Summary

Chapter 1

Continuity of care and harmony in cooperation between the different health care professionals are essential to streamline the care process of people with a chronic condition. One way to advance continuity of care is the delivery of integrated care. Integrated care is defined as inter-sectoral cooperation between care providers from both the health and social care sector in order to deliver continuous care to people with multiple and complex health care needs. Although uniform features of integrated care are lacking, literature provides some key direction about the components of integrated care like organisational structuring and coordination of care, a specially assigned case manager, use of protocols and patient empowerment. Research in integrated care mainly focusses on clinical pictures with the involvement of several health care professionals. However, special attention is paid to high incidence and high prevalence diseases having the effect of high direct and indirect costs. Despite the assumption that integrated care – by reducing fragmentation and discontinuity of care – results in high quality care and a reduction of health care expenditures, evidence supporting this assumption is sparse. In this thesis the possible value of integrated care for complex, costly, low incidence chronic disorders is assessed, i.e. intellectual disability (ID) and multiple sclerosis (MS). With reference to these two disorders the effect of integrated care on continuity of care, unmet health care needs, quality of life and the use of health care services is assessed.

Chapter 2

In chapter 2 an review is presented of recent studies into specific health care problems of people with an intellectual disability (ID) in common and specifically of people with ID living outside an institution. About two decennia ago, the Netherlands started with a policy directed towards the integration of people with ID into the community. Main aim of this policy was to alleviate the social isolation of these people by creating a more community oriented supportive structure. As a result of the advance in community care people with ID living outside an institution will have to turn to a general practitioner (GP) instead of to an institution doctor for their medical care. As the new providers of primary health care, GPs need to be acquainted with the specific health problems of people with ID, in order to be able to identify and adequately manage them.

In an attempt to reveal the actual specific health problems of people with ID, only studies with a control group (people without ID) are included in the literature review. There are only few studies focusing on health problems in people with ID in which a control group of individuals without ID is included. Most comparative research presents higher prevalence rates for epilepsy, diseases of the skin, sensory loss and (increased risk of) fractures. Besides comparative studies using a control group, also comparative studies are available
that – instead of a control group – make use of reported prevalence rates, for example of general health surveys. However, in this case data are mostly not collected at a similar way. Due to dissimilar data collection methods the research results that – in comparison with people without ID – the prevalence of certain health care problems is higher in people with ID have to be considered with caution.

Chapter 3

In chapter 3 the value of integrated care for people with ID is explored. Deinstitutionalisation of people with ID has resulted in problems in health care because of the massive and often unprepared shift of the delivery of primary health care from the institution doctor to the general practitioner (GP). Problems in health care for people with ID mainly consist of a lack of coordination of health care services and cooperation between health care professionals. As a consequence, too many health problems remain undiagnosed and untreated. Integrated care is regarded as offering solutions to some health care delivery issues through the achievement of improved coordination and cooperation between services in a way which will lead to gains in the whole care process. In a literature review the possible value of integrated care for people with ID is explored. The results of the literature review show that there are sufficient reasons to offer the care for people with ID in an integrated way. The first reason concerns the assumption that – despite a lack of data into fragmentation and discontinuity of care – many health care problems of people with ID, in particular the existence of undiagnosed health problems, can be attributed to fragmentation and discontinuity of care. Secondly, also the high costs associated with ID ask for a cost-effective approach. Since integrated care aims to deliver seamless care on a cost-effective basis, an integrated care approach may have advantages for people with ID. However, literature on the effects of integrated care for people with ID is lacking. As a result only in theory the potential value of integrated care is known and are the actual effects of integrated care for people with ID still unknown.

Chapter 4

In this chapter the results of an effect study on an experts’ network for people with ID are presented. The experts’ network consists of professionals in health care for people with ID from a variety of disciplines, including medical specialists, (special) educationalists and paramedics. A specialized doctor in health care for people with ID (AVG) acts as a case manager. In reaction to lacunae in primary health care for people with ID, in the year 2000 a start was made with the development of the experts’ networks. Due to a shortage of professionals familiar with the needs of people with ID the delivery of primary health care for this population seemed to be inadequate. By implementing the experts’ network it was expected that people with ID living outside an institution, their supervisors and the medical profession could make an appeal to the experts’ network for transitory diagnostics and
treatment of health care problems related to the cause of ID. Implementation of the experts’ network took place from September 2004 till May 2005. Aim of the effect study was to assess whether integrated care – in the form of an experts’ network – resulted in adequate referrals and, as a result in a higher quality of care, adequate treatment of health care problems, detection of undiagnosed and untreated health care problems and adequate use of health care professionals. The referrals to and the results of treatment by the experts’ network have been monitored for eight months. Within that time span only six patients were referred to the experts’ network and subsequently, the treatment of only one patient was completed by the expert’s network. As a consequence, only the results on the basis of one patient can be presented. However, these data are too limited to draw any conclusion and too limited to make clear whether integrated care contributes to a higher quality of care. In the discussion of the chapter several possible explanations why GPs hardly refer people with ID to the experts’ network are presented.

Chapter 5

Analogous to chapter 3 in chapter 5 the possible value of integrated care for people with Multiple Sclerosis (MS) is explored. The delivery of health care to MS patients is characterized by the involvement of a wide range of services which provide several strategies to help combat many of the health problems of MS patients. However, the coordination and continuity of care delivered by those services often seems seriously deficient; the services are fragmented, communication is poor and goals are often not shared. As a result, MS patients fail to receive the care they need and still do experience various unmet needs. For this reason adequate reorganization of the care process is desirable. The reform of the care process also should anticipate the high direct and indirect costs associated with MS. Since integrated care aims to deliver seamless care on a cost-effective basis, an integrated care approach may have advantages for MS patients. Besides the potential value of integrated care, also the actual value of integrated care for MS patients is explored. For this purpose a literature review is conducted. Only few studies on the effect of integrated care were available. On the basis of the limited data available, it is not possible to draw any conclusion about the actual value of integrated care for MS patients.

Chapter 6

In chapter 6 a pilot study on the applicability and the effects of a Transmural Care Model Multiple Sclerosis (TCMMS) is described. The TCMMS is developed in order to stimulate cooperation between health care professionals working in different settings. The main aim of the TCMMS was to reduce the number of health care needs of people with MS. The study design concerns a one-group design comparing 40 MS patients once before and three times after implementation of the TCMMS in order to estimate the effect of the
TCMMS. During the pre-measurement – five months before implementation of the TCMMS – 40 MS patients reported 57 health care needs. After 15 months delivery of health care according to the TCMMS, the number of health care needs was reduced to 15 but no differences were found in quality of life, burden of disease and disease severity. On the basis of the results of the pilot study one can conclude that integrated care actually contributes to the reduction of the amount of health care needs. A few adaptations are advised with reference to the practical applicability of the TCMMS. These advices mainly referred to the frequency of contact with the case manager, the exchange of information between the case manager and other health care professionals and the usefulness of the patient file.

Chapter 7

In chapter 7 the results of a quasi-experimental study on the effect of the structural implementation of the Transmural Care Model Multiple Sclerosis (TCMMS) are presented. In response to the pilot study (chapter 6) and due to practical reasons the implementation of the TCMMS is carried out somewhat different. The unstructured visits to the neurologist and the rehabilitation physician and the limited involvement of the GP in implementing the TCMMS are the most important differences in comparison with the implementation of the original TCMMS. Aim of the effect study was to assess whether the adjusted TCMMS also results in a reduction of the number of health care needs, a higher continuity of care, a higher quality of life and an adequate use of health care services. For this purpose 77 MS patients received care on the basis of the adjusted TCMMS. A comparison group of 96 MS patients received care-as-usual. All respondents were monitored by means of a questionnaire prior to and ten months after implementation of the adjusted TCMMS. Equal to the results of the pilot study (chapter 6) no improvement in continuity of care could be demonstrated after the implementation of the TCMMS, probably because MS patients of both groups already at baseline were very satisfied with the continuity of the care delivered. A reduction of health care needs hardly occurred during the provision of integrated care, it was only established when it came to personal care, defecation and vision. Also health related quality of life in MS-patients and the use of health care professionals hardly changed by delivering integrated care. Based on these results one can conclude that care according to the adjusted TCMMS demonstrates only limited benefits for MS patients. In the discussion of the chapter several explanations why the results expected remained forthcoming are elaborated on.

Chapter 8

In chapter 8 the results of the foregoing chapters are summarized. After the main findings, the methodological considerations of the different studies are discussed. With reference to the effect study on integrated care for people with ID the possible explanations why GPs
hardly refer people with ID to the experts’ network are argued. In the discussion it is also emphasized that – with reference to the study on the effect of integrated care in case of MS patients – the results have to be interpreted with caution due to some methodological shortcomings. On the basis of the studies presented in this thesis a common agreed statement regarding the effect of integrated care for people with costly, low incidence chronic disorders can not be addressed. With reference to the fact that results expected remained forthcoming, several possible causes are described, such as an inaccurate assessment of gaps in care-as-usual, the effect of other, simultaneous health care innovations on outcomes and the limited content of the integrated care initiatives. Nevertheless, taking into account these eventual causes, integrated care for both populations should deserve another chance. Progress of integrated care is in particular essential for these populations due to expected developments in policy, demographic and epidemiological trends and increasing patient empowerment.