Summary
Special informal care

Experiences of informal carers of people with an intellectual disability or psychiatric disorder

A great deal of research has been carried out in recent years on the extent of informal care and its impact on informal carers, informal care recipients and care professionals (De Boer 2005). Older people are the biggest ‘consumers’ of informal care and requests for support, advice, information and respite facilities accordingly come mainly from this group (Van Exel et al. 2002; Sombekke & Van Wijngaart 2008). Attention in the debate about care focuses principally on chronic diseases and people with physical disabilities. Not surprisingly, therefore, these groups are the best represented in research on care demand and needs, and most is thus also known about their needs (De Klerk & Schellingerhout 2006). This has implications for the development of support services for informal carers: in many cases those services are designed for and focused on those providing informal care to older people. In the perception of those providing informal care to people other than older persons (and people with physical disabilities), too little attention is devoted to the specific support needs of people providing this kind of informal care. These ‘other’ informal carers accordingly feel they have been overlooked when it comes to informal carer support (De Klerk et al. 2009).

Their complaints beg the question of precisely what those specific support needs are. In order to ensure that the support provided to informal carers also meets the needs of those providing informal care to people with an intellectual disability or psychiatric disorder (or meets those needs more effectively), a better insight into the support needs of these groups is required. In order to gain that insight, more information is also needed about the nature and extent of this kind of informal care. That information is not only important for ensuring a better match between support services provided by local authorities for informal carers providing all types of informal care, but also for present and future care professionals working in sectors other than the (long-term) care sector, such as intellectual disability care, mental health care or community care.

Against this backdrop, the Netherlands Institute for Social Research | SCP decided to carry out specific research in partnership with the Community Care department of Hogeschool van Amsterdam, University of Applied Sciences (HvA) among these two groups of informal carers. This study seeks to provide an answer to two related questions:

– What is the nature and extent of informal care provided to people with an intellectual disability or psychiatric disorder?
– What is the need for support among informal carers of people with an intellectual disability or psychiatric disorder?

To find answers to these research questions, a secondary analysis was first performed on the data from a national survey of informal carers carried out by SCP in 2007 (IH’07). Three groups of informal carers were consistently compared with each other: those
providing informal care to people with intellectual disabilities (ID), informal carers of people with a psychiatric disorder (PD) and ‘all’ informal carers. In addition, a qualitative study was then carried out among representatives of the two groups of ‘special’ informal carers in and around Amsterdam. Fourth-year students from HvA conducted a total of 53 structured interviews (26 ID, 27 PD); respondents were asked about things such as the burden they experienced from providing care, the resources to which they had access, whether those resources were enough to meet their support needs, what possibilities they see for reducing their care burden, and how much use they make of those possibilities (and thus which needs for support are not met).

Informal carers caring for someone with an intellectual disability or psychiatric disorder together account for approximately a fifth of all informal carers in the Netherlands (De Boer 2009). They turn out to be two special groups of informal carers: because they are clearly different from other informal carers, because they experience caring for a loved one in different ways, and above all because they have a different perspective on and opinion of professional care.

The differences between the various groups cannot be derived directly from their background characteristics as these emerged in the SCP survey. What can be seen is that the relationship with the care recipient is often different: informal carers of people with an intellectual disability or psychological disorder care for their parent(s) or parent(s)-in-law (much) less often than the ‘average’ informal carer. On the other hand, they (much) more often care for their child, a sibling or brother/sister-in-law and, especially where the care recipient has a psychiatric disorder, for a friend or acquaintance. Those receiving care are more often men and, with an average age of 40 (ID) and 53 (PD), respectively, are substantially younger than the ‘average’ care recipient (64 years). The reasons that these two groups provide informal care are found not to differ markedly from the motivations of other informal carers. Affection and seeing it as the natural thing to do are the most frequently cited motives for providing this care. Those providing informal care to people with psychiatric disorders report slightly more often than other informal carers that they provide care because no one else was available to do so. Informal carers of people with an intellectual disability relatively more often report that they did not want the care recipient to be admitted to a residential facility or institution. The differences between the two highlighted groups of informal carers and ‘other’ informal carers widen if we look at the content and duration of the care provided. Informal carers of people with an intellectual disability, in particular, are engaged in very long-term care situations, providing care for an average of almost twelve years. This care is also more intensive, at an average of 26 hours per week. The percentage of carers providing care for more than three months is higher than average among those providing informal care to people with psychiatric disorders. The care provided by these groups is also different from the care provided by the average informal carer. Informal carers of people with an intellectual disability provide more types of care on average; they provide less help with household tasks than in other care situations, but relatively more personal care and nursing, emotional support and
supervision, administration and support outside the home. Informal carers of people with psychiatric disorders provide relatively less help with household tasks, personal care, nursing and support, but (much) more help in the form of emotional support, supervision and administration. It also emerged clearly from the interviews with this latter group of informal carers that they devote a substantial part of their care time to providing emotional support. They have the feeling that they must be continuously available to listen to the stories of the care recipients and to calm them down or give them advice if necessary. They also provide constant supervision and are ready to step in when there is a problem. In this way, they also try to provide structure in the lives of the care recipients.

Despite the ‘naturalness’ with which most informal carers appear to provide their care, they may still find providing that care to be a burden. The comparison of the duration and intensity of the informal care provided to people with an intellectual disability or psychiatric disorder with informal care in general showed that the former is often more intensive and lasts for longer. It should therefore come as no surprise that these carers are more likely to report that they find providing this care to be a burden and report (much) more than average that they find it to be a heavy burden. This applies especially for informal carers of people with psychiatric disorders, who report that providing the care is a severe burden (even) more often than those caring for people with an intellectual disability. The interviews from the HvA study confirm this picture from the scp research, but also add detail and provide nuance. Informal carers of people with an intellectual disability often report that, despite the intensity of the care situation, they derive a great deal of pleasure from providing the care. They talk often about the pleasurable moments they experience and say they draw strength from this. However, their accounts also reveal the negative aspects of being a carer: the discriminatory reactions from the community, the constant pressure that providing care entails, the crumbling away of social contacts and the impossibility of undertaking (many) social activities. Carers of people with psychiatric disorders were often more negative about the care situation in the interviews. They find providing care to be a very intensive and burdensome activity and find it difficult to set boundaries. The constant care, the need to be alert at all times, demands a great deal of time and energy, and this often eats into the time that people (would like to) have for themselves. On top of this, their own social contacts dissipate and their social network shrinks. The taboo which still clings to psychiatric disorders serves as a catalyst here.

The scp comparison between carers of people with an intellectual disability or psychiatric disorder with all informal carers also reveals that the first group do not receive help any more or less often from other informal carers: just over half are able to share the care with other members of their social network. This does not apply for the second group, fewer than half of whom are able to share the burden of care. The respondents in the HvA study who care for someone with an intellectual disability are also often able to share the care provision with other family members. It should be noted here that this informal care network extends only to the immediate family members and is not especially large.
Although friends of the informal carers do become involved, that involvement does not extend to providing care directly to the recipient. Carers of people with psychiatric disorders less often receive help from other family members or friends, and finding supported by the HvA study. The social network of these informal carers is often very small, partly because relatives and friends find it difficult to deal with the problem and therefore avoid contact. These carers consequently more often have the feeling that they are dealing with the issues entirely on their own.

Like other informal carers, a majority of carers of people with an intellectual disability presume that family, friends or fellow household members would assume the care if the principal carer were unavailable for any reason. However, carers of people with psychiatric disorders more often think that admission to an institution would be inevitable in such a case, and are less inclined to assume that others would take over the care provision at home. This group of carers less often assume that the care would be taken over by members of their social network, and the risk of the care recipient suffering loneliness if their informal carer should not be available is therefore very real. This group of carers feel less able than other informal carers to ask for help from family members or friends. The respondents in the HvA study expressed disappointment at the willingness of their network members to provide help, and often encountered a lack of understanding and sometimes plain unwillingness in response to their requests for help.

In most cases, the informal carers of people with an intellectual disability or psychiatric disorder have lots of contact with care professionals. Carers of people with an intellectual disability can often go directly to the personal or residential support worker of the care recipient for help. In addition, these informal carers also receive help from several other professionals, such as speech therapists, physiotherapists, remedial teachers, etc.. The informal carers of people with psychiatric disorders share the care with several care professionals: community psychiatric nurses, personal support workers or a psychiatrist or psychologist.

The HvA study devoted a great deal of attention to the experiences of informal carers with the professional care system. The majority of carers providing care to people with an intellectual disability are extremely positive in their views, generally having good personal experiences with care professionals, who they feel are extremely committed and who not only have the interests of the care recipient at heart, but also those of the informal carer, something that is greatly appreciated by the informal carers. Some negative experiences were also reported – strikingly enough, mainly by informal carers who were not only providing care to someone with an intellectual disability, but also to someone with a psychiatric disorder. The negative comments related mainly to the organisation of the care: the informal carers struggled with bureaucracy, poor accessibility and the large number of referrals.

The interviews with informal carers of persons with psychiatric disorders also revealed a good deal more dissatisfaction with the professional care system. The overriding finding to emerge from the interviews was that the attitude of professionals, the way in which they approach the informal carer, is felt to be of crucial importance. Respondents complained that they did not feel acknowledged, either in terms of their expertise regarding
the wishes and capabilities of their loved one, or in terms of their rights as next of kin. The informal carers were frequently disappointed in the expectations that they had of care professionals: they had assumed that the relationship would be more one of partnership, but in reality experienced the situation as a power struggle. The respondents added that they felt that their negative experiences with care professionals contributed to the burden of providing informal care.

Where the professional care is well organised, informal carers experience it as a lightening of their own load. They also greatly appreciate it if it is possible to make arrangements on the division of the care tasks and if the professionals also display an interest in (the situation of) the informal carers themselves.

It emerged from the national SCP survey that relatively few informal carers articulate a need for support or actually make use of the provisions referred to in the study. This also applies, and sometimes to a greater degree, for carers of people with an intellectual disability or psychiatric disorder. The two groups of informal carers do however differ in their need for (-specific) forms of support. For example, carers of people with an intellectual disability have a greater need for provisions other than day-care, and other forms of support than just respite services and information meetings. Informal carers of people with psychiatric disorders have a greater need across the board for support than other informal carers. The fact that neither group make use of the available services may be due to their unfamiliarity with the facilities available, uncertainty as to whether they are eligible or fear that the services provided will not match their specific needs (De Boer et al. 2009).

In response to questions about the need for and take-up of support, it emerged in the interviews that some informal carers need no support at all and therefore make no use of the facilities available. These carers consider it so natural to provide care and know the care recipient so well that it does not occur to them that they might (themselves) need support. There are also informal carers who make no use of the (formal) support facilities because they are completely unaware of their existence. This is particularly the case with support facilities offered by local authorities.

The informal carers who would like to receive support draw a distinction between support for themselves and support for their loved one. As far as the care recipient is concerned, they would like more or different, or in any event more coherent care. Their greatest need for themselves is practical support: someone to help maintain an overview, help with finding their way through the plethora of regulations and more financial support. They would also very much like themselves and the care recipient’s network to be more involved in the care provided by the professionals, so that they have the feeling of being able to share more responsibility. As a corollary to this, they would like to have (more) contact with other informal carers, too. Moreover, respondents indicated that they would like the government (and therefore also the local authority) to show more interest in their situation.

All in all, the informal carers providing care to people with an intellectual disability or psychiatric disorder appeared to be special groups. They experience a higher than
average care burden, have less scope to share the care provision with their social network and have a different help profile. It would therefore be logical for these carers to have a great need for and make wide use of support facilities. This is found not to be the case, however, mainly because the existing provisions do not match their needs. To reduce their care burden, these informal carers would mainly like to see better support for the care recipient and greater involvement of the informal carer in this. In addition these carers, and especially those providing care to someone with an intellectual disability, would like the members of their social network to be more involved in the care. Both groups of carers also have a need for various forms of practical support, which matches their specific situation better than at present and which is readily accessible.

The Dutch government has announced a new package of measures to be introduced in the spring of 2012, in which support for people with more severe disabilities will be transferred from the centrally funded Exceptional Medical Expenses Act (AWBZ) to the Social Support Act (Wmo), which is implemented by local authorities (vws 2011). This means that, in addition to having a responsibility for providing support to informal carers, local authorities will now also be responsible among other things for supporting people with more severe intellectual disabilities or psychiatric disorders. This study shows that the burden of informal carers could be substantially reduced by not only improving the match between the facilities available in the various domains of life, but also, and perhaps especially, by involving informal carers more meaningfully in the care provision. In this respect, the findings of this study are an endorsement of the calls by family organisations in the Netherlands such as Platform vg, Ypsilon and the former Labyrinth/In Perspectief to develop an adequate family policy and to create a more structural role for family members in the care and support of people with an intellectual disability or psychiatric disorder.

The emergence of ‘new’ types of care recipients, and therefore ‘new’ types of informal carers, requires local authorities to broaden the range of support they provide and to ensure it matches the needs of these informal carers. At the same time, they can reduce the use of and above all the need for this informal care support by involving informal carers in their own policy and provisions. However, providing support for informal carers is not the task of local authorities alone; care professionals can also undertake activities to relieve the burden of informal carers of their clients or to offer them support. At the same time, informal carers say that their greatest need is to have their expertise recognised and to be treated as partners in the care provision. Investing first and foremost in these aspects would therefore appear to be an attractive option for care providers, and could reduce the need for support by informal carers.

(More) family policy by both local authorities and institutions could certainly reduce the burden of informal carers, but would most likely not be able to remove it entirely. This is after all a type of informal care in which the risk factors for overstrain appear to be cumulative. There is thus a need to support informal carers, especially with practical and financial support, respite facilities and information meetings. Greater variety
needs to be introduced here than is currently usual, in order to match the specific needs of these informal carers. There also seems to be a substantial need for more support in mobilising and activating the informal carers’ own social networks and those of the care recipients. This, too, ought to be part of the standard package of informal carer support. In developing the various forms of support, those providing them (local authorities as well as care providers) need to work together more closely, so that all available expertise can be deployed to increase the diversity of the supply.