorzakelijke mechanismen. Ouder worden met een beperking verhoogt het risico op ziekenhuisopname en opname in een verpleeghuis. Interventies die gericht zijn op het verminderen van beperkingen, zoals reablement programma's, zijn vaak niet effectief genoeg en onvoldoende theoretisch onderbouwd. In totaal werden 29 publicaties opgenomen in de uiteindelijke selectie. Alle beschreven modellen kwamen voort uit drie oorspronkelijke modellen en konden worden onderverdeeld in twee soorten: lineaire modellen en modellen over de interactie tussen de persoon en de omgeving. De resultaten gaven aan dat invaliditeit of het hebben van een beperking geen statisch concept is, maar een dynamisch en interactief proces dat kan fluctueren gedurende de levensloop. Beperkingen worden niet gezien als een eindstadium en kunnen omkeerbaar zijn als mensen

de juiste ondersteuning krijgen. Bovendien is het belangrijk om beperkingen te bekijken vanuit een sociaal en geïntegreerd perspectief, dat het individu weerspiegelt als deel van een omgeving of gemeenschap. Het bereiken van een optimale fit tussen het individu en zijn omgeving is de sleutel tot adequaat functioneren in deze omgeving en kan bijdragen tot het welzijn van het individu. Tot slot, ligt de nadruk meer op gezondheid en functioneren dan op beperkingen. Dit legt niet alleen de nadruk op wat iemand wel kan, maar geeft ook de mogelijkheid om te focussen op wat iemand zou willen doen in zijn eigen sociale en fysieke omgeving. Wanneer we iemand willen ondersteunen om ouder te worden, moeten we rekening houden met zijn of haar mogelijkheden en deze benadrukken, in plaats van ons alleen te richten op zijn of haar beperkingen in het dagelijks leven.

In **Hoofdstuk 3** wordt een tweede literatuurstudie gepresenteerd, met als doel inzicht te krijgen in de inhoud (bijv. doelgroep, duur, doelen stellen, etc.) en effectiviteit van internationale reablement programma's. Er werden dertien programma's geïdentificeerd, afkomstig uit zes landen. Alle programma's waren bedoeld voor thuiswonende ouderen met een beperkte (I)ADL-zelfstandigheid. De verschillende programma's hadden een aantal gemeenschappelijke kenmerken, zoals de uitvoering door een getraind en gecoördineerd multidisciplinair team en de implementatie van een instrument voor de intake en het stellen van doelen. Verder waren de belangrijkste interventies die werden toegepast om de persoonlijke doelen van ouderen te bereiken gericht op het ondersteunen van (I)ADL en fysiek functioneren en het verbeteren van de veiligheid in en rond huis. Van de 13 geïnccludeerde programma's toonden vijf een statistisch significante verbetering in (I)ADL functioneren, twee in fysiek functioneren, drie in kwaliteit van leven van de oudere, en drie toonden een statistisch significante afname in zorggebruik. Concluderend, reablement programma's hebben het potentieel om de kwaliteit van leven te verbeteren en het gebruik van gezondheidszorg te verminderen. De kennis van deze internationale programma's wat betreft de inhoud en gemeenschappelijke kenmerken kan daarom worden gebruikt voor de ontwikkeling van toekomstige interventies, gebaseerd op de principes van reablement, hoewel er ook rekening moet worden gehouden met contextuele verschillen omdat er geen aanwijzingen zijn dat ze in hun huidige vorm ook elders effectief zouden zijn.

**Hoofdstuk 4** beschrijft de ontwikkeling en inhoud van het I-MANAGE model. Het model is ontwikkeld door middel van co-creatie, inclusief literatuuronderzoek, observaties, individuele interviews en werkgroepsessies met zorgprofessionals, beleidsmakers, cliënten, mantelzorgers

en wetenschappelijke experts. I-MANAGE is een reablement programma voor thuiswonende ouderen om hun zelfmanagement en participatie in het dagelijks leven te verbeteren, en tegelijkertijd de kwaliteit van leven te verhogen en de belasting voor mantelzorgers te verminderen. Het programma bestaat uit zes onderdelen: 1) het verbeteren van de intake en het stellen van doelen; 2) het stimuleren van zelfmanagement tijdens zinvolle dagelijkse activiteiten; 3) het optimaliseren van het gebruik van de fysieke omgeving; 4) het optimaliseren van het gebruik van de sociale omgeving; 5) het verbeteren van de interprofessionele samenwerking; en 6) het ondersteunen van de mantelzorger. Deze componenten werden vertaald in een zorgproces van 5 fasen, inclusief praktijkgerichte training. Het programma kan dienen als model voor gebruik in verschillende lokale settings en laat ruimte voor aanpassing naargelang de specifieke behoeften en middelen van organisaties.

In **Hoofdstuk 5** geeft een kwalitatieve studie inzicht in de ervaren ondersteuning en betrokkenheid van mantelzorgers in een setting die de principes van reablement toepast (d.w.z. doelen stellen, interdisciplinair team) en hoe deze ondersteuning en betrokkenheid volgens hen verbeterd kan worden. In totaal werden negen mantelzorgers geïnterviewd, waarvan vijf twee keer om een volledig beeld te krijgen van hun ervaringen in de loop van de tijd. De ervaringen van mantelzorgers met ondersteuning door zorgprofessionals waren vaak ambivalent, waarbij ze aangaven een gebrek aan ondersteuning en informatie te hebben, maar ook dat ze niet verwachtten door zorgprofessionals ondersteund te worden. Er is behoefte aan meer begeleiding en betere communicatie en informatie. Daarnaast is een vertrouwensrelatie tussen de mantelzorger en de zorgprofessionals essentieel. Mantelzorgers willen betrokken worden; ze willen hun mening kunnen geven en betrokken worden bij de besluitvorming. Het is echter belangrijk om voorzichtig te zijn omdat meer betrokkenheid ook tot een hogere belasting kan leiden. Ten slotte vragen of accepteren mantelzorgers zelden hulp van hun sociale netwerk of van professionals, wat betekent dat een proactieve en op maat gemaakte persoonlijke benadering met voldoende ruimte om te participeren in het zorgproces de voorkeur heeft.

**Hoofdstuk 6** presenteert de evaluatie van het programma 'Langer Vitaal Thuis', dat gebaseerd is op het I-MANAGE model. Het doel was om de ervaringen van cliënten met betrekking tot reablement te onderzoeken, en meer specifiek hoe zij het stellen van doelen en het bereiken van doelen zagen in relatie tot het effect van reablement op hun zelf-ingeschatte uitvoering en tevredenheid met betrekking tot betekenisvolle activiteiten in het dagelijks leven. Er werd een



convergent mixed methods design gebruikt, waarbij individuele interviews gecombineerd werden met gegevens uit elektronische zorgdossiers en ingevulde Canadian Occupational Performance Measure (COPM) formulieren. In totaal namen 17 cliënten deel. De persoonlijke doelen die cliënten stelden, waren vooral gericht op zelfzorg en niet zozeer op vrije tijd of productiviteit. Deze doelen gaan vaak vooraf aan fundamentele levensdoelen en het kunnen uitvoeren van deze activiteiten draagt bij aan hun onafhankelijkheid en daarmee aan hun zelfvertrouwen en doorzettingsvermogen. Met betrekking tot het bereiken van doelen werd een statistisch significante en klinisch relevante toename in hun zelf-ingeschatte uitvoerings- en tevredenheidsscores waargenomen. Dit hoofdstuk benadrukt dat reablement positief kan bijdragen aan een grotere onafhankelijkheid door zich te richten op het stellen en bereiken van persoonlijke, zinvolle doelen.

In **Hoofdstuk 7** onderzoekt een kwalitatieve studie hoe professionals (d.w.z. operationeel, strategisch en organisatorisch) de implementatie van reablement in de eerstelijnszorg ervaren. De ervaringen van professionals werden verzameld door middel van focusgroep interviews met in totaal 32 deelnemers. De resultaten gaven drie hoofdthema's weer. Ten eerste werd interdisciplinaire samenwerking ervaren als een sterkte van reablement en facilitator voor de implementatie. Het vergroot het begrip van elkaars rollen en creëert een gevoel van gedeeld eigenaarschap. Wanneer er een gebrek is aan wederzijdse overtuiging, kan dit de implementatie van reablement in de eerstelijnszorg belemmeren. Ten tweede hangt het succes van de implementatie af van de integratie en borging van de reablement filosofie door alle betrokken professionals, waarbij het management een centrale rol speelt. Bijvoorbeeld door effectieve en voortdurende communicatie en het bieden van tijd, ruimte en middelen. Ten slotte is er, om reablement effectief te implementeren in de eerstelijnszorg, een cultuuromslag nodig binnen het gezondheidszorgsysteem. Dit benadrukt dat de huidige financierings- en vergoedingsregelingen de gewenste toepassing van reablement principes belemmeren – ze faciliteren bijvoorbeeld geen doelgerichte, holistische en persoonsgerichte thuiszorg – en interdisciplinaire samenwerking.

Tot slot worden in **Hoofdstuk 8** de belangrijkste bevindingen van alle in dit proefschrift opgenomen studies samengevat, gevolgd door methodologische en theoretische overwegingen. Wat betreft de methodologische overwegingen, reflecteert het hoofdstuk op het belang van een logic model voor complexe interventies en hoe dit ontwikkeld wordt. Ten tweede wordt stilgestaan bij het betrekken van ouderen en mantelzorgers bij ontwikkelings- en evaluatieonderzoek. De derde methodologische overweging geeft inzicht in het betrekken

van koploperorganisaties als onderzoekspartners en het risico van selectiebias. De laatste methodologische overweging reflecteert op de overwegend exploratieve en kwalitatieve aard van ons onderzoek. Met betrekking tot de theoretische overwegingen gaat het hoofdstuk in op de onmisbare rol van de mantelzorger binnen reablement, evenals de integratie van reablement – een nieuwe en innovatieve benadering – in de dagelijkse praktijk en dagelijkse routines. Verder presenteert het hoofdstuk verschillende implicaties voor toekomstig onderzoek, praktijk, beleid en onderwijs.





Impact

The studies presented in this thesis provide valuable insights into the essential components of reablement (e.g. **Chapters 2, 3, and 4**). Furthermore, **Chapters 5, 6, and 7** shed light on the experiences of family caregivers, older adults and professionals with receiving, delivering and implementing community-based reablement. This chapter reflects on the societal and scientific impact of these findings, as well as how they have been or will be disseminated to a broader audience.

## **Societal impact**

### **Practice**

Reablement is often cited in policy documents as a solution for the increasing pressure on the health-care system.<sup>1-3</sup> However, guidance on what reablement should entail and how it can be embedded into daily care practices was lacking.<sup>4-7</sup> This thesis highlights several important aspects for (future) reablement initiatives. It is imperative that these initiatives prioritise the optimal utilisation of both the physical and social environment of older adults. For example, by considering the physical and social environment as tools to achieve older adults' individual goals. Furthermore, investing in interdisciplinary collaboration, transcending care and welfare boundaries, is identified as a key factor in reablement. This enhances the understanding of each other's roles and creates a sense of shared ownership. As a result, care professionals in practice have been made aware of their own role and contribution within reablement services. This means, that these roles and mutual expectations are regularly discussed in practice – for example, during team meetings. Additionally, recognising the pivotal role of informal caregivers is crucial, highlighting the need for initiatives to provide substantial and tailored support, such as trainings or educational material.

These findings were shared with the involved care organisations through summaries of the results and by giving presentations during project groups or board meetings. Furthermore, these new insights were shared through workshops and other types of presentations – for example, at the 'Zoek het Uit!'-conference organised by Vilans,<sup>8</sup> the 'Senioren Sterker Maken' end symposium, and the Reablement symposium organised by the Living Lab in Ageing and Long-Term Care.<sup>9</sup> These were aimed at aiding care professionals, managers, and policymakers in launching their reablement programmes. We are often asked for advice by (care) organisations who are interested in implementing reablement themselves. Consequently, several Dutch care organisations have based their own reablement initiatives on the I-MANAGE

model. These care organisations have been considered frontrunners in reablement,<sup>10</sup> since they were one of the first in the Netherlands to start the implementation and deployment of reablement in their daily practice. Additionally, one of the reablement programmes evaluated in this thesis was mentioned in '*Nieuwsuur*' (2nd September 2023) as a best practice example. Furthermore, this research was embedded in the Living Lab in Ageing and Long-Term Care, which frequently shared new findings of activities related to this research through their communication channels – for example, by including it in the yearly report of the Living Lab in Ageing and Long-Term Care, highlighting the involvement of practice throughout the trajectory, as an example of transdisciplinary collaboration. Lastly, our findings shaped a new government-funded programme focusing on collecting, developing and sharing new knowledge and experiences of reablement.<sup>11</sup> The programme builds on the research presented in this thesis, and aims to facilitate and stimulate local initiatives concerning reablement. A community of practice (CoP) is set up through which our acquired knowledge and insights are shared.<sup>11</sup> Our findings and the products that have emerged from them nourish this CoP, thus creating a solid foundation for new organisations to implement reablement in their daily practices. Additionally, organisations can share their own experiences here, learn from each other, and subsequently build upon them in practice.

## Policy

The findings of this thesis contribute to the current ongoing growing interest in reablement and the ongoing debate about its place in the Dutch health-care system.<sup>1-3,10</sup> The Integral Care Agreement (*Integraal Zorg Akkoord*, in Dutch) aims for appropriate care and support, together with the client, in the right place, and with an emphasis on health rather than disease.<sup>12</sup> In light of this agreement, our findings showed the added value of reablement in achieving these aims toward more appropriate care. It emphasised the importance of interdisciplinary collaboration transcending care and welfare initiatives, but also including and supporting the social environment. Furthermore, the value-driven, person-centred approach of reablement was highly appreciated by all users and contributes to the focus on health rather than disease.

Our findings contributed to the national debate on integral funding of care services such as reablement. Several policy agreements (i.e. *Integraal Zorg Akkoord* (IZA),<sup>12</sup> *Gezond en Actief Leven Akkoord* (GALA),<sup>13</sup> *Wonen, Ondersteuning en Zorg voor Ouderen* (WOZO)<sup>3</sup>) advocate a preventive approach to care that encourages self-reliance and transdisciplinary collaboration –

all aspects that have been highlighted throughout this thesis as strengths of reablement. This thesis highlighted that current funding models impede the desired deployment of reablement when it comes to these aspects. As a result, conversations are currently taking place among organisations applying reablement, health insurers and the Dutch Healthcare Authority (NZA) to find a solution together.

Reablement is gaining interest, not only in the Netherlands, but also worldwide. The results of this thesis are shared within the international ReAble network.<sup>14</sup> As this thesis is embedded in the European TRANS-SENIOR research and training network,<sup>15</sup> the results are also being shared with international partners, which have a large impact in shaping future health-care policy (e.g. World Health Organization, AGE-platform). The findings and implications of this thesis were also mentioned as policy recommendations in a recent policy brief written by the TRANS-SENIOR consortium.<sup>16</sup> The policy brief advocates dedicating funding for further research on client-, family- and organisation-level outcomes of reablement and into the working mechanisms.<sup>16</sup> Additionally, it recommends prioritising funding for future implementation of reablement as part of policies efforts to address the growing pressure on financial and workforce resources in long-term care.<sup>16</sup>

## **Education**

Making sure reablement will be embedded in community care in the future starts with the education of future care professionals or professionals wishing to further develop their knowledge and skills. Incorporating the findings of this thesis (e.g. I-MANAGE model and the experiences of all target groups) into health-care education curricula (e.g. occupational therapy, physiotherapy, nursing, health sciences, etc.) will equip health-care providers and policymakers with the latest evidence-based practices. Reablement is already a topic in the bachelor Health Sciences at Maastricht University (e.g. as a case in problem-based learning), therefore these new insights can be easily integrated. Additionally, reablement has been the topic of several bachelor (i.e. Health Sciences) and master (i.e. Health Policy, Innovation and Management) theses over the past years. Furthermore, this research was embedded in the Living Lab in Ageing and Long-Term Care,<sup>17,18</sup> which also includes three educational institutes through which these new insights may be included into curricula of future health-care providers. Currently, conversations are ongoing with Zuyd University of Applied Sciences for a post-HBO course (higher professional education). Furthermore, there is also interest in our



findings to be integrated into vocational education and training programmes (*Gilde Zorgcollege* and *Vista college*) – for example, for (certified) nursing assistants.

## Scientific impact

The findings presented in this thesis contribute to several underexplored topics with regard to reablement research. It sheds light on the evolution of the concept of disability and its causal mechanisms (**Chapter 2**), the essential components of reablement based on literature research (**Chapter 3**), and co-creation with practice (**Chapter 4**). As a result, a theory-based model was created, serving as a foundation for (future) reablement initiatives to build upon. Furthermore, the gathered experiences from family caregivers, older adults and professionals (**Chapters 5, 6 and 7**) provide insight into the possible outcomes of reablement and guide new research opportunities to further explore these – for example, a larger robust evaluation of reablement in terms of (cost-)effectiveness and long-term effects on client-, family caregiver-, and organisation-level outcomes, or an investigation into the added value of reablement compared to other (innovative) care approaches. The above-mentioned government-funded programme allows us to build upon the findings presented in this thesis and explore these new enquiries in collaboration with practice. These findings have been disseminated through various scientific channels. All studies were published in international, peer-reviewed, high-impact, open-access journals, such as *BMJ Open* and the *Journal of Multidisciplinary Healthcare*. Additionally, the TRANS-SENIOR website hosts all published articles of this thesis, as well as a YouTube video summarising the overall project.<sup>15</sup> Furthermore, the findings of several studies were presented at (inter-)national conferences, including the Nordic Congress of Gerontology (Denmark), the Gerontological Society of America's annual meeting (USA), the International Conference on Integrated Care (Belgium), and the National Gerontology Conference (the Netherlands). Additionally, the results of this thesis were shared within the international ReAble network,<sup>14</sup> as well as among the TRANS-SENIOR consortium network through regular webinars and training events. By sharing our findings with these groups, peers can leverage the outcomes of our research to inform and enhance their own practices, interventions, and methodologies. Our findings may serve as a foundation for developing evidence-based strategies or improving the effectiveness of reablement. Additionally, sharing these findings may inspire further research inquiries, fuelling a cycle of continuous improvement and innovation within the field of reablement.

The scientific impact of this thesis lies not only in its findings and in the dissemination hereof, but also significantly in its innovative approach and collaboration with practice. The research performed and presented in this thesis stems from questions raised by practice, which were gathered through conversations with care professionals, older adults, and their informal caregivers. The co-creation process described in this thesis is a good example of transdisciplinary collaboration within the Living Lab in Ageing and Long-Term Care, an interdisciplinary collaboration between scientists, care providers, and educators in long-term care. By adopting a co-creation approach, the programme adheres to the needs and wishes of all parties involved. Furthermore, this thesis also contributes to the understanding of collaborative methodologies in the development of health-care interventions. The extensive description of the development process provides an understanding of the challenges, lessons learned, and the interplay of different stakeholders and sources. This enhances the programme's replicability, but also establishes a framework for future research in community-based reablement.

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Dankwoord

Zoals Taylor zingt in 'you're on your own, kid': *I gave my blood, sweat and tears for this*. Maar in tegenstelling tot Taylor, stond ik er niet alleen voor. De afgelopen jaren zijn er heel wat mensen op mijn pad gekomen zonder wie dit proefschrift er nooit was geweest en bij deze wil ik even mijn tijd nemen om hen hiervoor te bedanken.

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**Robin**, **Rose**, **Svenja** en **Lise**, mijn allerliefste roomies van 0.058, waar moet ik beginnen? Toen ik in het begin van de pandemie had laten vallen dat ik wel wat gezelschap kon gebruiken tijdens het thuiswerken, ging de bal aan het rollen. Een intense sollicitatieprocedure, maar vooral een lieve blik naar Brigitte later verhuisde ik dan ook naar 0.058, beter bekend als de (soms iets te) gezelligste kamer op Dub30. Iemand zei me ooit dat je kamergenoten je promotietraject maken of kraken en dat kan ik alleen maar beamen. Dankjulliewel voor al het self-care advies (dat we



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About the author





Ines Mouchaers was born on April 9, 1995 in Genk, Belgium. In 2016, she obtained her Bachelor's degree in Biomedical Sciences at Hasselt University. Subsequently, Ines started her Master's degree in Biomedical Sciences (Minor Clinical Biomedical Sciences) at KU Leuven (Katholieke Universiteit Leuven). During this period, she had the opportunity to take part in various internships at the University Hospital of Leuven, including research on healthy ageing by means of exercise and nutrition. She graduated her Master's degree with great honour in 2018.



In June 2018, Ines started working as a Safety Officer at a Belgian consulting company for pharmaceutical companies. However, she wanted to pursue a career in research. In 2019, Ines started her PhD research as a Marie Skłodowska-Curie early-stage researcher within the TRANS-SENIOR research consortium, a European Union's Horizon 2020 research and innovation program. Her research was part of a double doctoral degree between Maastricht University and KU Leuven and was also embedded within the Living Lab in Ageing and Long-Term Care. Her research was on the essential components of reablement as a strategy to avoid transitions to institutional care settings and gaining insight into users' experiences. During her PhD, Ines attended national and international conferences, supervised bachelor and master students, was ESR representative within the TRANS-SENIOR consortium (2019 – 2020), helped organising training events for the TRANS-SENIOR consortium, and became a member of the international ReAble network. Since December 2023, Ines is continuing her research on reablement as a postdoctoral researcher within the department of Health Services Research.



# List of publications

## International scientific journals

- Mouchaers, I.,** Buma, L.E., Verbeek, H., Zwakhalen, S., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2024). A qualitative exploration of professionals' perspectives on the implementation of reablement programs in community care. *Scientific Reports*, 14(1), 11391.
- Mouchaers, I.,** Verbeek, H., van Haaster S., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F (2024). What matters to you? A mixed-method evaluation of goal setting and attainment within reablement from a client perspective. *Scandinavian Journal of Occupational Therapy*, 31(1), 2356548
- Mouchaers, I.,** Metzelthin, S.F., van Haastregt, J.C.M., Vlaeyen, E., Goderis, G., Verbeek, H. (2023). Exploring the support and involvement of family caregivers for reablement programs: a qualitative study. *Journal of Multidisciplinary Healthcare*, 16, 2993-3005.
- Mouchaers, I.,** Verbeek, H., Kempen, G.I.J.M., van Haastregt, J.C.M., Vlaeyen, E., Goderis, G., & Metzelthin, S.F. (2023). Development and content of a community-based reablement programme to improve self-management and participation in daily life (I-MANAGE): A co-creation study. *BMJ Open*, 13(8), e070890.
- Mouchaers, I.,** Verbeek, H., Kempen, G. I. J. M., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2022). The concept of disability and its causal mechanisms in older people over time from a theoretical perspective: a literature review. *European journal of ageing*, 19(3), 397-411.
- Mouchaers, I.,** van Haastregt, J. C. M., Verbeek, H., Kempen, G. I. J. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2021). « Reablement » comme outil thérapeutique pour offrir aux personnes âgées une vie de qualité à domicile après une réadaptation gériatrique. *Revue Médicale de Bruxelles*, 42(4), 324-332.

## Conference contributions

- Mouchaers, I.,** Buma, L.E., Verbeek, H., Zwakhalen, S., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2024, 12-14 June). A qualitative exploration of professionals' perspectives on the implementation of reablement intervention programs

in community care. 27<sup>th</sup> Nordic Congress of Gerontology 2022, Stockholm, Sweden [oral presentation]

**Mouchaers, I.,** Verbeek, H., van Haaster, S., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2024, 8-9 February). Wat vindt u belangrijk? Een mixed-method evaluatie van het stellen van doelen binnen reablement vanuit het perspectief van de cliënt. Geriatriedagen 2024, 's Hertogenbosch, the Netherlands [oral presentation]

**Mouchaers, I.,** Buma, L.E., Verbeek, H., Zwakhalen, S., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2023, 8 – 12 November). Implementing Reablement in Community Care: How Do We Succeed? The Gerontological Society of America's 2021 Annual Scientific Meeting, Tampa, USA [poster presentation]

**Mouchaers, I.,** Metzelthin, S.F., van Haastregt, J.C.M., Vlaeyen, E., Goderis, G., Verbeek, H. (2023, 7 June). Exploring the Support and Involvement of Family Caregivers for Reablement Programmes: a Qualitative Study. CAPHRI Research Day, Valkenburg, the Netherlands [poster presentation]

**Mouchaers, I.,** Metzelthin, S.F., van Haastregt, J.C.M., Vlaeyen, E., Goderis, G., Verbeek, H. (2023, 22 – 24 May). Exploring the needs and wishes of next of kin for future reablement programs: a qualitative study. 23rd International Conference on Integrated Care, Antwerp, Belgium [oral presentation]

**Mouchaers, I.,** Verbeek, H., Kempen, G. I. J. M., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2022, 14 October). Wat vindt u belangrijk? Een mixed-methods evaluatie van doelgerichte zorg binnen het 'Langer Vitaal Thuis' programma. 16de Nationaal Gerontologiecongres 2022, 's Hertogenbosch, the Netherlands [oral presentation]

**Mouchaers, I.,** Verbeek, H., Kempen, G. I. J. M., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2022, 8 – 10 June). I-MANAGE: a reablement program to improve daily functioning and well-being of patient at home. 26<sup>th</sup> Nordic Congress of Gerontology 2022, Odense, Denmark [oral presentation]

**Mouchaers, I.,** Verbeek, H., Kempen, G. I. J. M., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2022, 10-11 February). I-MANAGE: het dagelijks functioneren en welzijn van patiënten na geriatrische revalidatie verbeteren. Geriatriedagen 2022, the Netherlands (online) [oral presentation]

**Mouchaers, I.,** Verbeek, H., Kempen, G. I. J. M., van Haastregt, J. C. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2021, 10-13 November). Developing a Reablement Program Aimed at Preventing Unnecessary Care Transitions After Geriatric Rehabilitation. The Gerontological Society of America's 2021 Annual Scientific Meeting, Phoenix, USA (online) [oral presentation]

**Mouchaers, I.,** van Haastregt, J. C. M., Verbeek, H., Kempen, G. I. J. M., Vlaeyen, E., Goderis, G., & Metzelthin, S. F. (2021, 11 September). « Reablement » comme outil thérapeutique pour offrir aux personnes âgées une vie de qualité à domicile après une réadaptation gériatrique. 55e congrès des Journées d'Enseignement Postuniversitaire, Brussels, Belgium [oral presentation]

### **Other presentations**

*Het bevorderen van zelfredzaamheid: innovaties en inzichten uit praktijk en onderzoek.* Workshop presented at 'Academische Werkplaats Ouderenzorg Limburg'-symposium, June 20 2024, Venlo, the Netherlands.

*Reablement, oude wijn in nieuwe zakken?* Webinar presented for 'Thuis als het kan'-project, November 2 2023, online, the Netherlands.

*Aan de slag met reablement.* Workshop presented at 'Senioren sterker maken'-symposium, April 20 2023, Rotterdam, the Netherlands.

*Aan de slag met reablement.* Workshop presented at 'Zoek het Uit!'-conference, September 7 2022, 's Hertogenbosch, the Netherlands.







Living lab in ageing and long-term care

## **Living lab in ageing and long-term care**

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, nine long-term care organizations (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Intermediate Vocational Training Institutes Gilde and VISTA college and Zuyd University of Applied Sciences, all located in the southern part of the Netherlands. In the Living lab, we aim to improve quality of care and life for older people and quality of work for staff employed in long-term care via a structural multidisciplinary collaboration between research, policy, education and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers, and older people themselves to develop and test innovations in long-term care.

## **Academische werkplaats ouderenzorg Limburg**

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Limburg, een structureel, multidisciplinair samenwerkingsverband tussen de Universiteit Maastricht, negen zorgorganisaties (MeanderGroep Zuid-Limburg, Sevagram, Envida, Cicero Zorggroep, Zuyderland, Vivantes, De Zorggroep, Land van Horne & Proteion), Gilde Zorgcollege, VISTA college en Zuyd Hogeschool. In de werkplaats, draait het om het verbeteren van de kwaliteit van leven en zorg voor ouderen en de kwaliteit van werk voor iedereen die in de ouderenzorg werkt. Zorgverleners (zoals verpleegkundigen, verzorgenden, artsen, psychologen, fysio- en ergotherapeuten), beleidsmakers, onderzoekers, studenten en ouderen zelf wisselen kennis en ervaring uit. Daarnaast evalueren we vernieuwingen in de dagelijkse zorg. Praktijk, beleid, onderzoek en onderwijs gaan hierbij hand in hand.

## PhD-theses Living lab in ageing and long-term care

### *Proefschriften Academische werkplaats ouderenzorg Limburg*

- Ines Mouchaers. *Managing Everyday Life. Exploring the Essential Components of Reablement and User Experiences.* 2024
- Lindsay Groenvynck. *The transition from home to a nursing home: The perspectives and experiences of older people with dementia, informal caregivers and professional caregivers.* 2024
- Svenja Cremer. *Undervalued & Unexplored. Underpinning and Guiding Nursing Care in Activities of Daily Living.* 2024
- Katinka Pani – Harreman. *The place to be. Guiding the activation of a community to facilitate ageing in place.* 2024
- Vincent Moermans. *Struggling with Daily Care Dilemmas. Insights in Involuntary Treatment Use among Persons Living with Dementia Receiving Professional Home Care.* 2023
- Chandni Khemai. *There is an I in WE. Collaborative Awareness in the dedicated palliative care approach for persons with dementia.* 2023
- Amal Fakha. *Improving the implementation of transitional care innovations.* 2023
- Tom Vluggen. *Towards improved multidisciplinary stroke care for older people: assessing feasibility and effectiveness of an integrated multidisciplinary geriatric rehabilitation programme for older stroke patients.* 2023
- Priscilla Attafuah. *Quality of life, health, and social needs of slum-dwelling older adults in Ghana.* 2023
- Ron Warnier. *Frailty screening in older hospitalized patients.* 2023
- Megan Davies. *Tri-national ethnographic multi-case study of person-centred care and quality of life in long-term residential care.* 2023
- Christoph Golz. *Technostress among health professionals: The blame game between health professionals and technology.* 2023
- Simone Paulis. *Dehydration in the nursing home. Research into the prevalence, risk factors, diagnosis, roles and current collaboration between (in)formal caregivers and nursing home residents.* 2023
- Sheizi Sari. *Pressure injuries in Indonesian community-dwelling older adults: prevalence, prevention and treatment by the (in)formal support system.* 2022
- Teuni Rooijackers. *Supporting older adults to STAY ACTIVE AT HOME. Process, effect and economic evaluation of a reablement training program for homecare staff.* 2022
- Anne van den Bulck. *Differences that matter: Understanding case-mix and quality for prospective payment of home care.* 2022
- Marlot Kruisbrink. *Towards enhanced management of fear of falling in older people. Unravelling interventions and measuring related avoidance of activity.* 2022

- Ruth Vogel. Nurses in the Lead: empowering community nurse leaders to implement evidence into practice. 2022
- Fabian Groven. The bed bath with or without water? It's a wash! Experiences with the washing without water intervention used for the bed bath. 2021
- Roy Haex. Take a look through my eyes: The development of an experienced quality measure with clients, informal, and formal caregivers in Dutch home care. 2021
- Sascha Bolt. The fundamentals of a DEDICATED palliative approach to care for people with dementia. 2021
- Angela Mengelers. To risk or to restrain? Involuntary treatment use in people with dementia living at home. 2021
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- Eveline van Velthuisen. Delirium in older hospitalised patients: diagnosis and management in daily practice. 2018
- Bram de Boer. Living at a green care farm. An innovative alternative for regular care in nursing homes for people with dementia. 2017
- Nienke Kuk. Moving forward in nursing home practice. Supporting nursing staff in implementing innovations. 2017
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- Ramona Backhaus. Thinking beyond numbers. Nursing staff and quality of care in nursing homes. 2017
- Martin Van Leen. Prevention of pressure ulcers in nursing homes, a big challenge. 2017
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- Hanneke Beerens. Adding life to years. Quality of life of people with dementia receiving long-term care. 2016 (Cum Laude)
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