

Summary

Changing care and support for people with disabilities

National evaluation of long-term care reforms in the Netherlands

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Summary, conclusions and discussion

S.1 Introduction

Around a third of adults living independently in the Netherlands have some form of disability (reference year 2015). More than a third of citizens aged over 16 provide informal care or volunteer in the care or support sector. As a consequence, the long-term care reforms (Hervorming Langdurige Zorg – HLZ) introduced on 1 January 2015, of which this report presents an interim evaluation, affect a large proportion of the population. Opinion surveys show that long-term care is a concern for many people.¹

Administrators and policymakers are concerned about the rapid rise in public spending on long-term care and about the quality of the available care and support. In fact, those concerns began long before the HLZ reforms. Initially, this led to the introduction of the Social Support Act (Wmo) on 1 January 2007. Measures to halt the rise in costs by restricting access to institutional care followed in 2013 and subsequent years. The Exceptional Medical Expenses Act (AWBZ) was repealed on 1 January 2015 and replaced by a raft of new legislation. In this evaluation study we look at the provisional results of these reforms, which include the impact of measures taken earlier.

S.2 Evaluation of long-term care reforms

The long-term care reforms (HLZ) have led to a change in the way social support and long-term care are organised in the Netherlands since 1 January 2015. That is care and social support for people with physical, sensory, intellectual and/or psychological disabilities or psychosocial problems. The long-term care reforms affect support funded through the Social Support Act 2015 (Wmo 2015), community nursing funded through the Health Care Insurance Act (Zvw) and long-term care provided under the Long-term Care Act (Wlz).² Examples include daycare, help with the household, nursing and care provided at home, and time spent in a nursing home or homeless shelter. Although parts of the Youth Act are also sometimes included under the long-term care reforms, they are left out of consideration in this evaluation.

At system level, the long-term care reforms have the following goals:

- better quality of support and care;³
- greater involvement in informal help (taking more care of each other);
- financial sustainability of long-term care and support.

In addition, there are a number of goals pertaining to people with a care or support need:

- more (equal) participation in society;
- giving people more control over their lives;
- more coping ability/independence;
- living independently for longer/as long as possible;
- less loneliness;
- better quality of life.

The Dutch Ministry of Health, Welfare and Sport asked the Netherlands Institute for Social Research (SCP) to evaluate the reformed system of long-term care, including the statutory evaluations of the Wmo 2015 and the Wlz. This evaluation covers developments over the period from 2015 to 2017 inclusive, the first years after the system change.

The evaluation of the long-term care reforms is based around two central questions:

- A To what extent are the goals of the long-term care reforms and the associated laws and measures being achieved, both from the perspective of (potential) users and for the legal system?
- B To what extent is the achievement of the goals of the long-term care reforms related to the implementation of the associated laws and measures and to the voluntary action of citizens? Which other factors play a role? Are there any desirable or undesirable side effects?

As this evaluation covers the first years following the introduction of the new system, it is too early to give definitive answers to these questions; our conclusion therefore focuses on whether we discern any movement in the direction envisaged by the legislator.

The two central questions above are elaborated into research questions regarding the goals and implementation practice (see sections S.3 and S.4). To answer these questions, SCP carried out a number of studies itself and also commissioned studies from third-party research agencies: NIVEL, BMC, KPMG, Vilans, Tranzo, Movisie and Stimulansz. Various methods were used for this, including literature review, quantitative survey research (digital and written), structured face-to-face interviews (quantitative), semi-structured face-to-face interviews (qualitative), focus groups (face-to-face and digital), analysis of jurisprudence and analysis of register data. A wide range of respondents were surveyed in this process:

- current and potential clients of local authority support services (Wmo 2015), community nursing (Zvw) and institutions in the nursing and care, disability care and mental health care sectors (Wlz);
- informal carers and volunteers;
- people involved in civic initiatives;
- (other) informal and formal representatives of (potential) clients during consultations on municipal Wmo policy;
- independent client support workers and supporters of informal carers and volunteers;

- care and support professionals: (community) nurses, carers, general practitioners (GPs), GP practice nurses;
- managers of institutions in the nursing and care, disability care and mental health care sectors;
- administrators and municipal officers (aldermen, policy officials, Wmo consultants and assessment officers who carry out assessments following applications for support under the Wmo 2015);
- staff of the Care assessment centre (CIZ), care administration offices and health insurers.

The empirical data cover the period from the end of 2015 to the autumn of 2017, with the emphasis on 2016 and 2017. The information on access to, and the results of, social support offered by local authorities to people who apply for support under the Wmo 2015 relates to the situation as at the end of 2015 and in the first half of 2016, respectively. These Wmo applicants and their informal carers were surveyed between March and October 2016; the local authority assessment officers were surveyed from May to December 2016. The data on independent client support and access to Wlz-funded care were collected in June and July 2016 and in the period April to November 2016, respectively. The data on the practice in institutions providing Wlz-funded care were collected in 2016. The survey of community nursing professionals and those who use their services (clients and informal carers) took place in late 2016 and early 2017. Local implementation practice and policy participation in the Wmo 2015 were investigated in late 2016/early 2017 and between February and October 2017, respectively. GP practice nurses and GPs themselves were interviewed in the second half of 2017. The study of jurisprudence was completed in early 2018.

Individual reports were published on most of the substudies (see chapter 1 for an overview). These contain the further elaboration of the research questions and a detailed methodological description (for all publications, see www.scp.nl).

This evaluation study was supervised by an external supervisory committee comprising both people from the field and members of the scientific community.⁴ An earlier version of this chapter ‘Summary, conclusions and discussion’ was also discussed with a supplementary group of experts from the field.⁵

Scope

In this evaluation we present an interim picture of a practice that is still in full development and for which the legislator does not provide any measurable benchmarks. Ideally, an evaluation makes a comparison between the old and new situations (pre- and post-measurement), and compares people who have and have not experienced a particular change (experimental group and control group). With national legislation, however, there is no control group. There are also few baseline or reference measurements in this case. In order still to be able to make some kind of comparison, in some cases we asked people about

their situation before and after 1 January 2015. In many cases, however, we were unable to make a comparison between the situation before and after 1 January 2015.

The main focus in this evaluation is on the experiences of current and potential clients, informal carers and professionals who are directly involved in the access to and provision of long-term care and support. However, not all stakeholders are represented in this study. For example, it contains no information on people who – either in their own assessment or according to carers – need institutional or community-based care or support but for a variety of reasons are not receiving it. These people are difficult to trace. The study also contains no information on people who are unable to participate in research due to the nature and/or severity of their disability. There were also too few clients with a migration background in the substudies to enable any statements to be made about this group. Owing to the lack of national registers, it was not always possible to determine whether a substudy was representative.

In view of the emphasis we placed on the perspective of care applicants, clients, informal carers and professionals, a number of aspects are largely left out of consideration in this evaluation study. These include the way in which long-term care and support are funded (size of budgets and how funding is organised), procurement processes, labour market effects, administrative burdens and the functioning of the personal budget.

In this summarising and concluding chapter, we restrict ourselves to the broad outlines of our study. For a more detailed substantiation of our findings, we refer to the main text of this report and the individual substudy reports (in Dutch). In this chapter we first discuss the implementation practice, then consider the extent to which the goals of the long-term care reforms have been achieved in the first years since their introduction.

5.3 Implementation of long-term care reforms in practice

In this section we look first at access to formal long-term care and support (section 5.3.1), then discuss experiences with formal and informal help (section 5.3.2). In both parts we look in turn at social support (Wmo 2015), community nursing funded through the Health Care Insurance Act (Zvw) and care provided under the Long-term Care Act (Wlz). Section 5.3.1.3 discusses jurisprudence in relation to access to social support.

5.3.1 Access to care and support

Are people who need support able to contact their local authority⁶, and do they do so? Are people who need nursing and care able to access community nursing services, and do they do so? How are requests for help dealt with and how do all stakeholders experience this?

S.3.1.1 Access to social support and community nursing services

Large majority of municipalities have (community) social care teams

Under the Wmo 2015, local authorities are responsible for organising all aspects of access to social support. Many local authorities (eight out of ten) meet this obligation by setting up (community) social care teams. The most common is a broad-based, integrated team which is able to help all people who need support. These teams, which comprise members from various disciplines, offer first-line support, information and advice, as well as providing access to personalised support such as help in the household, providing a wheelchair or individual support. For complex needs they consult specialists or refer applicants to second-line care services. The community social care teams in some municipalities also contain community nurses.

Wmo 2015 and community nursing reasonably well-known

Seven out of ten people with physical disabilities are aware of the existence of the Wmo help desk or (community) social care team; this is the case for six out of ten next of kin of people with an intellectual disability and four out of ten people with persistent and severe mental health problems.

Familiarity with community nursing is higher: nine out of ten people with a chronic illness or disability know about the existence of this service. One worrying finding is that lower-educated people are less familiar with these services than others, whereas they are the group who most often need them.

Accessing support difficult for some

It is not known how many people need care or support – either according to self-report or according to carers – but are not receiving it. When asked, 3% of adult Dutch citizens living independently reported in 2015 that they needed care and support (help with the household, care, nursing or support) but were not receiving it. That is the same percentage as in 2014. The figure is higher for people with moderate or severe physical disabilities (9%), whose greatest need is for help with the household. Having a need does not automatically mean that those concerned have actually applied for or sought support. There may be all kinds of reasons for this. We also know that people with a low education level, a low income or suffering severe loneliness make relatively little use of local authority support services. In addition, people with a disorder or disability such as dementia, intellectual disability or severe mental health problems often have little control over their own lives and little or no understanding of their condition, making it difficult for them to formulate and address an application for help. According to nurses and carers, community nursing services are generally readily accessible, though possibly less so for people with a migration background and people with mental health problems.

A quarter of people who apply to the local authority for Wmo support reported in early 2016 that they had found this a very difficult process. Being unable to find their way through the system, finding the system too complex, thinking they will not be eligible,

thinking their own contribution (co-payment) will be too high and finding the application procedure too long are key reasons for not using support.

It is not only clients who have difficulty in finding the best routes to support; professionals also share this view. For example, GPs, GP practice nurses and independent client support workers also say they often have to spend a lot of time finding the right bodies and the right people. GPs and practice nurses also report that they often have to spend a long time ringing round in order to find an available bed for clients requiring temporary residential care.

It may also be the case that formal support and care are not used because an application has been wholly or partly rejected. In our study, in early 2016 1.5 out of ten registered Wmo support applicants did not receive personalised support (either their application was rejected or they did not submit one). Only one in 25 Wmo applicants were referred to general provisions (see also section 5.3.2.1). As regards shelters and sheltered housing, based on indications from various reports, there appear to be capacity problems particularly in providing night-time emergency accommodation. Access to this type of care is currently not adequately assured. There are also indications that clients are unable to leave residential facilities due to their financial problems and (particularly in large cities) a shortage of affordable rented housing.

In short, access to support and care at home is not easy to find for everyone, sometimes including professionals.

[Applications often centralised for Wmo 2015 support, decentralised for community nursing](#)

Virtually all applications for Wmo support are routed through a central Wmo help desk or client contact centre. The surveyed municipalities with one or more (community) social care teams regard these teams as an important point of contact for applicants, even though in most cases they do not apply for help through these teams. In around four out of ten municipalities surveyed, these community teams proactively seek out people with (multiple) problems. This indicates that, contrary to expectations, this form of outreach work is not yet commonplace. In addition, many (community) social care teams do not get round to preventive action and early intervention.

Many local authorities are digitalising their services (further), but only a small proportion of applicants in this study applied online, suggesting that digital contact is not well suited to the Wmo target group. The most widely used medium for the initial contact is the telephone. The local authority assessment of the support need generally takes place during a home visit.

People who need community nursing (or their informal carers) often contact the care provider themselves. Contact is also made via care providers such as GPs or hospitals. The (community) social care team or local authority plays a lesser role in these cases.

Independent client support little known and little used

Independent client support, such as provision of information and advice for clients, is a right and in practice is provided by a third party which has no connection with the funding organisation (local authority or care administration office) or with the care provider.

Local authorities have a duty to offer independent client support at no cost to people with a care or support need. However, many people (eight out of ten Wmo applicants and around two-thirds of next of kin of people with an intellectual disability) are not aware of this possibility. Around one in ten Wmo applicants were using this form of support in our study. They rated this support positively. There are however indications that client support workers are not always independent (e.g. if they are also members of a community social care team).

Clients generally satisfied with access interviews, but sometimes encounter lack of knowledge of certain disabilities

Most clients (of both Wmo support and community nursing) are satisfied with the interview that takes place as part of their assessment by the local authority or a community nurse. Professionals (Wmo assessment officers and community nurses) are also satisfied. Despite this, roughly a quarter of the assessment officers say their knowledge of applicants with mental health disorders, psychogeriatric problems (including dementia) and multiple problems, such as homelessness and addiction, is inadequate. Around a quarter of Wmo applicants were dissatisfied with the expertise of the assessor. Assessment officers themselves also sometimes find it difficult to obtain a clear picture of the 'question behind the question' and to take account of (potential) informal carers and the financial situation of applicants when seeking a solution. Generally speaking, the local authority assessment following a Wmo application meets the procedural requirements set in the legislation. Community nurses feel that they are able to give a more precise assessment than staff of the Care assessment centre (ciz) did in the past, partly because they see clients in their homes.

S.3.1.2 Access to Wlz-funded care

Are people with a permanent, intensive care need able to access the ciz and the care administration office, and do they do so? How do these organisations deal with the demand for care and how do all stakeholders experience this?

The percentage who unintentionally do not end up applying for Wlz-funded care is unknown

The ciz received 111,035 applications for Wlz-funded care in 2017, suggesting that many people are able to find their way to the ciz. It is not known how many people need 24-hour care close by or require permanent supervision but do not apply for care to the ciz. Data are only available for those who do submit an application. There are however indications from parties such as GPs, GP practice nurses, community nurses and staff of hospital Accident and Emergency (A&E) departments that the care demand from some clients living at

home has become much more complex and time-consuming. How extensive and serious this is, or whether some of these people could apply for provisions under the Wlz, is not known. A substantial proportion of those on the waiting list for Wlz-funded care, including those who are not 'actively' waiting, and their informal carers, say that, in their own assessment, they are actually no longer able to manage at home. Some of the reasons given by applicants for Wlz-funded care for their application are: 'need for more professional care', 'partner is already under great strain and cannot provide any more care' and 'deterioration in health'. Whether all of this group apply (too) late for Wlz-funded care is not known.

Groups who do not receive Wlz-funded care, or only with difficulty

Around 13% of first-time applicants for Wlz-funded care had their applications rejected between January 2015 and January 2017. They include four groups who according to ciz staff find it difficult or impossible to obtain Wlz-funded care because they do not meet the access criteria, even though in some cases they are no longer able to continue living at home: vulnerable older persons with disabilities but no cognitive impairments; children and adolescents with (mild) intellectual disabilities; adults in need of intensive care but who are able to control their own care; and people with mental health problems. It is not known to what extent they are able to manage without this formal care, possibly using informal or privately paid help, support from the local authority and/or community nursing.

A study of access to Wlz-funded care suggests that some groups are rejected more often than others, including children, people with a mild intellectual disability and people with a physical disability but good cognitive functioning. The percentage who are rejected varies by age category. Those who receive a negative indication (rejection) more often say they are advised to apply by their local authority – which does not always know when someone is eligible for Wlz-funded care – and more often lack information about the criteria for access to this care than those who receive a positive indication. They also more often find applying very difficult.

Many clients have great difficulty understanding or finding information on the Wlz

The applicants for Wlz-funded care in this study took differing views on the clarity, accessibility and completeness of the available information. Around a third take a positive view, a high percentage are neutral and between a quarter and a fifth think the information is difficult to find, unclear and/or incomplete. The majority receive information about the Wlz and how to submit an application from care providers or from their partner/family/friends. Other sources such as the ciz and the Internet/newspaper/radio/television are mentioned by a small percentage.

According to professionals who manage access to care (staff of the ciz and care administration offices), applicants lack information about aspects such as the financial consequences of a particular choice, the existence of independent client support and what an indication implies (care profile). They point out that a lot of information is only available online and is

therefore difficult or impossible to find for people with no Internet access (such as older persons and people with a (mild) intellectual disability). They note that accessing long-term intensive care is complex, not only for potential users, but also for other stakeholders such as local authorities and health insurers. In practice, clients receive help when submitting an application to the ciz from parties such as a hospital liaison nurse, care provider or community nurse. The extent to which this happens is not known. GPs often play no role in the submission of applications, though they are occasionally asked for advice or information by the ciz in relation to the care needs assessment.

Care applicants are predominantly satisfied with the personal contact with the ciz and care administration office; professionals have mixed experiences with the access procedure

The majority of applicants for Wlz-funded care were satisfied or very satisfied with the time ciz staff devoted to discussing their application. The same applies for the way in which the interview was conducted by the ciz. The majority of applicants are not aware of the possibility of receiving independent client support; only a small proportion of care applicants (around 10%) say they were advised or informed by a client support worker regarding their application for long-term care.

The majority of applicants surveyed knew during the application process that they wanted to receive care in kind and also knew the care institution from which they wished to receive it. The client adviser from the care administration office only has contact with people who do not know how they wish their care need to be met (4% of care applicants), with people who wish to receive all or part of the care at home (more than one in three applicants) and with people wanting a personal budget (this group partially overlaps the latter). In general, over half of those who came into contact with the care administration office were satisfied with that contact.

ciz staff generally feel that the policy rules offer sufficient guidance when making decisions on the care required. Despite this, almost half think the policy rules are sometimes (44%) or frequently (4%) inadequate for this. This applies for older persons with physical disabilities but few cognitive impairments, for children, adolescents and young adults and for people with both psychiatric problems and intellectual disabilities. ciz staff take differing views on how clearly the legislative regimes are defined. The majority (almost six out of ten) felt that the definition was 'sometimes clear'.

People with mental health problems are still uncertain about the principles for inclusion in Wlz-funded care

When the Wlz came into effect, it was decided not to include psychiatric problems as a basis for access to Wlz-funded care. Since 2015, people with a need for mental health care have received this through the Health Care Insurance Act (Zvw). A decision was to be taken on 1 January 2018 regarding admitting this group of clients to Wlz-funded care, but this was suspended. People who are currently receiving mental health care under the Wlz were admitted to Wlz-funded care because on 31 December 2014 they had been receiving treatment in a mental health care institution for three years or longer. Since then, people have

only been admitted to Wlz-funded care if they also have another illness or disability, such as an intellectual disability or dementia.

5.3.1.3 Legal developments

What legal developments have taken place in relation to decisions by local authorities on requests for personalised support?

Relatively few complaints and objections lodged

Although a quarter of Wmo applicants were dissatisfied with the outcome of the local authority assessment in 2016, the number of complaints and written objections lodged was relatively small; most people do not have a clear idea of how to do this. One in ten Wmo applicants whose application was rejected filed an objection in 2016. Based on information from municipal policy coordinators, in 2016 there were 1.2 objections per 100 decisions issued (based on data from 130 municipalities). That is roughly the same proportion as in the Wmo evaluation 2010-2012. The number of objections peaked in 2015, at 2.2 per 100 decisions, probably reflecting the fact that 2015 was a transitional year with stricter access criteria for services such as help with the household.

Pertinent jurisprudence on Wmo 2015

In the period from 2015 to the present, there have been several hundred rulings on the 2007 edition of the Wmo and around a hundred on the Wmo 2015. The most pertinent rulings by the Administrative High Court (Centrale Raad van Beroep) are concerned with informal care and help with the household.

The rulings on informal care stipulate that this type of care is voluntary and can therefore not be enforced or demanded. Because informal care is by definition 'free', in a situation where a potential informal carer refuses to provide help without compensation from a personal budget, this cannot be referred to as informal care. Consequently, the local authority no longer has the power to stop the personal budget due to the presence of informal care. Recipients of a personal budget can be expected to use the personal budget to achieve certain results.

On 'usual help', the Court has ruled that local authorities must properly substantiate which help by fellow household members they regard as 'usual'.

A series of rulings have been issued on help with the household, from which the following conclusions can be drawn:

- Neither the text of the Wmo 2015 nor the parliamentary debate contains any indication that help with the household no longer falls within the scope of the Wmo 2015.
- Help with the household may be provided in the form of a general provision, provided a number of conditions are met. For example, the costs must be stated in the municipal regulation, the local authority must have contracts with providers of general provisions, the local authority must investigate whether the general provision leads to the envisaged result and whether it is financially appropriate for the person concerned.

- New standards for fixing the number of hours provided are permitted, but must be substantiated by objective research. It must also be clear that the number of hours' help provided based on those standards will be enough to achieve the envisaged result for the clients.
- Allocating support framed in a system of measurable results (e.g. a clean home that is fit to live in) must be based on a clear and objectively determined criterion.

In the context of the Wlz and the Zvw, opinions have also been issued by non-judicial bodies, such as the Dutch National Health Care Institute and the Health Care Insurance Industry Disputes Committee. We also looked at these opinions as a supplement to the jurisprudence on the Wmo 2015. The main findings from the analysis are set out in chapters 7 and 8 of this report.

5.3.2 Experiences with formal and informal help

What help do people with a care need receive and how do all stakeholders experience this? Is there sufficient coordination between all stakeholders? Does the available help meet the needs of both clients and informal carers?

5.3.2.1 Experiences with social support

Most people who apply for social support receive personalised support

The range of provisions and services offered is wide and consists of general provisions which can be accessed without a local authority assessment and personalised support which do require such an assessment. Over eight out of ten of those who applied to their local authority for support at the end of 2015 received personalised support following the local authority assessment. Around one in ten applicants received a suggestion that they should buy in support themselves or should ask for (more) help from family, friends or volunteers. Just under a tenth received a combination of personalised support and such a suggestion. A referral to general provisions, or to nursing or care services, was much less common (both around one in 25).

The number of unique users of personalised Wmo support is estimated at over 1 million in 2016. That figure is made up of 700,000 users of residential and transport provisions and aids, more than 400,000 users of household help and around 250,000 users of support, day care services and other individual and group-based support, plus around 35,000 users of residential services. Household help and aids and services were mainly used by older persons. Wmo clients can use several personalised Wmo provisions and in addition (or instead) can also use general Wmo provisions.

It is difficult to say whether a shift is taking place from use of more intensive (individual, specialist) to less intensive (general or collective) forms of support. The majority of the

local authority policy staff surveyed indicated that less intensive provisions are being used more than before the introduction of the long-term care reforms. The use of more intensive forms of care is however not declining to any great degree.

The total number of clients using emergency shelters in 2016 is estimated at at least 60,000, and appears to have remained stable over recent years. It is not clear how many of them have a residential place or receive only community-based help. The number of sheltered housing clients has decreased slightly since 2013, but the percentage of clients with a relatively intensive assessed care need has grown.

Coordination between care providers sometimes less than optimum

Around one in twelve Wmo applicants who receive services from several helpers/carers (sometimes provided under different legislative schemes) say they sometimes or regularly experience coordination problems between the helpers/carers. The help is coordinated in most cases, but in a third of cases it is not. Where there is coordination, that mostly comes from the applicant or their informal carer themselves, rarely from the local authority. This is reflected in the experiences of local authority assessment officers.

The importance of good coordination and the designation of a coordinator is underlined by the Dutch Health and Youth Care Inspectorate (IGJ) and the Council for Public Health and Society (RVS). It is all the more important for people living independently with multiple, complex care needs who are not able to exercise control over their own situation.

A third of clients in temporary shelters feel that the help they receive is not well coordinated. The extent to which clients in sheltered housing feel there is sufficient coordination in the support offered in various domains of life is not known.

Two out of three applicants are satisfied with the solution provided; informal carers are more critical

Two-thirds of those who apply for support from their local authority and receive an assessment are satisfied with the outcome. They are satisfied or very satisfied because the support resolves their problem, makes them more independent or relieves the burden on their informal carers. Informal carers are more critical: half are satisfied or very satisfied with the solution for the applicant, while two out of ten are dissatisfied or very dissatisfied. Their dissatisfaction is often related to the number of hours of help assigned to the care recipient. Other reasons for dissatisfaction are that the local authority assessment officer did not listen properly or that the solution is insufficiently personalised.

In many cases, informal carers are not asked about their burden (almost four out of ten assessment interviews) and there is no discussion of any support needs they may have (between four and five out of ten interviews); in the other cases these issues were discussed or the respondent can no longer remember. A majority of Wmo assessment officers feel they are successful in finding an appropriate solution for most applicants. They are more often positive on this point than applicants and informal carers.

Most applicants who receive personalised support in response to their application are satisfied with its quality.

Positive and critical voices about shelters and sheltered housing

Over two-thirds of people living in shelters take a positive view of the living conditions. A third feel they do not receive help as quickly as they need it, while the same proportion feel that staff do not devote enough time to discussing whether the help is still appropriate, do not give enough information and provide help that is not well coordinated. All in all, two-thirds of clients are positive about the results of the help, and a third are negative. In 2016, people with severe mental health problems, including clients in sheltered housing, were less satisfied with the help they received than in 2015. Those who are dissatisfied with the support they receive, refer to the negative consequences for their personal lives. The emphasis on independence and taking control means they have the feeling that their need for help is 'not welcome'. The mixing of groups in general daycare provisions is also not a good outcome for all clients.

S.3.2.2 Experiences with community nursing

Increasing use of community nursing and more complex care needs

People can receive nursing care, personal care or a combination of both if a nurse believes they are eligible. The nurse plays a pivotal role: he or she must decide together with the individual client and their social network what care is needed. The volume of community nursing (nursing and care together) provided under the Health Care Insurance Act (Zvw) increased by just under 2,000 hours between 2015 and 2016. Nurses and carers have experienced an increase in pressure of work since the introduction of the long-term care reforms due to the increased number of clients living independently with complex problems. GPs and GP practice nurses share this experience.

Clients often satisfied with the care and the coordination between carers

Most community nursing clients (nine out of ten) say the care they receive matches their assessed need; just under one in ten do not know or have forgotten, and an even smaller proportion state explicitly that they do not receive the care that was agreed with them. Just under two-thirds feel they always receive community nursing services when they need them; a third feel this is mostly the case and the occasional respondent says they rarely or never receive care at the times it is needed.

The cooperation between community nursing professionals and other carers is assessed as good by more than half of the clients; 13% rate this cooperation as reasonable and 3% as poor. Just over a quarter do not know. It may be that they have little information on this aspect, but they have evidently also experienced no major difficulties or gaps.

S.3.2.3 Experiences with Wlz-funded care at home

People who are eligible for Wlz-funded care can in some cases receive it at home, in the form of a full home care package (VPT), a personal budget or a modular home care package (MPT).

One in five Wlz clients receive care at home

At the end of 2017 almost 60,000 people were receiving Wlz-funded care at home; they account for almost a fifth of all Wlz clients. Five out of ten of them receive a personal budget, three out of ten receive an MPT and just under two out of ten receive a VPT. A personal budget or MPT is most often used by clients receiving disability care. The types of care provided in the recipient's home (VPT, MPT and personal budget) are generally chosen because people attach importance to living in their familiar home and with their partner/family. Where long-term care is provided at home, the recipient almost always receives (a lot of) informal care in addition to the Wlz-funded care.

According to clients and professionals, the quality of this care lies mainly in the combination of independence and the freedom to make decisions and the safe and secure feeling that help is nearby when needed.

Sometimes insufficient coordination between care professionals

Coordination between different care professionals is of particular importance for the quality of care provided at home in situations calling for complex, multiple care (see section S.3.2.1). At present, the coordination or control is not always adequate and not always well organised. There are also problems with the shared use of case files.

Wlz-funded care at home not always possible

People have both positive and negative experiences with the provision of Wlz-funded care at home. Clients who receive care at home are positive about the fact that they can decide more things for themselves than if they were in a care institution. Wlz-funded care at home is less suitable for certain groups, such as clients living alone with dementia, because 24-hour care close by and permanent supervision cannot always be guaranteed, potentially leading to unsafe situations.

There are indications that the transition of care and support provided under the Wmo 2015 and the Health Care Insurance Act (Zvw) to care provided through the Long-term Care Act (Wlz) is sometimes experienced as negative by clients receiving Wlz-funded care at home. This so-called 'care trap' occurs when a client with an indication for Wlz-funded long-term care receives a smaller volume of care (due to the requirement of cost-effectiveness: Wlz-funded care is capped at the amount of care the recipient would receive in an institution), whereas the client has to pay a bigger contribution (co-payment) (there is no co-payment for nursing care funded through the Zvw, but there is for care provided under the Wlz). For certain groups, such as terminally ill palliative clients, the maximum permitted costs have been increased by 25%. This could mean that long-term care clients who spend a long time on the waiting list for care in an institution may also receive less care and support than in

the old situation, whereas that old situation was the reason for them applying for long-term care under the Wlz.

5.3.2.4 Experiences with Wlz-funded care in an institution

How do nursing and care homes, as well as institutions providing disability and mental health care put the more extensive client support, new-style care plan discussions and use of informal help into practice? And how do clients, their social networks, volunteers and professionals experience this?

Care plan review is the norm

The introduction of the Long-term Care Act (Wlz) led to a tightening up of the system for care plan review, stipulating that care plans must be reviewed within six weeks of commencement of care delivery and at least twice per year thereafter. The client must also be involved in the review of their personal care plan, and the Wlz prescribes which topics must be reviewed. The purpose of the care plan review is to give clients a greater say over their own lives.

Care providers in the nursing and care, disability care and mental health care sectors devote more attention than in the past to care plan reviews, a development that has been ongoing for some time. The client and their social network are involved in the care plan review where possible. Clients see the care plan review mainly as an opportunity to be listened to, but see little difference between a care plan review and regular contacts with care professionals when it comes to discussing their wishes and needs. Managers state that their care institution offers wide scope for client input during the care plan review, and that this has increased since 1 January 2015.

According to care professionals, care plans and care plan reviews are not fully compliant with what is envisaged in the Wlz. The review topics listed in the Wlz are not discussed for every client, and not all care providers carry out a care plan review twice a year. Care professionals point to a number of practical problems: the care plan is not accessible for all clients; it is sometimes difficult to talk to a client about their needs and wishes because of their problems; and carrying out a review within six weeks of admission is not always achievable. Clients and informal carers also feel that the care plan is not always accessible and legible.

One in ten nursing home residents who are able to participate in surveys report that they are not aware of the arrangements set out in their care plan. Of those who are aware of these arrangements, a quarter say they never have an opportunity to share in the decision about what help is given when.

In mental health care, reference is made to the need to match care plans better to the pace that the client can manage. To assess what is essential to the client requires sustained and in-depth questioning during the care plan review. According to care professionals, this customised approach takes a lot of time and effort, while they feel that they do not have this time available due to the increasing complexity of clients' problems and staff cuts.

Independent client support still largely unknown

The majority of care professionals, clients and informal carers who took part in the studies in the nursing and care, disability care and mental health care sectors were fairly or completely unfamiliar with the term 'independent client support' or its function. Managers of institutions often did know about this.

Care providers often provide ways of supporting clients themselves. Most care professionals feel that the fact that these services are not independent does not cause problems for the client. They also point out that a client support worker may not have a bond of trust with the client. Opinions vary on whether this is a disadvantage or an advantage. Care professionals and clients' social networks feel that more attention is needed for client support and that more information needs to be provided about independent client support.

Members of the social network do not always step in

Care providers are making greater efforts to involve the client's social network in their care, a development which began long before the introduction of the Wlz. This can be difficult because of the change in mindset required, especially among informal carers of people who have been living in an institution for a long time. Family members may also be elderly and in need of care themselves, may be overburdened, have little time or live a long way away. Mental health care clients, in particular, often have a limited social network due to weak family contacts.

Overburdening of informal carers is an issue when it comes to the question of whether the input of the social network can be increased. According to care professionals, the burden on informal carers is increasing, mainly because relatives are providing longer and more intensive care because clients live at home and their care intensity is increasing. As a result, it is not always possible to increase the involvement of the client's family. Managers of nursing and care homes surveyed in this study more often report overburdening of relatives than managers in the disability care sector.

Recruiting volunteers is difficult

All three care sectors devote a lot of attention to involving more volunteers, though in most cases organisations (especially in the mental health care sector) are still looking for the best way to achieve this. Just over a third of managers in the nursing and care and disability care sectors have noticed a slight increase in the number of volunteers. At the same time, it is difficult to find volunteers and only a third of managers in the nursing & care and disability care sectors say they have enough volunteers. Recruiting and retaining volunteers is also seen as difficult in long-term mental health care, because clients have complex problems and do not always show gratitude. This causes volunteers, who have been recruited with great difficulty, to drop out again rapidly.

On average, there are more active volunteers per client in the nursing and care sector than the disability care sector. Volunteers are mainly involved in welfare activities, supervising activities and giving practical support. Volunteers appear to be taking over more and more tasks from professionals, especially in relation to welfare. However, it cannot be deduced

from this that institutions which do not have sufficient volunteers are not able to devote as much attention to client welfare. Only a fifth of managers recognise that volunteers are carrying out different tasks than in the past.

5.3.2.5 Experiences with informal help

What trends can be identified in the giving of informal help?

The government expects people to do more for each other. At the same time, the legislator wants to protect informal carers and volunteers against becoming overburdened. The government is accordingly focusing on support for informal helpers and on improving the link between formal and informal support and care. It is this latter aspect that is the subject of this section. Shifts in the extent of help and willingness to provide it are discussed in section 5.4.2.1.

Burden on informal carers and volunteers is stable but increasing in certain subgroups

Just under one in ten informal carers feel heavily burdened by the care they provide. That proportion was the same in 2016 as in 2014. In particular, informal carers who provide intensive help, who help their partner, someone with a terminal illness or someone with mental health problems, or who provide help because there are no alternatives, relatively often feel heavily burdened. Overburdening of informal carers leads to a risk of ‘derailing’ of care. Research by the Netherlands Institute for Health Services Research (NIVEL) shows that the percentage of heavily burdened informal carers of people with dementia increased from 10% in 2011 to 16% in 2016. Professionals also signal that there are groups who are heavily burdened and whose burden may be increasing. These are mainly informal carers providing care to someone within an intensive care need who is still living at home whereas in the past they might have been admitted to an institution. No hard figures are available on this, however. Local authorities say they are aware of the informal carer burden. Local authority assessment officers state that they ‘regularly’ or ‘often’ explore the resilience of informal carers during assessment interviews with Wmo applicants. However, over a third of informal carers of Wmo applicants say the local authority does not know that they are informal carers.

Volunteers may also find their task burdensome; this depends among other things on the type of activities and what kind of impairments the help recipient has. It seems that more and more is being asked of volunteers. Local authorities point out that a more diverse group of people have started volunteering and that a substantial proportion of those volunteers themselves need support.

Informal carers are often satisfied about the coordination with professionals, but professionals pay little attention to informal care

One in eight informal carers are the sole person providing help. Some informal carers help together with other informal carers as part of an informal network, while others provide help alongside professionals, though the percentage in the latter group has declined since

2014. It is unclear whether this means that less help is given by professionals or whether professionals are focusing more on situations where no informal carer is present. Informal carers are often satisfied with the collaboration with professionals and the way in which they are able to coordinate the care. Half do think that professionals pay them too little attention. Informal carers of Wmo applicants are mostly satisfied with the coordination with professionals (through the Wmo 2015 or community nurses); one in eight are dissatisfied.

Support for informal carers could be improved

One in six informal carers say they lack certain skills, and one in five feel they lack knowledge, for example relating to how to interact with the care recipient or more practical knowledge about their illness or condition. People helping someone with dementia, an intellectual disability, terminal illness or mental health problem, in particular, say they need more knowledge and skills. There are clear indications that increasing competencies and supporting informal carers helps to reduce or even prevent overburdening.

Local authorities offer all kinds of support, such as information, peer group contacts or respite care to provide temporary relief for informal carers. One in four helpers use this support; that is unchanged compared with 2014. One in ten informal carers need (more) respite support but do not receive it because the care recipient does not want this, but also because of a lack of capacity or because they feel it is too expensive. Informal carers who could benefit from support often do not use it, even though it is available. This could indicate that the supply does not match the demand, that informal carers are unaware of the support available or that they put off asking for support, perhaps out of embarrassment. Around three in ten informal carers are unaware of the support available.

S.4 The goals of the long-term care reforms

S.4.1 Goals for (potential) users

To what extent are the goals of the long-term care reforms and the associated laws and measures being achieved from the perspective of (potential) users?

The legislator has set a number of goals for people with physical, sensory, intellectual and/or mental disabilities or with psychosocial problems which have a very direct impact on their daily lives. We discuss the progress in achieving these goals below. To what extent the situation appears to be related to the long-term care reforms is discussed in section S.5.

S.4.1.1 Living independently

People with disabilities are living independently in the community for longer

One of the goals of the long-term care reforms is to enable people with disabilities to continue living independently in their own homes for as long as possible. This goal appears to

apply mainly for older persons. For people with intellectual disabilities, the purpose of support may be to enable them to live (more) independently, away from the parental home, while for people with mental health problems the goal may be concerned with a return to independent living, from a mental health care institution or sheltered housing. Older people are indeed living independently to ever greater ages, especially those with a partner. Several factors contribute to people living independently (for longer), including having a permanent helper, new technologies (such as telecare and domotics) and having meaningful daily activities. The latter gives structure to people's lives and relieves the burden on informal carers. Affordable rented homes are also important: a shortage in some municipalities impedes independent living, especially for people with an intellectual disability or with mental health problems. Waiting lists and the access criteria for admission to an institution exacerbate this, because some people who would previously have moved into an institution now (have to) continue living independently for longer. It is not clear how they are faring (see also section S.4.2.2). Semi-independent residential forms and informal care homes which would be a solution for some clients are being developed here and there, but are not yet available on a large scale.

S.4.1.2 Social participation and coping ability of people living independently

Social participation⁷ remains limited

Participating in society is not something that many people with disabilities can take for granted. It is known that people with a (severe) physical disability participate less often in all kinds of social activities and spend less time outside the home than those without disabilities. Intellectual disabilities and mental health disorders can also be an obstacle to participation in social life. At the start of 2016, applicants for Wmo support participated most in (adult) education and as informal carers. As regards employment (taking into account age), voluntary work and leisure activities, they appear to lag behind the general population. A third of Wmo applicants do not participate in any of these ways. A quarter have the feeling that they do not count in society.

The total participation by all people with a physical disability taken together neither increased nor decreased in the period 2008-2016, but among people with a mild intellectual disability it declined between 2012 and 2016, especially labour participation. Applicants who have recently received Wmo-funded support (personalised support or a general provision) and/or informal or private help if local authority offered this as a solution, score their participation opportunities at 6.2 out of 10. That is higher than the score they give for the participation opportunities they experienced prior to receiving their most recent support (5.5). The support thus appears to make a real, if limited, contribution to participation.

People see more participation opportunities as their resilience increases. There is also a negative relationship here: with advancing age and deteriorating health, people experience a decline in participation opportunities, despite the support they receive. Old age, fatigue,

pain or too many disabilities can make participation impossible at a certain point, and no amount of support appears able to alleviate this.

Coping ability⁸ increases with care and support – to a point

In early 2016, most people with disabilities who applied for support under the Wmo 2015 were not able to manage independently. Most of them were able to do so with formal and/or informal care and support, but between one and three in ten (depending on the domain of life concerned) still could not manage.

Around three-quarters of users of Wmo personalised support,⁹ and of Wmo applicants who receive personalised or general support and/or private or informal help, feel that the care and support offered helps them to manage. However, there is quite often still a residual need for help, among both people with and without help via the local authority. On average, Wmo applicants who have recently received Wmo-funded support (personalised or general) and/or private or informal help if the local authority offered this as a solution, score their coping ability at 6.7 out of 10. There was also a relationship with coping ability in the period prior to Wmo applicants receiving the support. Wmo applicants who were satisfied with the expertise of the local authority assessment officer reported higher coping ability than those who were dissatisfied. The coping ability of users of Wmo personalised support did not change between 2015 and 2016.

More than two-thirds of community nursing clients think they would manage less well in their daily lives, and over a third think their health would deteriorate without community nursing. Almost three out of ten clients also say they would then no longer be able to live independently. It is also striking that few of these clients think they would be able to manage by paying for the help they need themselves (5%) or by making more use of their next of kin (13%).

For people receiving Wlz-funded care at home (VPT, MPT or personal budget), ‘own control as far as possible’ is the main goal of the legislator, and not so much independent coping ability. People living at home with a need for 24-hour care close by and who receive Wlz-funded care have a fair degree of control compared with Wlz clients living in institutions. This does not always apply for (young) disabled people living with their parents, because people in a client’s social network have a tendency to take over the care and control from the client.

S.4.1.3 Loneliness and perceived quality of life of people living independently

Quality of life is related to the other Wmo goals of independence, participation and minimal loneliness. Given the current strong interest being shown in loneliness, the relationship between quality of life and loneliness is explored further in this evaluation.

Loneliness remains a problem

A third of the Dutch population aged 18 years and older feel moderately lonely, and a tenth feel very lonely. Loneliness is a problem in all age groups, but among elderly people it increases with advancing age.

Almost two-fifths of applicants for and users of Wmo support were moderately lonely in 2016, and one in five very lonely. In most cases, this was a combination of emotional and social loneliness.¹⁰ The share of those in receipt of Wmo personalised support suffering emotional loneliness increased from 17% to 22% between 2015 and 2016.

Among Wmo applicants aged 18 years and older and living independently, personalised support contributes to a reduction in loneliness. Most Wmo applicants who receive formal and/or informal help in maintaining contacts say this enables them to maintain (more than) enough contacts. Yet there is also a group who feel that this help does not make a difference. There are also people who say that they stay at home more often than they would like because they have not received personalised Wmo support.

Adult Wmo applicants living independently are less lonely if they see possibilities for maintaining contacts independently or with help, if they have an informal carer and/or if they receive personalised support under the Wmo 2015. It is worth noting here that loneliness is by no means always accompanied by a low quality of life; one in 25 applicants are lonely and give a low score for their quality of life, whereas one in seven are lonely but regard their quality of life as adequate. The first group differs from the second in the lower share of women, lower coping ability and participation, more difficulty maintaining contacts and greater frequency of severe disabilities.

The policy goal cited earlier of 'living independently for as long as possible' can conflict with the desire to combat loneliness. Almost one in three applicants for Wlz-funded care cite preventing loneliness as a reason for wishing to receive their care in an institution rather than at home (alongside other reasons).

Quality of life has not changed, but is systematically lower than in the general population

The perceived quality of life¹¹ of Wmo applicants averaged 6.6 in early 2016, more than one point lower than in the population as a whole. Personalised support under the Wmo 2015 has no direct influence on quality of life, but may have an indirect effect because it helps bolster their coping ability. Users of personalised Wmo support reported no change in their quality of life between 2015 and 2016.

S.4.1.4 Control, independence and quality of life of clients in long-term care institutions

Increasing attention for control and quality of life

Key goals of the Wlz are increasing clients' control over their lives and improving their quality of life. Research has shown that clients and care professionals mainly use terms such as 'control' and sometimes 'quality of life' rather than 'independence', 'independent living skills', etc. These topics are increasingly being raised according to professionals, but

they believe that this is part of a longer development and is not related to the introduction of the Long-term Care Act (Wlz).

Clients in the nursing and care, disability care and mental health care sectors say that care professionals devote attention to the control they have over their lives, and they appreciate this. Care professionals point out that if clients no longer have any control over their lives, it can be painful to confront them with this. Care professionals in the mental health sector see that clients need time to get used to the increasing scope to exercise control; they have often been hospitalised for a long time in mental health care facilities. Care professionals, volunteers, clients and the occasional care manager in the mental health care sector see an increase in clients' quality of life as they become more independent. As clients participate more actively in and connect to society, their self-confidence and sense of worth grows. This contributes to their recovery. Care professionals do however stress that it is important for this group to take small steps and that complete recovery is not always possible. The degree of independence achieved can vary from cooking one's own meals, for example, to living entirely independently.

Care plan review and informal help can contribute

According to care professionals and managers, the care plan review can help improve the client's quality of life, as can involving their social network and volunteers. Attention has increasingly focused on the wishes of the client in recent years, which care professionals sometimes describe as customisation. Disability care clients, in particular, feel that their independence increases as they are given more scope to undertake activities themselves. Care professionals experience a tension between the desire to give the client control over their lives and the risk of unsafe care.

Bringing in unpaid helpers (informal carers and volunteers) can contribute to quality of life, but can also impede the development of the client's independence and control, because they are accustomed to taking things over from clients. According to care professionals, a cultural change is needed here, which is currently in full swing, from 'caring for' to 'ensuring that' and 'caring with'. This change in mindset also applies for informal helpers.

S.4.1.5 Policy participation in the Wmo 2015

To what extent do local authorities involve residents in the shaping of their Wmo policy, and especially people with mental health problems? What works in this respect, and what does not?

Policy participation is a special form of social participation, involving participation by residents in the process of policy formulation in their municipality. Seen from this perspective, policy participation is a goal in itself, as sharing ideas and discussing with local policymakers are themselves forms of participation in society. Policy participation can also help foster a better match between local policy and the needs of citizens with disabilities (customisation), in turn contributing among other things to their participation and coping ability.

Local authorities are required to record how policy participation is organised locally in relation to care and support, but have a great degree of freedom in deciding how this is structured. In practice, outside the municipal council, local authorities mainly use formal participation structures, such as Social Domain boards. However, three-quarters of Wmo applicants know nothing of bodies such as these. People with mental health problems, intellectual disabilities or dementia are not well represented in formal participation structures. They would benefit from more informal forms of policy participation; these are becoming more common as local authorities increasingly attempt to organise direct and more informal contact with residents with disabilities.

S.4.2 Goals at system level

To what extent are the goals of the long-term care reforms and the associated laws and measures being achieved, from the perspective of the legal system?

The legislator has also set a number of goals at the level of the care and support system. These relate to informal help (taking more care of each other), the quality of the system (where possible, offering less or less intensive forms of professional help as well as more integrated help, rather than more intensive, specialist professional care) and public finances (safeguarding financial sustainability).

S.4.2.1 Taking more care of each other

An important reason for the long-term care reforms was the desire to increase people's involvement in informal help. The idea was that people should take more care of each other and become less dependent on paid and insured care. To what extent do people feel more involved and do they provide more informal help?

Changing opinions on providing informal care between 2014 and 2016

Around two-thirds of people aged over 16 think that caring for parents who need help is mainly a task of the government, not the family. This view was slightly less widespread in 2016 than in 2014 and 2010. Opinions depend on which tasks are involved. However, a majority (69% in 2016) feel that people should help family members who have health problems; around 60% think that people should help friends; and almost 30% that neighbours should help each other. The percentage of people aged over 16 who think that people should help family members when they need it was higher in 2016 than in 2014. The bigger the impact of providing help on the giver, the less people feel they should provide it. At the same time, the percentage who feel that people who need help because of disabilities should receive that help mainly from their social network has fallen sharply (from 41% in 2010 to 23% in 2016). In other words, people more often think that people should take care of each other (as envisaged by the legislator), but not that the care should be provided by the recipient's social network to *the maximum practicable extent*: informal help should mainly be supplementary to professional help, of which there should accordingly be an

adequate supply. Clients themselves do not in fact always want to receive help from their social network and to burden their network with providing this help.

Over a third of people aged over 16 give informal help; this share is constant

Almost a third (32%) of people aged over 16 had offered informal care in the year prior to the survey. Of this group, 70% provide help for longer than three months, but not intensively (maximum eight hours per week). 9% of Dutch citizens are active as volunteers in the care and support sector. This is occasional help and help that is not provided in an organised setting. A high proportion of volunteers also provide informal care. In total, 36% of people aged over 16 give informal help.

People can also be active in neighbourhood or civic initiatives; there are indications of an increasing number of such initiatives, though no hard data are available.

The share of adults providing informal care or acting as care volunteers did not change between 2014 and 2016, though in absolute terms, population growth meant that there were around 50,000 more informal carers and 100-150,000 more volunteers involved in care and support. If we look at the last ten years, we also find that the share of informal helpers is reasonably constant.

In the future, the population aged 45-64 years, who often provide informal help, will shrink and the number of very elderly people, who often need help, will increase. Internationally, the ratio between the number of people of middle age and the very oldest group is referred to as the 'oldest old support ratio'. There are currently 13 times as many 45-64 year-olds as people aged over 85 in the Netherlands; in 2040, that ratio will have declined to five times.¹²

S.4.2.2 Quality of the care and support system

In section S.3 we described the experiences of care applicants with access to care and support and the help they received. This tells us something about the quality of care in the eyes of (potential) clients. Here we look at the goal of 'quality' for the system. The aim of the new system is that where possible less and less intensive professional care should be given and that a more integrated approach should be adopted than in the old system. We look first at whether less intensive professional care is offered in the new system and then at whether a more integrated approach is being adopted, measured by the cohesion and coordination between the different forms of care and support.

Less, and less intensive, professional care

Fewer people living in institutions

The Long-term Care Act (Wlz) has largely succeeded in reducing the use of long-term intensive care in an institution, although to a lesser extent than originally anticipated. Instead of the figure of approximately 200,000 people that was being projected in 2013, there are actually 263,000 users of Wlz-funded care (as at 1 October 2017), including over 12,000 clients who fall under the transitional scheme. To some extent, the higher number of Wlz cli-

ents can be linked to the forecast demographic trends, the rise in the number of older persons, and especially the number of very elderly persons. Of those with an indication for Wlz-funded care, approximately 203,000 (68%) have been admitted to an institution, around 59,000 (20%) receive Wlz-funded care at home and approximately 36,000 (12%) are on the waiting list (both with and without transitional care).

The fact that fewer people are living in institutions is partly the result of the ongoing trend towards remaining at home for longer, in part due to the criteria applied in the care needs assessment (or their interpretation by the ciz). According to ciz staff, the requirement of 'permanent need for 24-hour care close by' or 'permanent supervision' also rules out seriously ill people who do not meet these criteria but who are no longer able to live at home. Approximately 13% of first-time applicants for Wlz-funded care had their application rejected between January 2015 and January 2017. It is not known to what extent they are able to manage despite this, what their quality of life is and whether they receive support or care (private, informal or provided by the local authority or community nursing services).

There are however indications to suggest that people sometimes continue living independently for too long, though the extent and severity of this problem is not known. A proportion of clients on the waiting list and their informal carers say that in reality they are no longer able to manage at home; one in 50 Wmo applicants report this.

No reduction in personalised support for applicants; use of general provisions has increased, but unknown by how much

In the large-scale survey of registered Wmo applicants, we found that four out of five had received personalised support. This corresponds with the finding that most municipalities report that the use of more intensive provisions has not changed. At the same time, they are seeing an increase in use of less intensive support. Only one in 25 Wmo applicants are referred to a general provision, but those provisions can also be used without the intervention of the local authority. More than a fifth of applicants report that they use general provisions. It is plausible that more applicants with intensive and complex care needs are turning to the local authority since the introduction of the long-term care reforms. At the same time, it is possible that other target groups of the Wmo have begun using more general provisions.

No increase in informal care and volunteering; increase in care at home unclear

People who need care and support and who live independently may receive help from informal carers and volunteers. The share of adults giving informal care or volunteering in the care sector is however not increasing (see previous section). Formal help can be provided by the local authority and community nursing service, but there is no uniform national registration of use of Wmo support across municipalities, especially for general provisions, though to some extent also for personalised support. It is consequently not possible to investigate whether people who would have gone to an institution earlier but now stay at home have applied for support under the Wmo 2015. The available data on trends in community nursing are also ambiguous. Whilst we can conclude that the amount of care provi-

ded in institutions is falling, therefore, we cannot say whether this is compensated by an increase in care at home.

Cohesion between the different forms of care and support

Coordination at the interface of the long-term care reforms could be better

There appears to have been an increase in the coordination between those involved with the Wmo 2015, the Zvw and the Wlz. However, there are still a number of problems, especially in the cooperation between local authorities and health insurers. Local authorities find it problematic that health insurers avoid direct contact with many (mainly smaller) municipalities and are difficult to reach. There is also a feeling that the coordination is time-consuming. In the field, there is room for improvement of the coordination of community nursing with other partners, such as local authorities, community social care teams and mental health professionals. This is a condition for a well coordinated, integrated care delivery system in the community. Innovation in care and support also benefits from cooperation between parties from different domains. At present, this innovation is stuttering.

Lack of clarity surrounding personal care

Coordination and cooperation are necessary to ensure that people with long-term and intensive care needs are not disadvantaged by barriers between different legislative regimes. There is a great lack of clarity surrounding personal care. Legally, the majority of personal care is provided under the Health Care Insurance Act (Zvw) (health insurers), with a small part falling under the Wmo 2015 (local authorities). The former includes personal care associated with nursing provided under the Zvw, the latter personal care that is related to support provided under the Wmo 2015. In practice, it is often unclear precisely which activities come under which regime.

Sometimes talks take place between health insurers and local authorities on community-based nursing care, because of a lack of clarity that exists here, too. Coordination sometimes takes place where care delivery is less than optimum for specific groups, such as people with dementia.

Room for improvement in cooperation between local authorities and Wlz parties

Cooperation and coordination between local authorities and parties concerned with the Wlz (care administration offices and ciz) are sometimes also less than ideal. Local authorities lament the lack of contact with these parties, find them hard to reach and experience problems with data sharing. For example, local authorities are not given sight of Wlz care need assessments (due to privacy legislation). ciz staff note that other stakeholders such as local authorities regularly refer people to the ciz, whereas it is clear to them that the person concerned is not eligible for Wlz-funded care. They consider this unfortunate for the referred client, because it causes delays in obtaining the (Wmo) care they need, as the application first has to be processed.

Wlz-funded-care at home less advantageous than care at home funded through the Wmo 2015 and the Zvw

The demarcation between the Wmo 2015 and the Zvw on the one hand and the Wlz on the other as regards the care that people can receive in their home can currently mean that people with long-term and intensive care needs are better off not (yet) applying for Wlz-funded care. This is because clients wishing to receive Wlz-funded care at home (and those receiving transitional care whilst remaining long-term on the waiting list) may be allocated fewer hours of care at home and with a higher co-payment than for care provided under the Wmo 2015 and Zvw (the so-called ‘care trap’). Because an indication for Wlz care is in principle lifelong, clients who regret receiving this indication cannot simply reverse it.

Both local authorities and health insurers sometimes feel that they ultimately end up being the ones offering the helping hand because ‘others’ fail to do so. Health insurers think this because community nursing is a low-threshold service which is ‘easy’ to apply for; local authorities think this because they have a duty to offer help to people in need. The difference in the character of the three legislative regimes may be the explanation for this. Of the three laws concerned (Wmo 2015, Zvw, Wlz), the Wmo 2015 offers the greatest decision-making freedom in dealing with requests for support. The Wlz defines very precisely who is eligible for Wlz-funded care and leaves little room for flexibility.

5.4.2.3 Financial sustainability of long-term care and support

Rise in spending on long-term care and support has levelled off

Expenditure on long-term care and support show a nominal increase every year in the period 2010-2017 (except 2013 and 2015) (in real euro terms). Nominal expenditure remained flat in 2013 and fell by 0.8% in 2015. If we adjust the expenditure for price increases (using the consumer price index), we also find that – again with the exception of 2013 and 2015 – expenditure rises every year. In total, real expenditure on long-term care and support fell by over 0.4 billion euros in real terms in 2015, the year the reforms were introduced. If we compare the real expenditure on long-term care and support with a government projection with unchanged government policy from 2012/2013, it transpires that real expenditure is lower than projected.

Real expenditure rose by an average of 3.3% in the period 2010-2012, fell by an average of -1.1% in the period 2012-2014, and rose again by an average of 0.6% in the period 2014-2017. As a share of gross domestic product (GDP), public spending on long-term care rose from 4.4% to 4.8% between 2010 and 2012, before falling gradually to 4.5% in 2017. The growth in spending on long-term care and support has thus levelled off in real terms.

Reforms have led to a shift in expenditure

If we take an overall view of spending on the Exceptional Medical Expenses Act (AWBZ) and the continuation of the core of that regime in the Wlz, we see that this expenditure peaked in 2012 at over 26 billion euros. The introduction of the long-term care reforms on 1 Janu-

ary 2015 meant that some of the care previously provided through the AWBZ was transferred to the Zvw and the Wmo 2015, leading to a fall of more than 6.5 billion euros in spending on the Wlz in 2015 compared with spending on the AWBZ in 2014. This refers only to expenditure for persons aged 18 years or older (care in kind plus personal budgets). These figures allow for the Wlz subsidy schemes for temporary residential care, community-based treatment and assistance with activities of daily living (ADL). Transferring services to other regimes and no longer providing indications for less intensive care packages for new clients led to a sharp increase in Zvw expenditure in 2015, and the same applied for the Wmo 2015. Spending in the latter two regimes together rose by slightly less in 2015 than spending on the AWBZ/Wlz fell.

Fluctuation in spending on Wmo 2015 and Wlz; spending on community nursing and temporary residential care rising

Nominal (not adjusted for inflation) expenditure on support funded through the Wmo of 2007 gradually reduced in the period 2010-2014 from 5.4 billion euros in 2010 to 4.9 billion euros in 2014, a net reduction of 9%. As stated, expenditure on the Wmo in 2015 increased sharply as a result of the transfer of provisions. Thereafter, expenditure fell slightly in 2016 and rose again slightly in 2017.

Nominal expenditure on community nursing in kind increased over virtually the entire period 2010-2017, with 2013 the only exception to this trend. There was a net increase in this expenditure from 2.3 billion euros in 2010 to almost 3.4 billion euros in 2017 (0.3 billion for community nursing funded through the Wlz plus 3.1 billion for community nursing under the Zvw), an increase of 47%. The increase occurred both before and after 2015. The funding for temporary residential care, which was transferred to the Zvw in 2017, and for which a separate subsidy scheme existed in the Wlz in 2015 and 2016, saw an increase in spending in both 2016 and 2017 (50% for both years together).

Spending on institutional care in kind funded through the AWBZ/Wlz, including institutional care transferred to the other legislative regimes, rose in the period 2010-2012 from 16.2 to 18.9 billion euros (a total increase of 17%) and to 19.0 billion euros in the period 2012-2014 (total increase 1%), before falling in 2015 by 0.1 billion euros and rising slightly again in 2016 and 2017.

Influence of client co-payments

There is a difference in the trend in expenditure between services for which clients are required to pay a contribution and those for which they are not: spending on institutional nursing and care funded through the Wlz, spending on Wlz-funded community nursing and community-based Wmo personalised support (often requiring a client co-payment) rose less than spending on community nursing funded through the Zvw (no client co-payments), or even fell. One exception is the rapidly growing use of the full home care package (vPT) under the Wlz. Apart from the effect of client co-payments, the above explanations also play a role in the trend in expenditure.

5.5 Relationship between goal achievement and implementation

To what extent is the achievement of the goals of the long-term care reforms related to the implementation of the associated laws and measures and to the voluntary action of citizens? Which other factors play a role? Are there any desirable or undesirable side effects?

In the foregoing we saw that the number of older people *living independently for longer* is increasing. This trend was already under way before the reforms and is reinforced by the policy of encouraging people to live independently for as long as possible. The stricter access criteria for admission to a long-term care institution have also contributed to this. It is not clear to what extent the Wmo support and community nursing services available in a municipality make older people want to continue living at home for longer, though users do say this help facilitates living independently for longer. The moral appeal from the government to people to become more independent may also play a role here. Although Wlz-funded care can be provided in the home, the additional criterion applies that it must be possible to deliver this care cost-effectively. This means that continuing to live independently is not possible in all cases.

One factor which stands apart from the policy on long-term care is that more people are remaining healthy for longer,¹³ and for that reason alone are able to live independently for longer. It is important in this regard that there are sufficient homes that are adapted to the impairments that older people have or could develop. Another important factor is the social network; the informal help provided by this network is important in enabling people to live independently, including those who have an indication for Wlz-funded care. The social network can also play a role in organising professional care and support. Possible side effects of living independently for longer are loneliness, especially for those living alone, and overburdening of informal carers. The increased pressure of work for nurses, GPs and their practice nurses is another side effect.

Another finding is that no increase can be observed at group level in *the social participation, coping ability and quality of life* of people living independently with disabilities, or users of personalised Wmo support. The amount of *loneliness* in the population is also not declining. Given the trend that more people with relatively intensive and complex problems (are continuing to) live independently, a deterioration in this situation might have been more likely. As regards the practical implementation, we have seen that in recent years local authorities have focused particularly on continuity of support and helping people who were previously receiving residential support or care funded through the AWBZ. In the experience of users, this support generally benefits their participation and coping ability and helps reduce loneliness. There are however limits to the extent to which people with disabilities can participate and continue to cope alone, even with care and support. For some groups, stabilisation may be the best they can achieve.

As regards residents of institutions, we have seen that they appear to have gained more *control* in recent years. The use of care plans and regular reviews of those plans have been particularly instrumental in raising attention for the wishes of clients and for giving them more control where possible. Involving their social network and volunteers more closely contributes to customisation and to the client's *quality of life*. However, they can also reduce the client's degree of control if they are inclined to take matters out of the client's hands. Professionals also point to a tension between giving control to the client and the risk of unsafe care. The envisaged cultural change in which professionals shift the emphasis in their work from 'caring for' to 'caring with' and 'ensuring that' is by no means complete. The pressure of work experienced by care workers, and the more complex care needs of people who are admitted, mean that staff sometimes opt for the 'old, familiar working practice'. One side effect of the goals set by the government can then be an increase in pressure of work: time and resources are after all finite (and rigidly defined within care packages).

Volunteers in Wlz-funded care appear to be taking over more and more tasks from professionals, especially in relation to welfare. This can lead institutions to become dependent on volunteers and, without them, to lose the ability to devote sufficient attention to client welfare. Some care professionals consider it an impoverishment of their work if they no longer have time to undertake welfare activities with their clients.

If we look at the *perceived quality of formal care and support received*, the conclusion is that opinions are predominantly positive: the majority of people receiving formal support and care at home are satisfied with it. This applies for Wmo applicants receiving personalised support from the local authority and also for recipients of community nursing services. In many cases, people living at home with long-term care needs also receive informal care. It is not simple to discover how clients experience the quality of Wlz-funded care in institutions; some of these residents are not or no longer able to say what they think of the care they receive. Professionals took a positive view of the use of care plans (more scope for customisation) and the greater involvement of clients' social networks. Factors other than those we studied also play a role in perceived quality of care, such as the time that nursing staff have for residents, the recreation opportunities and the ability to go outside.

The goal of improving the quality of the care and support system in terms of *less intensive professional care provision*, in combination with the goal of *greater financial sustainability of the system*, has been largely achieved. Partly due to the admission criteria for Wlz-funded care, fewer people are receiving care in institutions. This in turn has contributed to the levelling off of the growth in expenditure on long-term care and support. A side effect of the access criteria for admission to Wlz-funded care in an institution is that people sometimes appear to continue living at home for longer than is justified and/or desirable, and greater pressure (of work) for first-line professionals and informal carers (as referred to earlier). A shift is also expected in municipalities away from more intensive – and therefore more expensive – individual (personalised) support to less intensive and cheaper general provi-

sions. The requirements imposed by the Wmo 2015 for the local authority assessment could contribute to this. Local authority assessment officers are expected first to look at what people can do for themselves and whether informal help or general provisions could offer a solution, before offering personalised support. The registered Wmo applicants whom we surveyed, however, were generally allocated personalised support after an assessment interview. Qualitative research shows that local authorities and assessment officers do endorse the principles of the Wmo 2015, but that these are not always easy to put into practice. For example, care applicants do not always have a social network of which they are willing, able and comfortable to ask even more. For care applicants with complex problems, general provisions are probably inadequate. Nonetheless, outside the formal application and local authority assessment, there can definitely be an increase in the use of general provisions.

An important point for attention with regard to the foregoing is the increased complexity of the care needs of clients who live at home for longer. According to GP practice nurses and professionals responsible for access to Wlz-funded care, there is a (growing) number of clients with a need for institutional care which is not being met. The 'gap' may arise because the necessary care cannot be organised and delivered quickly enough for clients living at home with complex care needs, or because of a missing link in the available care. Interviewed GPs, for example, point out that provisions intended to facilitate living at home for longer have been cut back in some municipalities, for example help with the household and welfare provisions. Hospitals report that people are ending up in A&E wards who should not be there. There appears to be a lack of provision at present for clients with a temporary need for intensive care and supervision without there being a medical need for this, or for clients with a permanent need for slightly fewer hours of care close by or slightly less permanent supervision. This need may be the result of an accumulation of smaller problems and a reduced ability to exercise control, lack of care and support at home from a partner or informal carer, or the inability to organise their own lives, including their residential and care situation, in a way that ensures their well-being.

We also looked at the goal of improving the quality of support and care in terms of an *integrated approach*: the cohesion and coordination between the different forms of formal care and support. We saw that the long-term care reforms (in combination with the introduction of the Youth Act and the Participation Act) have encouraged the formation of community social care teams in municipalities. Additionally, local authorities and health insurers have begun working together more. However, there is still no integrated access structure¹⁴: although they work together in some community social care teams, few community nurses make assessments for Wmo 2015 support and Wmo consultants do not make assessments for nursing care. GPs sometimes do and sometimes do not play a role in guiding people towards care and support. There is currently also little by way of innovative, integrated care provided by collaborating providers. Several explanations can be offered for this. First, the current division of responsibilities between actors and the segregated

funding flows encourage parties to remain ‘within the boundaries’ of their own domain. Few local authorities, health insurers and care providers yet appear to be seeking out the limits of the regulations. Second, there are differences in the culture and language of the different actors: health care professionals such as community nurses and GPs are readily able to find each other, but the contact with Wmo consultants from the local authority sometimes leaves something to be desired. Third, professionals say that cooperation and coordination – aside from the benefits it offers – also takes a lot of time and energy, which they do not always have.

The goal of *taking more care of each other* does not appear to have been achieved yet. This is also much harder for policy to influence. In practice, people are not taking any more care of each other than a few years ago. This appears to be due not so much to the implementation practice as to the assumptions underlying this goal. We look at this and other assumptions underlying the long-term care reforms in the next section.

5.6 Concluding discussion

At the time of publication of this report (mid-2018), we can state that the implementation of the long-term care reforms is under way but not yet complete. The foregoing shows that the implementation practice is moving in the envisaged direction on some points and not (yet) on others. In the previous section we investigated whether the achievement of goals may be related to the implementation practice. In this section we investigate whether there is a relationship with the assumptions underlying the long-term care reforms.

5.6.1 Review of underlying assumptions

The assumptions underlying the long-term care reforms can be summarised as follows:

- people with disabilities are able to live more independently, participate more and live in their own homes for longer, and wish to do so;
- people are willing and able to take more care of each other;
- local authorities and professionals are willing and able to place greater demands on the capacities of citizens and their networks;
- local authorities, health insurers and care providers are willing and able to work together in an integrated approach.

The fact that people with disabilities are living at home for longer than in the past is evident from the trend data for older people living independently. Whether living at home for longer always delivers greater quality of life for the older person concerned and their informal carers than admission to an institution is difficult to say. There are indications that some older people are not receiving the necessary or appropriate care at home. This can adversely impact their quality of life, their health may deteriorate and there is a risk that their partner or informal carer will become overburdened. In particular, people living alone

with limited ability to control their lives, a small social network and poor health do not meet the ideal of the independent citizen with a supportive network, the resources and the will to organise their residential and care situation adequately themselves.

We do not know whether people with disabilities are able and willing to be more independent than in the past. However, this is an important assumption which has had an impact on institutional care, social support and community nursing. What is clear is that there is a group of vulnerable people for whom independence and participation is a step too far. The government would be wise not to underestimate the size of this group and to ensure that there is a sufficiently large safety net of care and support.

It is also questionable whether participation should be the main goal if it is interpreted primarily as 'participation in activities'. The need for such participation varies from person to person and often declines with advancing age. Focusing on goals that are difficult to realise for these groups, such as participation at the same level as people without disabilities, can exacerbate feelings of inadequacy and disadvantage. There are calls in the scientific literature for a reappraisal of vulnerability and dependence. Accepting that people with disabilities are dependent on others, and that a useful life can be different for someone with disabilities, could actually create greater equality between people

Based on our study, a question mark can be placed alongside the second assumption. Given people's opinions and behaviour, it is reasonable to assume that they will not spontaneously offer much more in the way of informal care and voluntary support than they do at present. In addition, there is the increasing numerical imbalance between people of middle age (who provide a high proportion of informal care) and older people (who are strongly represented among those who need care). If the societal reservoir of potential informal carers is not as large as hoped, the third assumption will also have little basis. Local authorities and professionals may well have the intention of handing over a larger share of care delivery to informal carers, but we have seen that this is not always possible in practice. This undermines the assumption that a substantial shift can be achieved from formal to informal help. Then there is the question of whether this care substitution is actually always a good thing from the perspective of quality of care. Moreover, some people with a need for care do not wish to be systematically dependent on their loved ones, while others find it difficult to ask for help from their (often already heavily occupied) relatives and friends.

The assumption underlying the goal of a cohesive system of long-term care and support is that local authorities, health insurers and care providers are willing and able to work together at the interface of the Wmo 2015 and the Zvw. Currently, difficulties are being experienced with respect to the ability to do this; separate regulations, funding, cultural differences and a lack of time all create obstacles. If we also bring the Wlz into the equation, with its own access route and providers, it becomes apparent that there are in fact three largely separate silos operating within the long-term care and support system. Clients discover this when they seek help from more than one of these domains simultane-

ously or successively: there is no party with overarching control over the different domains to help organise and coordinate the care. Client support workers and GPs also by no means always fulfil this role, and in practice this then often falls to informal carers in so far as they are present and able to do this.

5.6.2 What next?

The implementation of the long-term care reforms has only been under way for several years and is still in full swing. Over time, teething troubles – such as unfamiliarity with the new regulations by professionals and lack of contact between providers from the different domains – can be overcome as experience grows. In many municipalities, policy and practice in relation to social support are still developing. The cultural change from ‘caring for’ to ‘ensuring that’ in long-term care institutions still has a long way to go. However, not all the problems will simply disappear with the passage of time; solutions will also have to be actively developed. In our view, the government has two tasks here: repairing and reappraising. By repairing we mean tackling the problems that are occurring now within the system. Examples include improving client support and the provision of information on the access routes to and within the reformed long-term care, developing provisions which can fill the ‘gap’ between care and support at home and in long-term care institutions, and installing coordinators who can organise and coordinate care across the different domains. Reappraisal means reflecting anew on the policy ideology that underpins the present system. This report shows that some goals are not achievable for all groups with a care need, and that some of the underlying assumptions are not tenable. A reassessment of the goals and assumptions could ultimately lead to modifications within the system or to the system as a whole. First, however, a fundamental discussion will be needed about what is desirable and realistic within the system of long-term care and support.

5.7 Gaps in knowledge

This evaluation provides a good picture of the status of the Dutch long-term care reforms (HLZ) in 2016/2017, based on the perspectives and experiences of a large number of stakeholders. SCP deliberately opted to place the emphasis on the experiences of applicants, clients, informal carers and professionals. A number of (hard to investigate) aspects and groups have been left out of the picture as a result; we list the main ones here and conclude with the recommendation to continue monitoring.

Non-use and its consequences

It is not known how many people who need care or support receive it, nor what the reasons for non-use may be (e.g. assessment criteria, inadequate supply, client co-payments, lack of skills). Future research could focus on the causes and effects of this non-use (e.g. on participation or quality of life) and could investigate whether this non-use and its consequences differ between subgroups. It could also investigate to what extent people whose

application for personalised Wmo support or Wlz-funded care is rejected are able to cope adequately.

Consequences of living independently for longer

Use of care in institutions has clearly declined because the Wlz applies different, more stringent access criteria than the old AWBZ. It is not known to what extent people who would have gone to an institution in the past but who now remain at home have applied for help under the Wmo 2015, the Health Care Insurance Act (Zvw) or the Youth Act, and to what extent they are able to cope. Follow-up research could focus on the interface between the Wmo 2015 and the Zvw on the one hand and the Wlz on the other. To what extent do people who are not eligible for Wlz-funded care but who have serious disabilities receive adequate care and support? Are there people who remain living independently for too long? If so, in which situations does this happen, what are the causes and what problems do these people then face?

Trends in use

We are unable to answer the question of whether people with the same disability receive the same amount and the same adequacy of care after the long-term care reforms as before, because of a total or partial lack of data on use and trends in social support. For example, we have no information on the use of general provisions and informal or private help. Consequently, it is also difficult to determine to what extent a shift is taking place from use of more intensive to less intensive forms of support. To obtain this information, when constructing registers central government would have to deviate from the principle of decentralisation and require local authorities to record the use of general provisions in a uniform way. Population surveys would be needed to obtain a broader insight into the use of care and support (including informal and private help).

Permanent monitoring

The reforms in long-term care are still in full swing, and it is therefore important to continue monitoring developments. The data from this evaluation could then serve as a sort of baseline or reference measurement. Developments could be monitored by focusing on a number of key aspects. If we start from the perspective of the citizen, for example, this would entail gaining a periodic insight into the achievement of the goals of the reforms and the individual legislative regimes, for example in terms of the participation, coping ability and quality of life of people with disabilities who do or do not use different forms of care and support. It is also important to maintain a clear view of access to and use of different forms of support, for example personalised support as well as informal and private help and general provisions. Finally, it is important to continue monitoring the consequences of the reforms for those who provide informal help, for example by studying the extent of this help, the opinions of those who provide it, the burden they experience and the support they receive.

Research focused on monitoring implementation practice could concentrate on those aspects that are currently still in development or which could be improved further. Examples include coordination and cooperation between professionals working from within different legislative frameworks, but also the organisation of access to care and support: how are citizens provided with information, how is client support deployed, do local authority assessment officers have the knowledge and skills they need, including in relation to specific target groups?

One question that needs to be answered here is whether the central government's overall system responsibility extends to obtaining a picture of (local) implementation practice, or whether it is sufficient to monitor the achievement of goals for people with disabilities.

Notes

- 1 Ridder, Josje den, Paul Dekker & Pepijn van Houwelingen (2017). *Burgerperspectieven 2017*³. The Hague: Sociaal en Cultureel Planbureau (Netherlands Institute for Social Research).
- 2 Combating violence in relationships of dependency (Wmo 2015) and community-based treatment for people with sensory disabilities (Zvw) are left out of consideration in this evaluation. Also, no evaluation was carried out of the placement under the Zvw of the second and third year of treatment involving admission to a mental health care institution. The study devotes limited attention to temporary residential care (initially funded through the Wlz, later the Zvw).
- 3 This can be regarded as a goal both at client level and system level (see chapter 3). In this report we treat 'quality of care and support' as one of the system goals. We also discuss the experiences of clients and informal carers as an indicator for their perception of the quality of care.
- 4 The committee was chaired by Professor dr. Louise Gunning-Schepers. The members were Professor dr. Caroline Baan, Professor dr. Werner Brouwer, Angelique van Dam, Professor dr. Petri Embregts, Irma Harmelink, MBA-H, drs. Ineke Smidt and drs. Rieta van Staalduine. Observers on the supervisory committee were Marinka Wildeman, MSc (Ministry of Health, Welfare and Sport) and drs. Bob van der Meijden (Association of Netherlands Municipalities).
- 5 This took place during a reflection meeting chaired by Professor dr. Louise Gunning-Schepers. The following were in attendance: Ineke Boerefijn (College for Human Rights), Betty de Groot (Tintengroep social welfare organisation), Désirée te Marvelde and Carlijn van Aalst (Netherlands Organisation for Health Research and Development – ZonMw), Michael Mekel (Council for Public Administration), Adrie van Osch (BrabantZorg care organisation), Jeanine Stam (National Ombudsman) and Marianne Veenstra (MEE Zuid-Holland Noord care and support organisation).
- 6 Including professionals from other organisations commissioned by the local authority.
- 7 We look here at social participation in the broadest sense: participating in sociocultural activities and leisure activities (association/club membership, cultural and religious activities and use of neighbourhood amenities), volunteering and informal care, participation in the labour market and education, and having a say in the local administration.
- 8 This refers to what people can do themselves and with the help of others in areas such as the household, mobility, filling their day, personal care and managing their finances.
- 9 People who not only applied (or for whom an application was made) to the local authority but who actually received and use support.
- 10 Emotional loneliness concerns the lack of emotional connectedness, a close intimate bond with one other person (in most cases a partner). Social loneliness is a lack of social connectedness in a network of social relations.

- 11 In this report, quality of life is interpreted as people's satisfaction with their lives, in other words their subjective quality of life.
- 12 International measures are often based on the ratio between 50-74 year-olds (rather than 45-64 year-olds) and people aged over 85. Using this measure, there are currently 15 times as many 50-74 year-olds as people aged over 85 in the Netherlands, falling to six times as many in 2040 (see also chapter 9).
- 13 See <https://www.staatvenz.nl/kerncijfers/levensverwachting-goed-ervaren-gezondheid> and CBS (Stat-Line), accessed on 6 April 2018.
- 14 The National Ombudsman has also referred several times to problems with the access to long-term care and support, including in May 2018.