

Summary

An evaluation of the Social Support Act 2015

Experiences of applicants, informal carers and assessment
officers

Peteke Feijten
Roelof Schellingerhout
Mirjam de Klerk
Anja Steenbekkers
Peggy Schyns
Frieke Vonk
Anna Maria Marangos
Alice de Boer
Liesbeth Heering

Original title:
Zicht op de Wmo 2015
978 90 377 0842 4

The Netherlands Institute for Social Research
The Hague, October 2017

Conclusion, courses of action and summary

Peteke Feijten and Roelof Schellingerhout

The Netherlands Institute for Social Research (SCP) carries out the evaluation of the reform of long-term care on behalf of the Dutch Ministry of Health, Welfare and Sport. Part of this evaluation involves a survey of applicants, informal carers and assessment officers. This survey examined whether the Social Support Act 2015 (Wmo 2015) was helping applicants achieve the goals in respect of independence and societal participation, how local authorities were providing social support for citizens with disabilities and how the connection with the community nursing service was organised. The data from the survey cover the last months of 2015 (for the application and the assessment) and the first half of 2016 (concerning the envisaged goals of independence and participation). The survey thus mainly covers a transitional period.

This was a quantitative survey involving a good deal of fieldwork. It was carried out between 9 March 2016 and mid-December 2016 in 39 Dutch municipalities.¹ It broke down into a survey of applicants for Wmo support,² a survey of informal carers of applicants and a survey of local authority assessment officers³. Face-to-face interviews based on structured questionnaires were used for applicants. Assessment officers and informal carers were surveyed using structured paper or online questionnaires. The three constituent surveys were largely carried out in the same municipalities, enabling the perspectives of different actors to be compared directly. While the findings from this study cannot be generalised with complete certainty to the entire population (applicants, their informal carers, assessment officers and local authorities), it is currently the only study in which applicants, assessment officers and informal carers of applicants have been surveyed on this scale. The results provide a broad picture of the variation in experiences of applicants, informal carers and assessment officers with the Wmo 2015 and expose a number of problem areas. This chapter addresses the research questions and presents a number of policy recommendations and courses of action derived from the study findings. This is followed by a summary of the findings.

5.1 Conclusion

The survey findings show that in late 2015/early 2016, the implementation of the Wmo 2015 and the achievement of envisaged goals for applicants was broadly in line with the aims of the Act. The municipalities surveyed all operate a system of access to social support for people with a diversity of disabilities and support needs. In most cases, the support received enabled applicants to retain their independence and participate in society. The law sets a number of requirements regarding access to social support, beginning with the requirement to record every application. This study shows that most municipalities did indeed record every application.⁴ They carried out an assessment of the support need of

the vast majority of Wmo applicants in this study. Assessment officers compiled a report for virtually all applicants, though in one in five cases they did not submit this to the applicant. According to applicants themselves, a third did not receive a report. Four out of five applicants discussed their support need with an assessment officer. According to assessment officers, they frequently or always raised the topics required by the Act, such as the purpose of the support. Applicants, however, did not always recall this being the case, with varying topics not being raised in between two and five of the ten assessment interviews. The Act also prescribes that applicants must be informed about the possibility of submitting a personal support plan and of the possibility to access independent client support. Assessment officers felt that they regularly inform applicants about these possibilities, while one in six and a quarter of applicants, respectively, say they were informed. It thus appears that the legal requirements in relation to the assessment are not always being met, especially in the recollection of applicants. Assessment officers report substantially more often that they often or always meet the statutory requirements, and these two findings provide an important signal: most local authorities have structured their Wmo access procedures in accordance with the legal guidelines, but applicants do not always recognise or remember this as being the case. The law contains requirements designed to guarantee that the assessment is carried out with all due care and forms a good basis for a decision on providing social support. This finding therefore begs the question of to what extent these assessments always provide this solid basis.

The study revealed wide variation in the way local authorities realise access to support provided under Wmo 2015, but all local authorities in this study were working on the transformation in their own way. Detailed analyses of six municipalities confirmed this variation. As well as variation, however, there were also correspondences. For example, most local authorities used area-specific teams and the assessment officers had as a minimum a higher professional education level (hbo). This suggests that access to Wmo 2015 had been configured by local authorities in line with the frameworks set in the Act, utilising the possibility of arranging that access according to their own insights. Many assessment officers also felt that Wmo 2015 offered better opportunities for collaboration with other domains, though they also regularly encountered problems in that collaboration. Based on these findings, the 'new' system introduced by Wmo 2015 appears to offer opportunities for improving the coordination between youth care services and Wmo 2015 social support/community nursing (because of the greater scope for local policy), but at the same time leads to potential new pinch points (e.g. lack of clarity regarding allocation of responsibilities).

In several cases, assessment officers reported that they knew too little about the problems facing certain groups, especially people with mental health and psychiatric problems, people with psychogeriatric problems such as dementia and people with multiple problems (e.g. homelessness and substance dependency). Applicants themselves were sometimes very unhappy about the expertise of assessment officers regarding their disability. Lack of knowledge by local authorities about specific groups seems to be a stubborn problem, for the Wmo evaluations for 2007-2009 and 2010-2012 had already found that local authori-

ties have difficulty obtaining a good picture of the problems faced by people with mental health problems (De Klerk et al. 2010 and Kromhout et al. 2014).

Informal carers were more critical than applicants, both regarding the application process for those for whom they were caring and regarding the attention for their own position.

A substantial proportion of informal carers stated that the assessment officer paid no attention to the care situation of the applicant (for whom they were caring) in the assessment interview. This picture is confirmed by the findings of the assessment officers. The idea behind discussing the informal care situation is that the informal carers can be given support where needed to enable them to continue caring for as long and in as good health as possible, thus delaying the need to call on professional support. The law placed great emphasis on informal help as a precursor to publicly funded help. Informal care can only fulfil this central role if informal carers are supported and not overburdened; if local authorities are unaware of the situation of informal carers, the latter is a real risk.

There was a notable difference in the experience of applicants for whom the assessment did or did not lead to the allocation of personalised support (even allowing for personal characteristics such as severity of the disability); both satisfaction with the assessment and its outcome, as well as the perceived independence, were significantly lower among applicants who were not allocated personalised support. Logically, the outcome of the assessment should make no difference: assuming that a proper problem analysis is performed, that the proposed support arrangement is an adequate solution for the problem and that the solution has come about in discussion with the applicant, one would expect the experience to be uniform. Yet it seems that, for many, personalised support is still the 'holy grail', and that applicants feel less supported by solutions which involve them to some degree 'helping themselves'. The significantly lower satisfaction among applicants who were not allocated personalised support also suggests that in late 2015/early 2016 people expected that the local authority would provide them individual support in the first instance.

While the goals of Wmo 2015 for people with disabilities – independence, participation, continuing to live at home for longer with minimum loneliness, and quality of life – were achieved for some applicants, this was not the case for a substantial proportion. The most striking results were that a quarter of applicants do not participate in any of the ways covered in this study and that almost a fifth feel seriously lonely.

Over a fifth of applicants were allocated personalised support. Although the law does not stipulate that the allocation of personalised support must be reduced (compared with the past), other provisions and measures do suggest this, such as the reduced budget for household help, the greater emphasis on 'self-help' and the adage of 'no allocation, unless' (TK 2013/2014a: 30). The high share of personalised support allocated appears out of line with this implicit policy objective, though there are a number of caveats here. First, it is quite possible that fewer people reported a need for support to the local authority or deferred doing so than before 2015, possibly because they were persuaded by the government's moral appeal or were discouraged by media reports about changes to the care system. They may have provided their own solution, from their own network, for longer than in the past – basically what the law envisages. And when they finally did turn to the local

authority, they probably have had more serious problems than under the 'old' Wmo, and it is then not surprising that they were in many cases allocated personalised support.

Whether the Wmo applicants in this study had more severe disabilities than applicants in the Wmo evaluation 2010-2012 (Kromhout et al. 2014), is difficult to determine because the target group (and thus the respondent group) for the Wmo 2015 is more diverse than in the 'old' Wmo, and because this study focused on 'applicants' and the 2012 study on 'clients'.

People with a support need who did not refer themselves or who were not registered by the local authority as applicants were by definition not included in this study. Second, it is plausible that Wmo applicants who were allocated a 'self-help' solution or were referred to general provisions were less inclined to take part in this study (e.g. because they more often felt that the topic 'support after contact with the local authority' did not apply to them). If this is the case, the share of personalised support allocations as a proportion of all support arrangements will be lower in reality than suggested in this study.

One in 20 applicants declined to accept all or part of their allocated personalised support because of the required co-payment. The intention of the co-payment system is that people should make a contribution that is appropriate for their financial means. Evidently, this contribution was still too high for these people (in their own view). They may subsequently have arranged support themselves (at lower cost). However, if declining the personalised support means that people have to manage without any support, this could negatively impact their independence, participation and the burden placed on their informal carers. Some applicants who received no personalised support felt that this had negative consequences (in their own view); a third reported that they stayed at home more often than they would like, and a sixth said they had fewer social contacts than they would like. These are undesirable outcomes in the light of the Wmo objectives of 'participation' and 'minimal loneliness'. This is of course a subjective measurement – people with 'fewer social contacts than they would like' are not by definition lonely. Nonetheless, these findings are an indication that when offering a solution there is always the risk that underlying objectives will not be achieved, perhaps because people's own resources are overestimated during the assessment or because the 'question behind the question' did not emerge, for example due to lack of knowledge about specific groups on the part of the assessment officers.

This study also measured the resilience of applicants, as it is known from the literature that resilience has a positive impact among other things on the ability to deal with illness and setbacks. The findings of this study confirmed that resilient applicants had better outcomes than less resilient applicants: they were more independent, had more social contacts, felt less lonely, more often took part in leisure activities, were more satisfied with the solution based on the assessment and more satisfied with their lives. Resilience is partly related to character, but also to skills that can be learned. This could offer avenues for skills training for Wmo applicants and those associated with them.

The applicants' survey was carried out in 28 municipalities. Applicants in a given municipality all deal with the same local authority configuration of Wmo 2015, and in some cases (especially in smaller municipalities) spoke to the same assessment officers. The statistical

analyses accordingly calculated the extent to which applicant outcomes corresponded with their shared municipality.⁵ The analyses of the access and application procedure confirmed that the specific municipality is relevant, but the analyses of the envisaged objectives (independence, etc.) did not. There are evidently so many other aspects which influence the latter that the influence of the municipality disappears.

The period about which respondents in this study were questioned (autumn 2015, the end of the transitional year) was a busy period for many assessment officers and an uncertain one for many applicants. This may have had an extra impact on the perceived quality of assessment interviews and the way the assessment was carried out. Roughly a fifth of applicants and informal carers in this study found the assessment to be a negative experience, whereas the assessment is actually the crucial element in providing personalised social support. To achieve the objectives of the law, constant efforts will have to be made to hear *all* applicants and their informal carers and to offer them appropriate support. During the period studied, the fallout from the reforms had by no means fully settled, and this probably explains, at least partly, why certain implementation elements had not been introduced everywhere and that some applicant outcomes left something to be desired. A study of these topics after a few years could shed light on which aspects of local implementation and which applicant outcomes have improved and which require ongoing attention.

This study pinpointed a few specific signals of lack of clarity in the law regarding access to care and support, for both applicants and assessment officers. Assessment officers regularly experienced difficulties in the transition of clients from youth care to Wmo support, with some young people being left without help for a long period, while the open responses revealed that some applicants and their informal carers found accessing (the right) support to be a time-consuming and frustrating process. This could affect their independence, participation and well-being, and could have a discouraging effect on some, possibly leading them to avoid care.

Comparing different perspectives in a combined study produced a number of interesting results. For example, applicants were less critical than their informal carers, while assessment officers, despite having a more positive view of their own functioning, often highlighted the same problems as applicants and informal carers. Our findings regarding sticking points in implementation often match those from other studies, providing confidence in the reliability of the data. Obtaining the cooperation of local authorities during our fieldwork period was difficult, and it proved impossible to achieve the targeted number of municipalities. This experience made clear that dependence on local authorities is a risk factor in performing this kind of study. To optimise the chance of cooperation from local authorities, it would be necessary to ensure that the fieldwork does not clash with the implementation of the mandatory client experience surveys by local authorities themselves, or else to arrange with local authorities that the fieldwork for the national evaluation survey could be combined with the client experience surveys.

People with a need for support because of a disability who had not referred themselves to the local authority or whose application had not been registered were not included in this

evaluation. It is very difficult to involve these people in quantitative research, making it virtually impossible to collect statistical material on them. This study did however include applicants who did not apply for personalised support. That is an improvement compared with the 2007-2009 and 2010-2012 Wmo evaluations and with many register data, in which this group was/is not included. This study also has an advantage over studies for which participants were able to refer themselves or were drawn from a panel; the respondents in this study were randomly selected and had no direct interest in participation in or the outcome of the study, thus improving the reliability of the findings.

5.2 Courses of action and recommendations

A number of options and recommendations have been derived from the conclusions of the study which could be useful in the further development of the Wmo policy and its implementation in practice.

Independent client support and personal support plans are tools provided by the law with a view to ensuring that applicants are well prepared to engage in dialogue with the local authority. They are little used and little known, but further questioning revealed that a proportion of applicants would benefit from them. The provision of information on these tools could therefore be improved.

- (Independent) client support officers: draw your role to the attention of potential applicants, for example in community centres and general practice surgeries.
- Local authorities/assessment officers: draw the availability of these tools more actively to the attention of applicants, for example by not only providing written information but also by always informing them verbally (during the first contact) about the existence of these tools.

The lack of knowledge among local authorities/assessment officers about certain groups, such as people with mental health issues, is a stubborn problem.

- Training providers and trainers: devote more attention to specific Wmo target groups, especially people with mental health problems, with dementia and with multiple problems (e.g. people who are homeless and substance-dependent).
- Local authorities: when recruiting new assessment officers, give more weight to knowledge about specific Wmo target groups. If this is not feasible for smaller municipalities, (further) regional collaboration in conducting assessments could offer a solution.

Many local authorities are digitalising their services (further), but only a small proportion of applicants in this study made a digital application, suggesting that digital contact is not well suited to the Wmo target group.

- Local authorities: beware of an overly one-sided focus on digital service delivery for older people and people with disabilities.

The loneliness experienced by applicants for Wmo support was considerable (one in five felt seriously lonely), but the proportion of applicants citing loneliness as the reason for their application was much lower. Loneliness thus appears to be a topic that people do not typically report, whereas it is certainly relevant.

- Local authorities and training providers: ensure that assessment officers have sufficient (conversational) skills to bring to light any loneliness, including where this does not appear to be immediately obvious.

Applicants who were allocated personalised support reported higher independence levels and were more satisfied about the assessment and the solution offered than applicants who were allocated 'self-help' solutions. This suggests that personalised support is regarded as a more adequate solution than a 'self-help' solution. In principle, this difference should not exist, if we assume that every solution is tailored. Equal acceptance of personalised support and self-help solutions could be fostered by giving assessment officers the skills to drill down into the 'self-help' capability of applicants and by offering a broad, integrated palette of general provisions.

- Local authorities and assessment officers: when allocating solutions which do not include personalised support, be extra careful to ensure that the applicant finds this acceptable and is offered sufficient support to enable them to utilise their own self-help capability.
- Local authorities: continuously develop the range of general provisions available so as to continue meeting the support needs of people with disabilities as adequately as possible.

This study pinpointed a few specific signals of lack of clarity in the law regarding access to care and support, for both applicants and assessment officers. Assessment officers regularly experienced difficulties in the transition of clients from youth care to Wmo support, while some applicants and their informal carers found accessing (the right) support to be a time-consuming and frustrating process.

- Local authorities: improve the integration of (access to) support governed by different decentralised regulations.
- Local authorities, implementing agencies and client support officers: provide people with a support need with complete and correct information about where they can access the help they need.

Applicants with high resilience were often found to have better outcomes than applicants with low resilience.

- Local authorities, welfare organisations and patient associations: offer people with a support need training to strengthen their resilience.

The assessments by no means always addressed the care provided and the burden borne by the informal carer, even when the carer was present during the assessment. Many informal carers were dissatisfied with the contact with the local authority regarding the care recipient or their own support needs. Many of them said they often felt unheard.

- Local authorities: devote more attention to informal care in the assessment and take sufficient account of the informal carer in allocating support. More generally: give consideration to informal carers, even when they do not push themselves to the foreground.

Roughly a sixth of informal carers expressed a desire for a greater say in the overall care provided to the person they were caring for when professional caregivers were also present.

- Caregivers and support workers: work together with informal carers and give them a say in the care provided, especially in the allocation of care times and who provides which care how often.

Some informal carers in this study did not feel they had the necessary expertise to perform certain actions.

- Caregivers: support informal carers in performing certain tasks so that if possible they can learn how to do it themselves.

Providing good support for informal carers means devoting more attention to the accessibility and familiarity with the available support, so that informal carers can ask for it in good time.

- Local authorities (Wmo service desks, informal care help desks, community social care teams): seek out informal carers more actively to inform them and offer support.

One in 20 applicants declined to accept all or part of their allocated personalised support because of the required co-payment. If these are capable applicants with their own organisational skills this is not a problem, but in other cases it may be.

- Local authorities: discuss with the applicant whether the solution chosen is financially feasible and enquire after some time whether the solution proposed following the assessment has been realised. This could reveal that the solution is not financially feasible, enabling a solution to be sought together with the applicant.

5.3 Summary

Research question 1: To what extent are the goals of the long-term care reforms and the associated laws and measures (social participation and independence, living independently for longer, less loneliness and the best possible quality of life) being achieved for Wmo applicants?

Many applicants not achieving Wmo goals of independence and participation

Independence is a multifaceted concept. Around a quarter of applicants were not able to manage their household despite receiving help and support, and a fifth had difficulty in moving around, again despite help and support. A quarter of those unable to spend their day usefully independently were also unable to do so with help and support. Finally, applicants were asked to rate their own overall independence on a scale from 1 to 10. People who had not recently received support gave an average score of 5.9; Those who had recently received support rated their independence at 6.7, and assigned a score of 4.8 for their independence prior to receiving the support. These scores are lower than those for Wmo applicants in the Wmo evaluation 2010-2012 (7.9 after support and 5.2 before support) (Kromhout et al. 2014). This may be because the profile of the target group of Wmo 2015 has changed, with local authorities being made responsible from the introduction of Wmo 2015 for people who need enabling support.

Social participation was broadly interpreted in this study and includes participation in education, paid employment, voluntary work, informal help, unpaid political and administrative functions and/or various types of leisure activities. Viewed across this broad spectrum, most applicants were found to be capable of participating in society. However, more than a quarter took part in none of these activities, and in this regard were on the sidelines of society. Yet not everyone in this group regarded their low participation as 'being on the sidelines': a third of them agreed with the statement 'I feel that I count in society' (compared with more than half of those who did participate).

Only one in six Wmo applicants aged between 16 and 70 were in paid employment, and one in seven were in education (which could also include a refresher training course, etc.). One in ten applicants were themselves providing informal help to sick or disabled relatives, friends, acquaintances or neighbours.⁶ Logically, this was often a different kind of help or support from that which they themselves were receiving. One in seven applicants did organised voluntary work (non-organised voluntary work was left out of consideration). A total of one in five applicants were supporting others by providing informal care or volunteering. Given the often severe disabilities these applicants have, this appears to be a very favourable number. In reality, providing occasional help or non-organised volunteering was probably more common, both aspects which were not measured in this study. Almost half of applicants actively engaged in clubs or societies or other leisure activity outside the home on a weekly basis, and a further one in ten did so slightly less frequently but still at

least a few times per month or per year. One in 14 applicants had occasionally contacted a politician or council official, and one in 12 had at some time attended an information meeting or civic participation meeting or had taken part in a local referendum in their municipality. An even smaller number of applicants had at some time spoken to the local authority about the rules and arrangements for people with disabilities.

Regular active participation by applicants thus most often took the form of leisure activity. Of course, to some extent this is related to the high proportion of older persons among Wmo applicants, whose age means they are no longer in work or education. Whilst most applicants were active in some way, therefore, they rated their ability to participate after receiving Wmo support at just above satisfactory (6 out of 10), and beforehand at non satisfactory. We conclude from this that there is room for improvement in the participation of Wmo applicants.

When Wmo applicants were asked if they expect to be able to continue living at home for the foreseeable future, almost nine out of ten said 'yes', though a tenth answered 'perhaps' and one in 50 responded with 'no'. A quarter of this latter group had an indication for temporary or permanent admission to an institution – which means that three-quarters did not. In absolute numbers, this probably involves several thousand people.

Subjective loneliness was high among applicants. More than half felt lonely and one in five seriously lonely. Applicants who lived alone, had motor disabilities or mental health and/or psychosocial problems experienced more loneliness than applicants who did not have these disabilities or problems. They can be regarded as risk groups. Applicants who had weekly contacts with family, friends and/or neighbours and who reported higher resilience, felt less lonely than their opposite numbers. Most applicants (seven out of ten) reported that they were able to maintain contacts independently, and this applied for virtually everyone with help; nonetheless, a proportion evidently felt lonely.

Wmo applicants scored their quality of life (measured as satisfaction with life) at an average of 6.6 on a scale from 1 to 10. This average is more than one point lower than in the general population in 2014, and also lower than among Wmo applicants in 2012⁷ (both 7.8) (Bijl et al. 2015 and Feijten et al. 2013, respectively).

In short, Wmo applicants often faced limited independence and participation, and many of them felt lonely. It does have to be borne in mind here that these are people who had referred themselves to their local authority precisely because they were no longer able to manage, participate or maintain social contacts independently. Support compensated to some extent for their disabilities (as they reported that their situation was better after receiving the support), but often not completely. Although the Explanatory Memorandum to the Wmo refers to 'participation on an equal footing', therefore, it would be unrealistic to expect people with a disability, once they start receiving social support, to be able to participate to an equal degree and be just as independent as people without disabilities (and it may be that some Wmo applicants feel less need to participate). One in four engaged in no participation at all, making the ideal of 'everyone takes part' seem a long way away.

As well as rating their own situation before and after receiving support (see previous paragraph), respondents were also asked directly how much they felt that the support helped. In all areas of independence, participation and maintaining social contacts, the majority reported that the support helped – though the perceived independence was lower among applicants who did not receive a personalised support package, even after controlling for background characteristics. This suggests that personalised support makes a bigger contribution to achieving the envisaged policy goals than other types of support. As general provisions are so rarely cited as a solution, it was not possible to determine to what extent they contributed to these goals. Whether support was related to loneliness and life satisfaction was not measured directly, though we did find that people with higher levels of independence and participation less often felt lonely.

Apart from the support itself, other aspects of the application process were also found to be related to the envisaged goals.⁸ Firstly, we found that applicants reported a higher independence score when a wider range of life domains was discussed with them. We also found that applicants who were satisfied with the five measured characteristics of the assessment procedure also had a higher independence score than applicants who were neutral on this, and that members who were dissatisfied with the procedure reported even lower independence scores.⁹ In addition, applicants who were satisfied with the assessment less often said that they needed more support than those who were dissatisfied with the assessment (four out of ten versus six out of ten). Finally, subjected independence was lower in applicants who declined support because of the co-payment and those who experienced problems coordinating the support and help services.

Research question 2: How do people with a need for support contact their local authority¹⁰? How do local authorities deal with requests for help and how do all stakeholders experience this?

Access to Wmo mainly governed by local authorities, but also outsourced to implementing agencies

Access to the services provided under Wmo 2015 is generally governed by local authorities themselves: more than six out of ten assessment officers in this study were employed by the local authority. However, employees of implementing agencies may also receive applications on behalf of the local authority and carry out the assessment (1.5 out of ten assessment officers worked for a care institution, one in ten for a welfare organisation and one in 12 for an independent client support agency). The vast majority of local authorities (27 of the 33) use (community) social care teams, but we do not know whether those teams also controlled access to the Wmo. According to most assessment officers, each application came in via the central Wmo service desk or contact centre. Most assessment officers also stated that every application was recorded. In most cases, on the first contact of an applicant with the local authority/district's social care team, a general clarification of the need was carried out.

Most assessment officers were educated to higher professional level and had worked in the Wmo field for many years. The detailed analysis of six municipalities confirmed the picture of substantial variation in the way in which access to Wmo 2015 was organised.

Transfer of clients between Wmo 2015, Care Insurance Act and Long-term Care Act generally not 'warm'

Assessment officers sometimes had to deal with the transfer of applicants between schemes operated under Wmo 2015, the Health Insurance Act (Zvw) and the Chronic Care Act (Wlz). They reported that these transfers were mostly 'adequate' (on a scale of good-adequate-moderate-poor). Yet these transfers were by no means always 'warm'¹¹: this was rarely the case for transfers from Wmo 2015 and/or Zvw, according to the assessment officers, while the other forms of transfer were regularly warm (though not frequently or always). This may have been related to a reluctance to discuss client records with unknown care providers in order to protect client privacy. When asked about the transfer of clients from and to different legal regimes, the assessment officers reported that privacy legislation did indeed sometimes (ranging from 'rarely' to 'regularly') make it difficult to share client records.

Assessment officers reported that they did regularly consult with community nursing services on individual clients. Most assessment officers are not community nurses. According to a majority of assessment officers who were not community nurses, referrals from community nurses regularly included clients with mild intellectual disabilities, dementia and former clients of youth care services, who needed both social support and nursing care. A very small proportion of assessment officers were also community nurses (working in community social care teams). They assessed the indication for nursing or care provision and when asked indicated that this was working well with new clients.

The transition from youth care to Wmo support was not an entirely smooth process according to assessment officers. It regularly proved problematic, a care continuation plan was rarely available and there were indications that young people had been left for long periods without help. Assessment officers reported that there were sometimes coordination problems, when it was unclear who had which role and who was responsible for which aspects.

In addition to these problems, the assessment officers also reported opportunities (strikingly enough, the opportunities largely corresponded with the problems, even within one and the same local authority). Coordination of the care and collaboration between the various parties was better than before the introduction of Wmo 2015. Clients received more personalised support, more use was made of their own capacities and networks, and efforts were made to find local solutions.

Four out of five applicants underwent an assessment as a result of the application

Most applicants (just under two-thirds) contacted the Wmo service desk by telephone; a smaller proportion (just under a fifth) made personal contact, and an even smaller number (less than one tenth) made digital contact (by email or via a website). It was quite com-

mon for the applicant not to have made contact themselves, but for this to have been done on their behalf (a quarter) or together with them (just over a tenth).

People also contacted the Wmo service desk for a variety of reasons; a tenth were looking for information that could in many cases be resolved by providing information directly or referring them on; just over six out of ten made contact to request support or ask if they were eligible for it. Assessment officers dealt with these kinds of applications most often ('regularly' to 'often'). Such requests for help require a situational analysis, and four out of five applicants accordingly had a discussion with the local authority about their support need. In most cases, this discussion was preceded by a preparatory letter (half) or telephone call (a seventh). To prepare for the assessment, applicants could call on an independent client support officer or submit a personal support plan, though relatively little use was made of these possibilities (a twelfth and an eighth, respectively, of applicants). The assessment was most often (including according to assessment officers) carried out in the applicant's home, though it was sometimes carried out in a community centre or elsewhere outside the applicant's home (a seventh) or by telephone (an eighth). New applicants, reassessment clients and applicants with severe disabilities were given an assessment at home significantly more often than others.

The assessment generally covered the topics recommended by the law, but there was often a lack of attention for the informal carer

The assessment often covered all areas of the applicant's life, with attention being given to the aspects recommended in the law (Staatsblad 2014, art. 2.3.2, paragraph 4) (briefly: the needs, personal characteristics and preferences of the applicant and what contribution could be made to the support using the applicant's own capacities, informal care (with attention for the informal carers themselves), general provisions and the performance of socially useful activities). This approach is confirmed by both applicants and assessment officers. In around one or two out of five assessments, a number of themes were insufficiently discussed – though of course there may be good reasons for this. Mostly (in six out of ten cases) the assessment officer did not perform the assessment with the applicant alone, but in the presence of a relative or carer, for example. The survey of informal carers who were present during the assessment showed in most cases they felt that the assessment officer paid a little or no attention to the support they themselves were providing, whereas this is recommended in the legislation. Assessment officers themselves also reported that they did not always devote attention to this aspect.

Two-thirds of applicants say they were not informed about the possibility of a personal budget. A third felt that after the assessment they had not been (properly) informed about the subsequent procedure and a third did not receive a report of the assessment. A quarter knew that in addition to the assessment, information about their situation had been collected by third parties, but the same proportion did not know this. Practice is thus at variance with the intentions of the law on these points (which prescribes that applicants should be informed of the possibility of receiving support in the form of a personal budget (Staatsblad 2014, art. 2.3.2, paragraph 6), that they should receive a report of the assess-

ment (Staatsblad 2014, art. 2.3.2, paragraph 8) and that the local authority should seek their consent for obtaining personal information from third parties.¹²⁾

Satisfaction with the assessment among applicants relatively high, but unfriendly approach by assessment officer a regular source of dissatisfaction

Most applicants, informal carers and assessment officers were very satisfied with the assessments. Most applicants felt that the assessment officer took sufficient time for the assessment, listened properly, showed expertise, took their wishes into account and involved them in finding a solution. But there was also dissatisfaction: almost a quarter of applicants were dissatisfied with the expertise of the assessment officer, and almost a quarter with the degree to which the assessment officer took their wishes into account. A tenth and a seventh, respectively, were dissatisfied with the time allowed by the assessment officer for the assessment and the way in which he/she listened to the applicant. Supplementary information given by respondents suggested that this was often due to the unfriendly or rushed approach by the assessment officer. Lack of expertise, lack of interest and provision of incorrect information were also regular sources of dissatisfaction. The assessment officers were generally positive about the assessments with Wmo applicants. They felt that they had adequate or more than adequate knowledge of the various target groups, adequate or more than adequate knowledge of the support available in their municipality and more than sufficient skills to clarify the support needs of the client. Most assessment officers also felt that they mostly succeeded in finding an appropriate solution, together with the applicant. They thus appear to be more positive across the board about the assessment than applicants and their informal carers. Despite this, they also recognise that there are areas for improvement. Roughly a quarter reported that their knowledge of applicants with mental health or psychiatric disorders, psychogeriatric problems (including dementia) and multiple problems, such as homelessness and addiction, was inadequate. And although they regard their skills as adequate, they did not always manage to clearly elicit the 'question behind the question', i.e. the deeper-seated need. They also indicated that they by no means always discussed the informal care situation of the applicant during the assessment. This is also a point about which informal carers (where they had been present during the assessment) were often satisfied, as well as about the limited extent to which assessment officers took account of their wishes.

Research question 3: What help do Wmo applicants receive and how do all stakeholders experience this? Is there sufficient coordination between all stakeholders? Does the available help meet the needs?

Most applicants receive a personalised support package as a result of their application

A tenth of those who contacted the local authority for social support were allocated a 'self-help' solution (buying in help themselves or asking others for help); just under a tenth were allocated a combination of personalised support and a self-help solution, and more than

eight out of ten were allocated only personalised support as a solution for this specific application.¹³

A referral to general provisions, or to nursing or personal care, was much less common (both occurring in roughly one in 25 cases), but it is of course possible that applicants were already making use of general provisions before making contact in relation to Wmo support.

A proportion of applicants who were not allocated personalised support stated as the reason that: 'the local authority didn't consider it necessary' or 'the application was rejected'. They were also asked what consequences this had for them. A third said that they stayed at home more often than they would like and a sixth that they had fewer social contacts than they would like.

One in ten applicants who were allocated personalised support opted for a personal budget. The stricter criteria applying for personal budgets in Wmo 2015 do not appear to have reduced the frequency with which people choose them: in the Wmo evaluation 2010-2012 (Kromhout et al. 2014) roughly the same proportion opted for a personal budget.

One in four applicants dissatisfied with the solution that emerged from the assessment

Three-quarters of applicants who were allocated personalised support following the application were satisfied or very satisfied about this. One in ten were neither satisfied nor dissatisfied, and two out of ten were dissatisfied or very dissatisfied. Those who were dissatisfied were relatively often well educated, had severe physical disabilities, psychosocial problems or low resilience. A quarter of applicants were dissatisfied with the solution that emerged from the assessment, citing reasons such as unaffordability and the absence of (extra) support from their network. This is in line with the finding that more than a quarter of assessment officers felt they themselves had difficulty in finding a solution which took into account potential informal carers and the financial situation of the applicant. Around half of informal carers were satisfied with the solution provided to the person they were caring for.

One in 20 applicants declined personalised support because of co-payment

More than three-quarters of applicants who were allocated personalised support had to pay a contribution (co-payment). Eight out of ten of them stated that they had been informed of this in advance, but a substantial proportion said they had not been told how much the payment would be. Almost one in ten applicants reported that they had got into financial difficulties because of the amount of the co-payment, despite this being tested on the income and financial means of the applicants.

One in 20 applicants had declined all or part of the personalised support because of the amount of the co-payment. If those rejecting the support have sufficient financial means and are able to organise support for themselves, this is not a problem (and is also in line with the intention of the law). But assessment officers did regard rejection of support due to co-payments as a problem, including when asked in an open question to report any

obstacles to access to Wmo support. These respondents believe that rejecting support because of co-payments mainly affects those on middle incomes.

Most applicants receiving household help satisfied with quality

Wmo applicants who were receiving household help (either as a result of the application or before this) were generally satisfied with its quality. Nine out of ten recipients of household help felt that the helper performed their tasks well. It made no difference who this help was received from (informal help, privately purchased help or professional help) Dissatisfaction among both applicants and their informal carers with the solution offered was greatest when it concerned (a reduction in the number of hours of) household help. Further analysis showed that people who had contacted (or been contacted by) the local authority in connection with a reassessment were more often dissatisfied with the solution 'household help' than other applicants. This is probably linked to the sometimes deep cuts made by some local authorities in household help in the period covered by our study (end of 2015), which saw people sometimes having their household help hours cut during a reassessment.

One in ten applicants whose application was rejected appealed against the decision

A quarter of applicants who were not allocated personalised support had received an official rejection of their application (the others had not submitted an application). Just over a tenth of them appealed against this decision, roughly the same proportion as in the Wmo evaluation 2010-2012 (Kromhout et al. 2014). Just over a quarter of these objections were upheld, and half were rejected (the rest were still being processed). The cuts in applications and formal requests would lead to expectations of a reduction in the number of appeals, because a proportion of applications with the chance of success are intercepted at the point of initial application. It may be that the austerity of household help prompted an equally high proportion of objections.

Lack of awareness by applicants that they could submit a complaint (e.g. about the attitude of the assessment officer or the quality of the support) is fairly widespread, applying for more than half. A fifth of applicants had a vague idea of where they could submit a complaint, and just over one in four knew precisely. Around a third of applicants who were dissatisfied (with the assessment or the solution offered), and who knew where to submit a complaint, did so. It is not known whether these were always official complaints or also included verbal complaints, for example.

Research question 4: What is the need for and use of support among informal carers and what are their experiences with the coordination of care?

Two out of three informal carers could not do any more than they were already doing

Seven out of ten Wmo applicants were already receiving help before 1 January 2015, in the form of informal help, private help, professional help or a combination. Just under half were receiving informal care in the first half of 2016.

There appears to be support among Wmo applicants for making greater use of their own capacities and help from their own network: six out of ten reported that they would be willing to ask for (more) help from their own network. However, five out of ten reported that they would not be willing to do this, and six out of ten also found it difficult constantly asking the same people for help. Eight out of ten applicants felt that the government was asking too much in terms of help from family, friends or neighbours.

Just under two-thirds of informal carers said they would not be able to do any more if this were necessary. Those who felt their care task was a burden, in particular, reported that they were unable or unwilling to provide more help. They felt they had reached their limits. It is important for this group that other helpers are or become available with whom they can share the help when the need increases. They rarely saw scope in their own situation to pay more towards care and support or to leave the care provision more to relatives, friends or volunteers.

Over half of informal carers reported an unfulfilled need for support

Almost six out of ten informal carers felt they needed some form of support that they were not receiving. This often meant financial support, but also someone who could occasionally take over the care from them. People also cited help in applying for support for the person they were caring for, as well as more understanding and consultation. The main reasons for not using informal carer support provided by the local authority were insufficient knowledge of the possibilities, inadequate or unclear information on what support was available and the bureaucracy involved in applying for support.

Majority of informal carers positive about coordination with professional carers, but one in eight dissatisfied

Three-quarters of informal carers in this study shared the provision of help with home care workers, Wmo support workers or community nurses. Four out of five informal carers in this study felt they had sufficient expertise for the tasks they performed, but one in ten felt they did not and that they could benefit from training or support in performing their tasks. Almost seven out of ten participating informal carers reported that they felt less burdened thanks to the professional help provided through the Wmo or community nursing service, and almost half said this meant they had more time for themselves. The majority of informal carers in this study who had been in contact with professional help services felt that the professional Wmo support workers or community nurses took them seriously (roughly eight out of ten), took their wishes into account (around two out of three), supported and appreciated them and discussed how they could work together to offer the best support. Nonetheless, there was also a group in this study who were less satisfied: around one in eight informal carers felt that the Wmo and community nursing staff regarded them as having little or no expertise, gave them with little or no support and appreciation and did not discuss with them how they could work together to provide the best support.

From their perspective, the applicants are often not aware of problems in coordinating help provided by different carers (both professionals and informal carers). Nonetheless, slightly less than one in ten found that this coordination was (occasionally) problematic. Logically, the coordination problems were more common when there were more helpers involved. Where coordination of the help occurred, applicants reported that they either did this themselves, or a friend or family took care of it. In almost no cases was the coordination carried out by someone from the local authority; assessment officers did report that they played a role in the coordination of care, though they often did not verify whether the formal and informal help was properly dovetailed.

Notes

- 1 Both applicants and assessment officers took part in 22 municipalities; in six municipalities only applicants took part and in 11 municipalities only assessment officers.
- 2 People who refer themselves/who are referred to the local authority because of a question or problem in relation to social support.
- 3 Professionals who on behalf of the local authority assess support needs in dialogue with applicants who have referred themselves or who have been referred to the local authority for support. This includes professionals from other organisations commissioned by the local authority.
- 4 The preliminary study showed that it is not possible to determine precisely whether local authorities register all applications, firstly because not all local authorities define applications in the same way, and secondly because application, assessment and request are not distinguished as separate processes in all municipalities.
- 5 Taking into account personal background characteristics of applicants.
- 6 In principle, informal care for partners was also included, but people do not always themselves see this as such (often regarding it as natural to care for each other and therefore not reporting it in response to this question) In reality, therefore, this figure could be rather higher.
- 7 It is possible that the financial crisis led to a reduction in life satisfaction, so that the figures are not entirely comparable.
- 8 Both bivariate and multivariate. Only relationships with multivariate significance are referred to in this section.
- 9 This was also the case when we looked only at those who received support as a result of the application.
- 10 Including professionals from other organisations commissioned by the local authority.
- 11 We understand a 'warm' transfer as a client transfer arranged between professionals in a telephone conversation or joint consultation.
- 12 'The local authority shall where necessary seek the permission [of] the client [...] to use relevant information which it holds from other sources or to obtain such information from third parties' (TK 2013/2014a: 30).
- 13 General provisions (as a solution following the application) have been left out of this classification because they occurred so rarely that further analysis was not possible.