The focus of this dissertation is on families raising children or taking care of adults with an intellectual disability, with specific attention to families raising children with severe or profound intellectual and multiple disabilities (PIMD). Raising a child with an intellectual disability can be challenging and stressful for parents. With the growing emphasis on family centred services, parents are seen as experts who know their child best. Every family is seen as unique and is considered an important constant factor in a child’s life. This is in line with family systems theory, which sees families as complex, interactive and social systems: units of interdependent individuals influenced by each other and by members’ experiences. This perspective emphasizes the importance of the well-being of all family members, not only of the person with the intellectual disability/PIMD. Furthermore, previous research showed that partnership between professionals and parents is beneficial both to children with intellectual disabilities/PIMD (and their development) and to their parents. Acknowledgement of the role and position of family members of people with an intellectual disability/PIMD and the importance of their wellbeing resulted in a growing interest in the experiences of family members of a person with an intellectual disability/PIMD and the impact this person has on family life. In this study, research focused on the views and experiences of family members of a person with an intellectual disability/PIMD, living either at home or in a residential facility.

This dissertation consists of two parts. The first part (chapter two and three) focuses on parents (or legal guardians) of people with an intellectual disability who do not live at home. In the second part of this dissertation, we focused on a specific category of family members, namely parents, brothers and sisters of children with PIMD living at home. These children (with PIMD) are dependent on others in all areas of daily life. According to the family systems theory, it is important to gain knowledge about the impact of
these children (with PIMD) on family members, in order to support these families adequately. Previous research focused mainly on families with children with less severe intellectual disabilities, while few studies have been conducted on families raising children with PIMD. The aim of the second part of this study (see chapters four, five and xix) was to acquire knowledge about the objective (in terms of time) and subjective impact on parents and siblings of a child with PIMD.

Chapter one is an introductory chapter describing the research context.

Chapter two and chapter three report on studies concerning the opinions of parents and/or legal guardians on the quality of support provided for people with intellectual disabilities in residential care facilities in the Netherlands. In close cooperation with parents, a questionnaire (the Groningen Care Barometer) was developed. Consisting of 25 questions, this questionnaire measured the opinions of parents and/or legal guardians concerning the quality of support to their children in a residential facility and covers five areas: daily care, housing, day services, leisure activities and communication. A total of 1,058 parents and/or legal guardians participated. The results in chapter two showed that on average parents and/or legal guardians on average rate the quality of support given to their child in residential care a 7.3 out of 10 (SD:1.2). The majority of parents and/or legal guardians (65.0%) rated the quality of support at between 7.0 and 10.0. However, a substantial proportion of participants rated the quality of support as inadequate (lower than 6.0; 10.0%) or only marginally satisfactory (6.0 to 7.0; 25.0%). The highest percentage of parents and/or legal guardians that ‘inadequate’ ratings pertained to leisure activities (24.2%), while daily care showed the lowest percentage of insufficiency according to parents and/or legal guardians (6.0%). A statistically significant model for the overall quality of support
emerged from a multiple regression analysis, but the variables used in the analysis (the number of years the person with ID had lived away from the family home, the number of visits per month) accounted for only a small proportion of explained variance in the data for the overall quality of support. Based on the results, it can be concluded that the majority of parents and/or legal guardians were satisfied with the quality of the support provided, but that a substantial group indicated that there is room for improvement.

Although differences in the level of satisfaction about the quality of support were found among parents and/or legal guardians, it remained unclear how these differences can be explained. Some studies indicate a relationship between the severity of the disability and the quality of support. Chapter three therefore examined the relationship between the opinions of parents concerning the quality of support and the severity of the disability of the person with the intellectual disability. For this purpose, the group of respondents was divided into two groups: parents of people with mild to moderate intellectual disabilities and parents of people with severe to profound intellectual disabilities. The second group was further divided into a two subgroups: one of parents of people with severe additional disabilities and a subgroup of parents of people without severe additional disabilities. The data from all groups was analysed to establish whether the opinion of parents and/or legal guardians with regard to the five areas of quality of support was related to the severity of intellectual disability, and/or to severe additional disabilities, while taking into account other co-variables. The results showed that the opinion of parents and/or legal guardians about the quality of support was related to the severity of the disability in only one area: the leisure activities area. In all other domains, no differences were found between the groups of participants. Also, no significant differences were found between the opinions of parents and/or legal guardians of people
with and without severe additional disabilities. These results led us to conclude that the opinion of parents is not related to the severity of the disability of their child.

Chapter four describes a study of the time use of parents raising a child with PIMD living at home. Data was collected from a convenience sample of 27 fathers and 30 mothers raising children with PIMD, and a control group of 66 fathers and 109 mothers raising typically developing children was used. To map the time use of parents, an application was developed for mobile phones and tablets, which enabled parents to record 24 hours a day what activities they were performing. The results show similarities in the average time use of mothers and fathers of children with PIMD in contracted time (paid work and study) and necessary time (personal care, eating and drinking, sleeping) when compared to the time use of parents of typically developing children. Important differences were found in the average time used by mothers and fathers of children with PIMD on activities involving the care and supervision of their children and leisure activities. Parents of children with PIMD spend significantly more time on the care and supervision of their children and have significantly less free time compared to parents of typically developing children. It can therefore be concluded that, notwithstanding the substantial number of hours of professional support (on average 41 hours per week), the amount of time used daily by parents raising a child with PIMD is still substantially higher and more taxing than that used by parents of typically developing children. It is therefore important not only to ensure that the child with PIMD is supported sufficiently, but also to understand parents’ needs and wishes concerning support of the child and the family, and to support them accordingly.
chapter five reports the positive and negative appraisals by both mothers and fathers of the impact of raising a child with PIMD on family life. The Family Impact of Childhood Disability questionnaire was used to collect data for this purpose. This questionnaire consists of ten positive and ten negative items in which parents could indicate their appraisal of the impact of raising a child with PIMD on their family life on a scale from 1 (not at all) to 4 (to a substantial degree). Most fathers (n=27) and most mothers (n=52) appraised the impact of raising a child with PIMD on family life as substantially positive (respectively M=31.4 and 32.8) as well as substantially negative (respectively M=31.3 and 28.5). Items appraised negatively by the majority of parents usually concerned problems of time use, such as extraordinary time demands, reduction of time with friends, a disruption of habits and a worsening of the financial situation of parents. Items appraised positively by the majority of parents were mainly non-material, such as the awareness of family members of the needs and struggles of other people (family members) with persons with disabilities. Even more striking, parents of children with PIMD appraise the impact of their child on family life both more positively and more negatively than parents of children with less severe disabilities in previous research. Apparently, parents raising children with PIMD should be seen a group with their own perspective, experiencing more outspoken positive and more negative impacts. Despite the positive appraisals of parents, the strong negative appraisals of both mothers and fathers indicates that the impact of raising a child with PIMD on family life should not be underestimated.

Since children with PIMD not only have an impact on the lives of their parents, but also on the lives of their siblings, chapter six describes the positive and negative experiences of siblings of children with PIMD. A convenience sample of 18 siblings of children with PIMD (9 boys, 8 girls)
aged between six and 13 participated in this study. The children were given
the assignment to take photographs of moments they liked being a sibling of
a child with PIMD, and photographs of moments they feel they dislike being
the sibling of child with PIMD. Based on the photographs, the children were
asked to talk about their experiences with having a sibling with PIMD in a
photo elicitation interview. A thematic analysis of the interviews showed that
the children described both positive and negative aspects of having a sibling
with PIMD. This corresponds to a meta-analysis study by Rossiter and
Sharpe (2001), which indicated that the negative impact of having a sibling
with an intellectual disability was at most minor. The majority of children in
the current study expressed that they enjoyed activities with their siblings,
although they also expressed a need for private time (both time for
themselves and time alone with their parents). Although a number of children
talked about their acceptance of the disability of their sibling, others
mentioned forbearance and the problems they experienced with the disability-
related behaviour of their sibling. A topic not mentioned is professional
support for siblings of children with PIMD. It is unknown whether this is due
to the method used, or if siblings did not mention this topic because support
was not available, or siblings felt they did not need it.

The dissertation ends with chapter seven, in which the conclusions of the five
studies are presented and are reflected upon. The overall conclusions of this
thesis are as follows. First, a large proportion of parents and legal guardians
was satisfied overall with the quality of support provided to their children
with an intellectual disability in residential care facilities, although a
considerable proportion of parents was not or only marginally satisfied,
especially in the domain of leisure activities. Despite our more in-depth
analysis, it remains unclear how the differences in opinion among parents can
be explained. Second, raising a child with PIMD at home has objective and
subjective consequences for all family members. Parents spent a substantial part of their time on child care activities, compared to parents of typically developing children, and they experience these extraordinary time demands as a burden, in particular with regard to their social activities and unwelcome disruptions of the family routine. On the other hand, both mothers and fathers also appraise the impact of raising a child with PIMD on family life positively. Similarly, siblings of children with PIMD experience some difficulties, but their overall view is rather positive. The results underline the importance of being aware of the opinions and experiences of parents and siblings in order to better understand the needs of families with persons with ID/PIMD and provide optimal support.

The emphasis on family systems theory has contributed to increasing concern for the experiences of family members of people with ID/PIMD, the assumption being that the wellbeing of one family member affects the wellbeing of other family members. This dissertation contributed to current knowledge on the opinions and experiences of family members of a person with ID/PIMD by asking all family members about their personal opinions or experiences. This knowledge is important for our understanding of the support needs of the people with intellectual disability or PIMD and their families. Previous research has shown that professional support is one of the most important predictors in promoting positive family outcomes. The needs and wishes of all family members should therefore be taken into account when offering professional support to families raising children with PIMD. A more interpretive approach which recognizes all family members as experts is critical. Only by listening to and integrating the perspectives of all family members will it be possible to offer support that is adapted to the needs and wishes of families raising a person with ID/PIMD.