Chapter 6

General discussion
INTRODUCTION

This dissertation addressed two main topics regarding (1) the developmental changes and outcomes of psychopathology in children and adolescents with ID, and (2) child and family factors associated with these changes and outcomes. The effects of child factors such as the level of ID and age, on the developmental changes in psychiatric disorders, emotional and behavioural problems in comparison to the general population were studied. The influence of family factors, such as family functioning and parental psychopathology, were also topic of research in this dissertation. To find promising factors regarding potential reduction in psychiatric outcomes, these factors were related to developmental changes in psychopathology.

This Chapter will discuss the findings on the two main topics in order to answer the research questions as proposed in the Introduction. These questions have been the main focus in the four preceding Chapters. To address these topics, a sizeable sample of children and adolescents (age 6-18 at the initial assessment) with borderline to mild ID (MiID) and moderate ID (MoID) were studied three times across a 5-year period. At the final assessment the children and adolescents had matured into adolescents and young adults. Chapter 2 described and compared trajectories of the developmental course of emotional and behavioural problems in young individuals with and without ID. In Chapter 3 the developmental course, stability, persistence and onset of emotional and behavioural problems was studied in youths with MiID versus MoID. Chapter 4 revealed associations between changes in potential risk factors and changes in emotional and behavioural problems in youths with MiID and MoID. In Chapter 5 the prediction of psychiatric disorders in adolescents and young adults with ID from child and family characteristics when they were five years younger was studied. Risk profiles consisting of relevant risk indicators were determined and also the relevance for effective prevention programs was studied.

The present Chapter, Chapter 6, summarizes and integrates the findings presented in the preceding Chapters. First, the integrated findings from this dissertation will be discussed by answering the questions formulated in the introduction and repeated above. Next an analysis of the strengths and limitations will be presented. The final part of this Chapter discusses the clinical implications of the findings, and includes suggestions for directions in future research.
DISCUSSION OF THE RESULTS

Similarities and differences in the developmental course of behavioural and emotional problems in children and adolescents with and without ID

Previous studies showed a 3-7 times higher prevalence of emotional and behavioural problems in children and adolescents with ID, compared with their typically developing peers. The question remains unanswered however, whether the developmental course differs or not. Concluding from findings in Chapter 2 the first research question of this dissertation can be answered:

To what extent is the developmental course of behavioural and emotional problems in children and adolescents different from their course in childhood and adolescence from the general population?

The trajectories of emotional and behavioural problems in children and adolescents with ID were directly compared with those in children and adolescents without ID. In short, the developmental course of psychopathology does not seem very different for these two groups. The overall level of problem behaviour, however, was higher for children with ID and continued to be higher when they grew into young adults. As was already found in studies in the general population and in the ID population, the level of most emotional and behavioural problems decreased over time. As neurological deficits and ID-related syndromes, and also lower levels of independence and difficulty in expressing feelings are more prevalent in people with ID, this study hypothesised that, with increasing age, these stable conditions in people with ID would lead to less changes in the level, and higher stability of the developmental course of psychopathology in young people with ID, as opposed to young people without ID. This was, however, not found.

No difference in developmental course or in gender effect on the developmental course was found between youths with and without ID for internalising problems. This suggests that the emotional development in puberty and the accompanying different coping styles for male and female adolescents without ID (e.g., Birmaher, Ryan, Williamson, Brent, & Kaufman, 1996; Birmaher, Ryan, Williamson, Brent, Kaufman et al., 1996) play a similar role in the development of internalising problems in adolescents with ID. The effect of having ID on emotional problems does not seem to increase with age.

The only differences in developmental course of behavioural problems between young people with and without ID found in this study, were larger decreases in aggressive behaviour and attention problems. Previous studies in ID found attention problems to be more persistent in primary school children without ID (e.g., Handen et al., 1997), suggesting a smaller decrease in contrast to the larger decrease found in this study. In this study, adolescents who entered secondary school were
also included. Entrance into (specialised) secondary education might reduce the cognitive school
tasks for children with ID, because they are taught more practical subjects instead of theoretical
subjects. This might lead to lower levels of observed attention problems.

The decreasing developmental course of externalising problems found in this study was consistent
with other studies in both young individuals with (McCarthy & Boyd, 2001) and without ID (e.g.,
Bongers, Koot, van der Ende, & Verhulst, 2004; Kraatz Keiley et al., 2000; Stanger et al., 1997).
However, since disruptive behaviours were found to be very persistent over time in children and
adolescents with ID, despite a decline in severity (e.g., Einfeld et al., 1999; Richardson et al., 1985;
Tonge & Einfeld, 2003), the larger decrease across age in externalising behaviours in young people
with ID than in young people without ID was unexpected. A possible explanation might be that the
level of these behaviours is especially higher at younger ages. Children and adolescents with ID
might go through developmental stages at a reduced pace and, due to lacking or delayed
communication skills in childhood, they express their feelings of discomfort, inattention and
impulsivity in aggressive behaviours. Around the age of 18 these skills seem to have matured to a
level that no longer inflicts increased levels of externalising behaviours compared to their typically
developing peers.

**Prevalence of psychiatric problems in relation to age and level of ID**

In some people who experience emotional and behavioural problems as described above, the
problems are so severe, that these problems can be classified as a psychiatric disorder. In Chapters 3
and 5 of this dissertation the following research question was addressed:

> What is the prevalence of psychiatric problems in adolescents and young adults with mild and
> moderate ID? How does this relate to age and level of ID?

Almost 30% of the adolescents (ages 11 to 17) and young adults (ages 18 to 24 years) met the
criteria for at least one DSM-IV diagnosis, as measured with the DISC-IV. The percentages for any
anxiety disorder, mood disorder and disruptive disorder were 18%, 3% and 16%, respectively.
Young adults were at a marginally higher risk for a mood disorder compared to their younger
adolescent counterparts, who in turn were at a somewhat higher risk for disruptive behaviours. No
differences in the prevalence of psychiatric disorders were found between adolescents/young adults
with mild and moderate ID. In relation to age, however, initially younger children were a higher
risk for a disruptive disorder, whereas initially older children ran a higher risk for mood disorder.
In Chapter 3 it was described that at the initial assessment almost 25% of the parents indicated that their child (ages 6-13 years) had a deviant level (i.e. score above clinical cut-off) of emotional and behavioural problems. At the final assessment, five years later (ages 11-18), this percentage had declined to 18%.

In a review Costello, Copeland and Angold (2011) described that across studies, the average rate of any adolescent psychiatric disorder was 21.8%. That percentage of psychiatric disorders is more or less the same as the prevalence of psychiatric disorders found in the present study. It should however be noted that the review study in adolescents from the general population also included drug abuse or dependence, which was the most common diagnosis (12%), whereas this disorder was not included in the present study. When looking at the average prevalence of anxiety (10,7%), mood (6,1%) and disruptive (3-4%) disorders found in the review study (E. J. Costello et al., 2011) however, the difference in prevalence of disruptive disorders (16% vs 3-4%) is noteworthy. It could be concluded that adolescents with moderate to borderline ID have a higher prevalence of disruptive disorders.

**Developmental change in behavioural and emotional problems related to level of ID**

As mentioned earlier, developmental change in problem behaviour can be described by changes in the mean level, stability of relative scores of individuals, persistence and onset of deviant levels of emotional and behavioural problems. These changes in relation to level of ID were studied in Chapters 3 and 4. Findings from these Chapters can answer our third research question:

*To what extent is level of ID related to developmental change in behavioural and emotional problems?*

Differences between MiID and MoID in developmental changes found in this dissertation were limited. When differences were found, the group of children with MoID had higher levels of stability, and higher onset of deviant levels of emotional and behavioural problems than the group of children with MiID. The level of ID is hardly related to these developmental changes. This will be portrayed in more detail below.

Adolescents and young adults with MoID were expected to show less change than their MiID peers in mean level and higher levels of stability of psychopathology over time, higher persistence of existing psychopathology and lower onset of types of psychopathology that tend to increase in adolescence. In Chapter 3, an overall decreasing developmental course of emotional and behavioural problems was found. Contrary to our expectation, the 5-year change in mean level of
psychopathology did not differ between MiID and MoID on any emotional or behavioural problem syndrome. Chapter 3 also showed that adolescents and young adults with MoID, compared to MiID, did have a higher stability of disruptive/antisocial behaviour, self-absorbed behaviour and social relating. This indicates that, despite the lack of difference in change between MiID and MoID as a group, individual differences in psychopathology are more stable in young people with MoID than MiID, confirming the hypothesis of higher stability in MoID. Similar conclusions were found in Chapter 4; adolescents and young adults with borderline to mild ID were found to have bigger differences between the actual and the predicted level of emotional and behavioural problems than adolescents and young adults with moderate ID, except in disruptive behaviour, where no significant differences for level of ID were found. These findings indicate that the individual changes were bigger in adolescents and young adults with MiID, indicating lower stability. Furthermore, Chapter 3 described onset and persistence of emotional and behavioural problems. Adolescents and young adults with MoID had a higher onset of communication disturbance and anxiety across the 5-year study period. The risk at persistent deviant levels of emotional and behavioural problems was similar in individuals with mild ID and moderate ID. An exception to this was self-absorbed behaviour, which was found to be more stable and persistent in individuals with moderate ID. Communication disturbance had a higher onset in young people with moderate ID.

The 5-year persistence rate (42%) found in this dissertation was lower compared to the 4-year persistence rate (65%) reported in the Australian study on children with ID (Tonge & Einfeld 2000). This study also found a lower rate of onset (8%) than was found in the Australian study (19%) (Tonge & Einfeld, 2000). This study found a higher persistence rate of some problem behaviours (self-absorbed, social relating) in youths with MoID, which is consistent with the assumption that chronic neurological deficits and genetic syndromes, which are more prevalent in youths with MoID, contribute to less overall change in mean level of psychopathology (Bregman & Hodapp, 1991; State et al., 1997; Thompson & Reid, 2002). Self-absorbed behaviours (e.g., eating inedible things, humming, and hitting or biting self) are challenging behaviours associated with people with MoID (Allen, 2008). The present study confirmed the hypothesis that these behaviours are more persistent in young people with MoID than in young people with MiID.

The subscale Social relating (e.g., underactive, depressed/unhappy) had the highest onset and persistence of all problem behaviour scales. When looking at the specific scale items that make up the Social relating scale, some are related to symptoms also seen in depression. In a study into social development and depression (Kovacs & Goldston, 1991) social functioning was also found to be impaired in depressive adolescents without intellectual disability. It might be that the high onset
found in the Social relating scale represents an increase of depressive symptoms. However, the present study did not find a lower onset of depressive symptoms in youths with MoID.

A lower onset of delinquent symptoms was expected in youths with MoID compared to those with MiID. However, no significant differences between MiID and MoID were found for disruptive/antisocial, except for stability, which was higher in girls with MoID than with MiID. Boys from the two intellectual disability levels did not differ significantly on the onset or stability of disruptive/antisocial symptoms. From studies into delinquency among girls without intellectual disability, an increase of delinquency in adolescence is known (Silverthorn & Frick, 1999). It might be that this increase of delinquency is the case in girls with MiID, but not with MoID, resulting in a lower stability of disruptive/antisocial behaviour in girls with MiID. The study presented in Chapter 3, however, only looked at differences between age-groups and was therefore not able to detect a potential adolescent increase of delinquency. The development of delinquency in girls with MiID versus MoID needs to be studied in more detail to reveal whether girls with MiID indeed show an increase of delinquency in adolescence.

Changes in child and family factors related to developmental change

In the above, changes in the level of emotional and behavioural problems were addressed, these changes all occurred naturally in the course of a five year period in the lives of the adolescents and young adults. The development of the child is a product of the continuous dynamic interactions of the child and the experiences provided by his or her family and social context (Sameroff & Mackenzie, 2003). This study looked into the effect of changes in their lives in relation to changes in their emotional and behavioural well-being. Therefore, in Chapters 4 and 5 the following research question was addressed:

To what extent are changes in child and family factors related to developmental change in psychopathology?

This dissertation is the first to relate change in potential risk factors to change in psychopathology in a relatively large and random sample of youths with ID. This study confirmed the hypothesis that changes in child, family, and environmental factors are significantly associated with changes in psychopathology over a 5-year period in predictable directions. Changes in child factors had the strongest association with change in psychopathology, followed by change in family and environmental factors, as was expected based on the ecological model of Bronfenbrenner (1986). Furthermore, change in physical symptoms (e.g., pains, nausea, sleeping problems) and daily living
skills (e.g., prepares food using a stove, handles money correctly) were most strongly associated with change in the level of problem behaviours. Changes in communication skills (e.g., talks to peers, reads magazines, writes messages) and parental psychopathology, and experience of negative life events (e.g., moving house, loss of a family member) were found to be significant moderating factors between change in other risk factors (e.g., physical symptoms) and change in psychopathology. Several factors, including adaptive behaviours, physical complaints and parental psychopathology seem to stand out as highly influential, although the causal direction between change in these factors and change in psychopathology could not be determined.

The concept of vulnerability might explain the reciprocal association between change in adaptive behaviour and change in problem behaviour. By acquiring increased levels of daily living and communication skills across time, children seem to become less vulnerable to the stresses involved in daily life, which is expressed in decreases in levels of psychopathology. Conversely, decreasing psychopathology might alleviate stress levels and free the resources needed for improvement of adaptive skills. The results from this study also suggest that the consistent finding of elevated levels of psychopathology in young people with ID in comparison to young people from the general population (e.g., Wallander et al., 2003) is likely to be partly attributable to the lowered competence of these young people. Interventions aimed at competence-gain may be fruitful in preventing (increase in) behavioural/emotional problems in this group. Another important child factor appeared to be physical illness. As indicated above, the influence of having physical problems (headache, tiredness, muscle-ache) on children and adolescents emotional well-being is well known and our results suggest that in young people with ID the improvement of physical symptoms might be associated with an improvement of all types of emotional and behavioural problems and vice versa.

At the family level a consistent relation was found between mental health of adolescents and emotional well being of their parent. As suggested by our findings, changes in the levels of child/adolescent and parental psychopathology are associated with each other, even despite other shared environmental influences possibly affecting both child/adolescent and parental well being (e.g., family functioning and negative life events).

In summary, decreasing levels of physical symptoms, adaptive skills and parental psychopathology were significantly associated with decreasing levels of psychopathology in young people. Moreover, when children mature into adolescence and adulthood, their childhood levels of child and family factors are still associated with psychiatric disorders. This finding extends the findings of Dekker and Koot (2003b), who looked into the 1-year predictive value of these child and family factors for the development of DSM-IV disorders in children. This dissertation also showed that, apart from childhood levels of psychopathology, the levels of adaptive functioning, ill physical
health and parental psychopathology are valuable risk indicators for developing DSM-IV disorders at post-puberty ages.

**Potential effective strategies in preventing psychiatric outcome**

In the above, child and family factors were identified as being associated with reciprocal change in emotional and behavioural problems and psychiatric disorders. The final research question addressed in this dissertation, took these findings a step further in the direction of preventive strategies:

*What are the most promising factors regarding potential reduction in psychiatric outcomes?*

Chapters 4 and 5 described that not only childhood levels of psychopathology, but also child factors like inadequate adaptive functioning and family factors like parental psychopathology are important risk indicators for emotional and behavioural problems and DSM-IV disorders in young people with ID who all went through puberty. Risk factors that had the largest impact on the development of psychiatric disorders were childhood internalising and externalising problems, childhood adaptive behaviour skills and ill physical health, and parental psychopathology. Candidate factors for preventive strategies should contribute to change and be sensitive to intervention. According to findings in this dissertation, the percentage of adults with a psychiatric disorder might be diminished, by improving communication skills, social competence and physical mobility in childhood. But preventive strategies should not only focus on young people, but also include families. This study found that improved family functioning and decreased levels of parental psychopathology have a suppressive influence on the development of psychiatric disorders. Built on these findings, disorder specific risk profiles could be computed that are able to identify approximately 70% to 95% of the young people who will develop a DSM-IV disorder 5 years later. The results suggested that intervention programs should be disorder specific, since specific associations were found for specific psychiatric disorders. This study found that parental psychopathology was the only significant risk indicator for mood disorders and that this factor solely can identify 20% of the cases of mood disorders in young people with ID. Other relevant factors found in our study may be less sensitive to manipulation, but do occur in daily life (e.g., physical symptoms, negative life events), stressing the importance of further studies on children and adolescents that are vulnerable in this regard. Apart from the important risk indicators included in this study, there might be other factors, which are valuable risk indicators of psychiatric disorders.
too, such as genetic vulnerability and expressed emotion in the family (e.g., Burt et al., 2005; Hastings et al., 2006).

In addition, a cumulative effect for risk factors on the development of psychiatric disorder was found in this study. The greater the number of risks young individuals encountered in their lives, the higher the risk of them developing a psychiatric disorder. The effect of the presence of multiple risks as opposed to a single risk in a young individual on the development of DSM-IV disorders had been found before in general population studies (e.g., Rutter, 1979; Sameroff & Rosenblum, 2006). They showed that the more risk indicators present in the child and their family, the bigger the risk of psychopathology in the child. In a study into risk indicators in children aged 2-3 years, it was shown that children who had come upon 3 or more risks, were at a 50 times higher risk of problem behaviour (Koot, 1993). This pattern of cumulative effect was also found in adults with ID for the influence of life events on the development of psychopathology (Hatton & Emerson, 2004). Some risk indicators (e.g., inadequate communication skills) are present in the majority (88.8%) of the present sample. This makes the chance of having 2 or 3 risk indicators high. The high percentage of multiple risk indicators in people with ID might explain the high prevalence of psychopathology compared with the general population, as found in many studies (e.g., Borthwick-Duffy, 1994; Dykens, 2000).

In conclusion, reducing child and family factors associated with increased risk of psychiatric problems should be the focus of preventive strategies, hence targeting multi-problem families. A combination of treatments directed at both the child/adolescent and the family seems most likely to be effective in reducing psychiatric problems. Examples of potential intervention-targets could be improving adaptive behaviours (e.g., communication skills) in the young individual and diminishing psychological problems in the parents. Especially young people with higher levels of childhood emotional or behavioural problems should be targeted. Early detection of children at risk and early interventions in the children and adolescents and their families is recommended.

**Strengths and limitations, and suggestions for future research**

This dissertation unites findings from four studies (Chapters 2 to 5), which were all part of a bigger epidemiological study including a representative, large (N = 1007) school-based sample of children and adolescents (6-18 years) with borderline to mild and moderate ID, who were followed-up three times in a five-year period. The results from this study are reliable due to a combination of good sampling at the initial assessment (See: Dekker & Koot, 2003a, 2003b, 2004; Dekker, Koot et al., 2002; Dekker, Nunn, Einfeld, Tonge, & Koot, 2002; Dekker, Nunn, & Koot, 2002), and maintaining a high response level throughout the three assessments. The overall study response rate
across a five year period, calculated from the target sample of 1403 at the initial assessment, was 53.4%. This dissertation included both parent and teacher information concerning a broad spectrum of psychopathology (emotional and behavioural problems, and psychiatric disorders) and associated child and family factors (e.g. adaptive functioning, physical symptoms, parental psychopathology and negative life events). Besides these strengths, this study had some limitations. Below, the limitations will be addressed and suggestions for future research will be made, linked to the key features of this study.

**Psychopathology**

A strength of this dissertation is that it included measures of psychopathology both as continuous scores on a behavioural and emotional checklist, and as categories on a diagnostic interview derived from traditional psychiatric taxonomy, DSM-IV (APA, 2000). However, since this was an epidemiological study, as opposed to a clinical study, the prevalence of psychiatric problems was relatively low, especially mood disorders, limiting its statistical power. Future studies should focus on a larger sample of young people with ID and/or clinical samples in order to address the influence of level of ID, gender and other associated factors such as parental psychopathology in the development of psychiatric disorders such as mood disorders.

This dissertation included three major DSM-IV disorder groups (i.e., anxiety disorders, mood disorders and behaviour disorders), developmental disorders were not addressed since ID is an exclusion criterion for most developmental disorders. It would however be interesting to know the actual prevalence of co-morbid ID and developmental disorders. For instance, attachment problems seem to be co-morbid frequently in child and adolescent psychiatric clinics for young people with mild to borderline ID. It might be related to multi-problem families, however, and proper assessment and effective treatment methods seem to be lacking even in the non-ID population. Clearly, further research is required (Minde, 2003; O'Connor & Zeanah, 2003). Future studies among a clinical sample of ID-youths should include developmental disorders and attachment disorders to study whether child factors, family factors, or the interplay of various factors (e.g. multi-problem families) can explain the high frequency of attachment problems.
Standardised instruments

A methodological strength of this dissertation was the multi-method approach to psychopathology. The DSM-IV disorders were studied by using a structured interview; the DISC-IV (Ferdinand & van der Ende, 1998; Shaffer, Fisher, Lucas, & Comer, 2000) and emotional and problems by using standardised questionnaires; the CBCL (Achenbach, 1991a, 1991c; Verhulst et al., 1996; Verhulst, van der Ende, & Koot, 1997) and DBC (Einfeld & Tonge, 2002; Koot & Dekker, 2001). This multi-method approach broadened the spectrum of psychopathology and made it possible to compare interview-based data with questionnaire-based data.

As stability and change over time was the main question in this study, the same standardised instruments were used at all three assessments as far as possible. This improved comparison possibilities across assessments and between samples from other studies. However, at the initial assessment all children were aged 6 to 18, whereas five years later, some had reached up to 24 years. Most instruments used in this study were not validated for use in young adults. Although not validated for ages over 18, it was assumed that the questionnaires and interview schedule would also apply well to the group of youths with intellectual disabilities aged 19–24 at the final assessment, as this group still has limitations in intellectual functioning and adaptive behaviour (e.g. conceptual, social and practical adaptive skills) (AAIDD, 2011).

Most questionnaires and the diagnostic interview used in this study were designed for the general population. The CBCL was found to be reliable in the ID population (Dekker, Koot et al., 2002; Dekker, Nunn, & Koot, 2002). It might be that people with ID express symptoms of disorders in a different manner than people without ID (e.g., expressing feelings of depression require the ability to communicate at a high level). When available, instruments were used that were validated for people with ID. If not, instruments commonly used in research among children from the general population were used. Further validation of instruments for their use in the ID-population is needed to improve research in this group in general.

Multiple informants

The multi-informant design made it possible to compare information from parents and teachers. A limitation of this dissertation is that self-reports of the adolescents and young adults were not included. Adolescents and young adults were only assessed via self-reports at the final assessment. These self-reports were not included for several reasons. The response rate was low, and inclusion of this information would have seriously reduced the study sample. Furthermore, self-reports were only included once, so the main focus of this dissertation (development over time) could not be
accomplished. In an article on self-reports of the adolescents and young adults with ID that was part of the larger study this dissertation is part of, it was found that young people with borderline and mild to moderate ID are capable of answering questions about their behaviour and feelings (Douma, Dekker, Verhulst, & Koot, 2006). Future studies are encouraged to include self-reports of children, adolescents, young adults and adults with ID.

Longitudinal data

As our sample was studied on three occasions the data analytic possibilities were limited to testing linear effects only. This study suggests future studies on the developmental course of psychopathology in young people with ID should test for curve-linear effects by including extra assessment-waves. This could provide more detailed information about the age of onset of increase and decrease of problem behaviours. Also, latent classes of problem behaviours (e.g., adolescence-limited or life-course persistent delinquent behaviour) might be revealed when multiple assessments are included.

The diagnostic interview addressing DSM-IV defined disorders was first used at the second assessment. Due to time and money constraints, the second assessment only included half of the sample. This, in combination with the small number of adolescents and young adults who could be diagnosed with a disorder based on the DISC-IV, made analysis of longitudinal data on the DSM-IV disorders limited and was therefore not included in this dissertation. Future longitudinal epidemiological studies should assess the presence and absence of DSM-IV disorders multiple times, in order to study changes in psychiatric outcome from childhood into adulthood and confirm and elaborate on the findings from this study.

Level of ID

In the initial assessment children were included in this study when they visited a school for the educable or the trainable. Due to the school inclusion criteria in The Netherlands at that time, this was considered a valid representation of respectively borderline to mild ID and moderate ID. At the final assessment intelligence was assessed when parents and the young people themselves agreed to this. In this group, there was an overlap in IQ-scores between the MiID (school for the educable) and MoID (school for the trainable). In this dissertation youths were assigned to intellectual disability-level groups based on their initial educational level, as admission to both types of
educational systems in the Netherlands was usually based on both intellectual and adaptive behaviour, in accordance with the AAIDD definition of mental retardation (AAIDD, 2011). Future studies are recommended to assess IQ scores and adaptive behaviour in order to study effects of the level of ID in relation to psychopathology.

Child and family factors
This dissertation described the course of psychopathology and associated changes in child, family and environmental factors, however, without manipulation of the potential risk or protective factors. This prevented us from concluding whether or not the risk or protective factors included in this study were causal factors. Future studies should investigate, whether change induced in these factors by targeted intervention does indeed result in changes in psychopathology. Candidate factors that contribute to change and are sensitive to intervention, were daily living skills, communication skills, social competence and parental psychopathology. Other relevant factors found in our study may be less sensitive to manipulation, but do occur in daily life (e.g., physical symptoms, negative life events), stressing the importance of further studies on young people that are vulnerable in this regard.

Implications
This study provides several implications for clinicians and policy makers in mental health care. Below, the implications for the understanding of mental health will be addressed first, followed by implications for intervention programs. Finally, the implications from this study for the current political debate on people with ID in current society will be discussed.

Implications for mental health
Higher levels of problem behaviour in childhood are a strong indicator of the development of psychiatric disorders later in life. As mentioned earlier, compared with children and adolescents without ID, the natural decrease of externalising behaviours is stronger in children and adolescents with ID. However, the level of all emotional and behavioural problems stays significantly higher throughout childhood, into adolescence and young adulthood. This study provides clinicians, parents and caregivers, and researchers with important information on the course of emotional and
behavioural problems and psychiatric disorders in young people with ID. A slower development in general of young people with ID makes them more vulnerable to emotional or behavioural problems and psychiatric disorders. Parents, mental health care professionals and other caregivers should be aware of this. Professionals should inform parents of the capabilities, behaviour and emotions of their child and assist them in being realistic about expectations. The high stability of problem behaviour shows the importance of tracking the development of children with ID into adulthood. Youths with MoID and boys are especially likely to show stability in problem behaviour. This suggests that extra attention should be paid to supporting families in raising these children and adolescents, and to help them coach their children through young-adulthood by offering professional help when needed. Parents and teachers should inform each other not only of how they view their child’s or pupil’s behaviour at present, but also how they think about changes over the past years. Parents can inform teachers about the development of their child over a longer period, while teachers can discuss the young individual’s development from their perspective. This might improve the detection of changes in behaviour, which are important in the care of a child or adolescent.

Implications for intervention programs

Significant clinical changes are not likely to occur spontaneously. Parents, teachers and health care professionals should be aware of this, even though in general, youths with ID tended to show a decrease of problem behaviour over time. This natural decrease over time might be sufficient in families with enough resources and resilience to cope with the mental health problems in their child/adolescent with ID. However, families with less resources and resilience, for example due to parenting stress, psychopathology or intellectual disability in one or both of the parents, might struggle more in coping with the mental health issues of their child. These families are more likely to suffer from mental health problems that evolve into a psychiatric disorder. Family functioning and mental health in the young individual are likely to influence each other mutually. Therefore it is crucial to stop this vicious cycle, by intervening at an early stage. Early identification within for instance school settings, and appropriate psychiatric interventions might be necessary to diminish the high stability and persistence of problem behaviour found in this study, assuming interventions can help improve problem behaviour (Klasen & Crombag, 2013). The development of problem behaviour in childhood, adolescence and young adulthood is the result of a complex interaction of child, family and environmental factors that mutually influence the change in problem behaviour. Although causality could not be ascertained, findings from this study
suggest that improving social competence and daily living skills in a training-program could be a valuable addition to intervention procedures aiming at psychopathology specifically. By handing children and adolescents the opportunity to improve their resources (e.g., by improving communication skills and physical mobility), psychopathological problems may be improved or even prevented.

Clinicians should also be aware of the relationship between change in parental psychopathology and family functioning, and change of psychopathology in their young individuals with ID. When treating children and adolescents, it could be helpful to monitor not only improvement in the psychological well-being of the young individual, but also whether or not factors like adaptive behaviour skills, physical health, parental psychopathology or family functioning are subject to change as well. Furthermore, treatment of children and adolescents could profit from including parents. When parents seem to be encountering a lot of stress due to negative life events and when the family has few coping strategies or low ability to adapt their family functioning, it is fruitful to also focus on the family.

In this dissertation it became clear that the group of young people with ID is vulnerable in multiple ways. In order to be able to prevent DSM-IV disorders in this group it is necessary to focus on all the different areas in which these children experience negative influences instead of on one single problem at the time. Parents, caregivers, teachers and health care professionals should work together in monitoring young people with ID.

It is dictated by health insurance companies in the Netherlands that interventions should be proven to be effective, i.e. evidence-based. In a review study into the effectiveness of treatment options such as Multi Systemic Therapy (MST) and Multi Family Therapy (MFT) for aggressive children it was found that the most effective programs combine interpersonal skills training with parent management training (Hage, Van Meijel, Fluttert, & Berden, 2009). Another example of an evidence-based intervention that is focussed on an integrated approach to treat multi-problem families is Functional Assertive Community Treatment (F-ACT). This treatment model is effective in reducing mental health problems in children and their families in the general population (Drukker et al., 2008; Lamb, 2009). However, the evidence-based effective treatments have only been researched in the general population, thus far. An integrated approach might also be a suitable course of action in the intellectually disabled population. Treatment methods for psychiatric disorders in children, adolescents and young adults with ID only need some minor adjustments compared with treatment methods in regular child and adolescent psychiatry. Adjustments need to be made in order to improve understanding, by minimising verbal information, simplifying texts, and adding visual components to verbal information, also the emphasis should be on doing instead of talking. In order to improve effectiveness, sessions need to be short, while the number of sessions
might need to be increased, and the treatment period stretched over a longer period. These latter two aspects might prove to be difficult, since health insurance companies in the Netherlands force healthcare providers to reduce treatments in length and in frequency. Finally, to improve generalisation to all aspects of the lives of the youths with ID and their families, practise situations at home, school or work need to be included in intervention programs.

Concerning treatment, four conclusions can be drawn; first, prevention should start at an early age, when the first symptoms of emotional and behavioural problems appear. Second, adaptive skills of the children should be improved, to improve their resources to face the challenges of life. Third, when parents experience mental health problems or intellectual disability themselves, they will have fewer resources to raise and support their child, and therefore these parents need support. Treating the parents for their own mental health problems should be part of the treatment package for the children and adolescents. Finally, regular treatment methods with minor adjustments should be used in treating psychopathology in young people with borderline to moderate ID. Health insurance companies, government and policymakers should facilitate healthcare providers in developing and providing effective treatment methods for this specific group.

The political debate

Young people with ID who develop psychiatric problems do not only take a toll on their families, but also on society, especially when the psychiatric problems are disruptive disorders such as vandalism, aggression and delinquency. Boys with ID are at increased risk of engaging in criminal activities (Douma, Dekker, de Ruiter, Tick, & Koot, 2007), for example because of their additional impulsivity and sensitivity to being lured into thrill seeking behaviour by peers. Recently, the police department, the public prosecutor and the city of Amsterdam composed a list of the top-600 recurrent criminals (mainly 18-24 years) in Amsterdam. These 600 people were targeted; their activities were followed, they were incarcerated when they partook in criminal activities, and their families were offered guidance in order to reduce criminality levels. Shortly after the list was issued, it became clear that a large percentage of those recurrent criminals had borderline to mild ID. Looking at the population in prisons, the group of people with moderate to borderline ID are also over represented (Teeuwen, 2012). A high percentage of these criminals are only being diagnosed with an ID for the first time when they enter the judicial process around puberty. However, children who are identified as having an ID at a younger age, and who subsequently receive proper guidance, are less likely to engage in criminal activities. It is suggested by Teeuwen (2012) that early detection of ID in children is crucial in order to decrease criminality among people with ID. Furthermore, changeable factors such as social skills and environment should be improved
as early in life as possible. These young people and their families need long-term support in order to prevent frustrations, feelings of incompetence, and exclusion from society due to high cognitive demands. Teachers, but also medical staff (e.g., ‘Centrum voor Jeugd en Gezin’, ‘consultatiebureau’), law-enforcement (e.g., police, judges) and society (e.g., ‘buurtvaders’, sport clubs), should be aware of this vulnerable group of young people, and recognize and help them at an early stage in life. Instead of punishing them once they have reached puberty or adulthood, and already caused trouble for themselves, their families and society. The long-term effects and costs for society should be investigated, including decreasing criminality levels, and not just the short-term costs of single treatments, as was done in some preliminary studies in the general population (e.g., Bonin, Stevens, Beecham, Byford, & Parsonage, 2011; O'Neill, McGilloway, Donnelly, Bywater, & Kelly, 2013). These studies showed that the costs of treatment were more than compensated, by saving costs for society in the long run due to for example lower criminality and thus lower imprisonment costs.

**Concluding words**

Maturing from childhood into young adulthood, emotional and behavioural problems diminish in most young people with ID. However, when unattended these children with ID are at risk for developing psychiatric problems during and after adolescence. This is especially true when combined with other risk factors, such as limited adaptive skills, parental psychopathology and experiencing negative life events. Prevention and intervention programs should target communication skills, social competence and physical mobility of the child/adolescent. Family functioning and parental psychopathology are family factors that should be attended to in these programs as well. An integrated approach seems most promising in multi-problem families. The larger the number of risk indicators a child/adolescent comes across in their life, the larger the risk at developing a psychiatric disorder. Mental health caregivers and politicians should focus on improving the well being of children and adolescents with ID growing up in families with a variety of problems such as mentioned above (e.g., parental problems, negative life-events).