RISK FACTORS FOR THE DEVELOPMENT AND OUTCOME OF CHILDHOOD PSYCHOPATHOLOGY

APPENDICES
Appendix I: Data collection procedures, response rates and measurement instruments

In the second part of this thesis (i.e. chapter five to eight) data were analyzed that were collected in families with a child with psychopathology at the time the child was evaluated at a child and adolescent psychiatric outpatient clinic (first assessment) and one to five years later (second assessment). These data were gathered in four child and adolescent psychiatric outpatient clinics: 1) GGZ inGeest, department of child and adolescent psychiatry, 2) de Bascule, academic hospital for child and adolescent psychiatry, 3) the Erasmus University Medical Center-Sophia Children’s Hospital, department of child and adolescent psychiatry/psychology, and 4) UvA Minds, the Academic Treatment Center for Parent and Child at the University of Amsterdam. All clinics mainly treated children with ADHD, conduct behavioral disorders, autism spectrum disorders, anxiety and/or depressive disorders.

Part of this data collection was funded by the Netherlands Foundation for Mental Health (20096398), and the Netherlands Organization for Health Research and Development Grant: “Genetic influences on stability and change in psychopathology from childhood to young adulthood” (ZonMW 912-10-020). This includes the data collection for the first assessment at GGZ inGeest and the Bascule, and for the second assessment at GGZ inGeest and Erasmus MC. This appendix describes these data collection procedures, final response rates and the administered measurement instruments.

The data collections at the first assessment at Erasmus MC and at the first and second assessment at UvA Minds were independent from these data collections. Given the large similarities in the data collection procedures and instruments used across studies (see chapters five to eight) it was decided to simultaneously analyze the data.

Data collection

First assessment

A pilot study was conducted between April 2010 and May 2012 to optimize procedures for data collecting of psychopathology in parents of children evaluated at two child and adolescent psychiatric outpatient clinics in Amsterdam: the department of child and adolescent psychiatry of GGZ inGeest and at two different branches of de Bascule (i.e., the emotional disorders, and autism spectrum disorders). With the
invitation for the first appointment at the clinic, parents received information on this study and were asked to participate by completing a survey assessing their own psychopathology, in addition to the survey they completed on their children’s psychopathology as part of the usual clinical practice. Families were excluded when Dutch language was not sufficient to fill in the survey. Non-responders were reminded by letter or telephone call by research assistants. The family-response rate was 18.5%. Surveys were completed by both parents in 110 families, by mothers in 66 families and by fathers of 15 families. The pilot data indicated that 37.3% (n=66) of the mothers and 31% (n=39) of the fathers had a score in the (sub)clinical range for any of the disorders assessed. Further diagnostic assessment was offered and an interview by phone was completed for 43 mothers and 20 fathers (the Composite International Diagnostic Interview, see ‘assessment of psychopathology’ below).

Given the high rates of parents with psychopathology as observed in the pilot study, screening of parental symptoms was implemented as a standard procedure in the first assessment of the child at the department of child and adolescent psychiatry at GGZ inGeest. In case of (sub)clinical scores, parents were offered further diagnostic assessment and treatment. Families were excluded when Dutch language was not sufficient to fill in the survey (42 out of 751 families, 5.6%). From May 2012 until December 2016 the family response rate was 72.11%, (surveys from 511 out of 709 different families). Of the 511 families, 36.5% (n=176) of the mothers and 22.5% (n=67) of the fathers had a score in the (sub)clinical range on any of the disorders assessed. Additional assessment was completed for 96 mothers and 50 fathers, which revealed a clinical diagnosis (either current or in remission) in 64 mothers and 33 fathers. The article of van Veen et al. [266] on the feasibility of the implementation of screening parents of new registered children for psychopathology and offering parents further psychiatric assessment and if necessary treatment, reported that eventually 14.3% of the parents who completed the survey at the first assessment made use of the offer to get treatment. Data from 117 surveys of 86 different families were excluded for the analyses described in this thesis as they refused consent for the use of the collected data for research purposes. In 9 families, a survey was excluded for one parent, while the survey of the other parent was included. Data were available for research purposes from both parents of 222 families, from mothers of 183 families and from fathers of 29 families.
Second assessment: Follow-up

Families that completed the first set of surveys were approached approximately between one and five years later to complete the same survey assessing their child’s and their own psychiatric symptoms. From April 2014 until October 2016, at intervals, a total of 320 families from GGZ inGeest sample were approached. In 70.31% of the total families, the child was 12 years or older and therefore received a self-report survey assessing their psychiatric symptoms. Non-responders were reminded by letter and twice by telephone call. The family response rate was 34.06% (surveys from 109 different families were received). Data were available from both parents of 39 families, from mothers of 61 families and from fathers of 8 families. Data from children older than 12 were available for 49 families.

From April 2015 until October 2016, a total of 382 families from the Rotterdam sample were approached. In 78.5% of the total families, the child was 12 years or older and received a self-report survey assessing their own psychiatric symptoms. Non-responders were reminded by letter and twice by telephone call. The family response rate was 31.4% (surveys from 121 different families were received). Data were available from both parents of 46 families, from mothers of 57 families and from fathers of 13 families. Self-reports from children were available for 51 families.

Collection of biological material

Families that participated in the pilot study or before August 2014 in GGZ inGeest were also asked to participate in the collection of biological material sometime after the first assessment, either by letter or telephone call. From August 2014 until December 2016, families that visited GGZ inGeest were asked to collect buccal swaps, in addition to completing the surveys at the time of the first assessment. The buccal swabs [267] were collected for DNA isolation. Families were provided with 4 sets of buccal swabs per family member and a return envelope. The family response rate of the pilot study was 55.5% (53.32% of these families willing to participate actually returned the buccal swab samples). The family response rate at GGZ inGeest at the first assessment was 38.9% (with 60.2% of those families returning the buccal swab samples) and for the follow-up 22.1% (with 67.6% of those families returning the buccal swab samples). In total, DNA samples were returned by 173 children, 187 mothers and 137 fathers.
Appendices

Assessment of psychopathology

Behavioral and emotional problems in parents and children were measured with the age-appropriate versions of the questionnaires belonging to the Achenbach System of Empirically Based Assessment (ASEBA), i.e., the Child Behavior Checklist (CBCL), the Youth Self-Report (YSR) [99] and the Adult-Self-Report (ASR) [175]. All three questionnaires measure comparable problems over ages and include the following DSM-oriented syndrome scales: depressive, anxiety, somatic, attention deficit/hyperactivity, oppositional defiant and conduct problems. In addition, the ASR offers the avoidant and antisocial personality problem scales.

Demographical information on age, sex, nationality, educational attainment, work and family composition was obtained in a separate questionnaire (Appendix II).

From May 2012 until August 2013 participants were offered the option to choose between a paper and an online version of the survey. From August 2013 until August 2014 the survey was only offered on paper due to the transition to a new online survey program. From August 2014 until December 2016, parents were provided with personal log-in details to complete the survey online, with the option to receive a paper version of the survey. Overall, about a two third of all surveys were filled in online, while the remaining third were completed in paper form.

In GGZ inGeest, if parents scored in the (sub)clinical range for any of the empirical and DSM-oriented syndrome scales assessed by the ASR, further diagnostic assessment was offered. Additional diagnostic assessment in the parents consisted of the Composite International Diagnostic Interview (CIDI) [232] a fully standardized diagnostic interview administered by me, or another trained research assistant, by telephone. The following disorders were assessed: anxiety (social phobia, generalized anxiety, panic disorder and agoraphobia), mood (depression, dysthymia) and alcohol use (alcohol abuse and dependence). The Conners’ Adult ADHD Ratings Scale (CAARS) [233] was added in the diagnostic interview as an additional module to assess attention deficit/hyperactivity in adults. The outcomes from the clinical interview were used as additional information to assess the treatment need of parents.
Appendix II: Questionnaire about demographical information

A. Biografische gegevens

1. Datum van vandaag: ...... - ...... - ............
2. Geboortedatum van het aangemelde kind: ...... - ...... - ............
3. Uw geboortedatum: ...... - ...... - ............
4. Uw geboorteplaats: ............................................................................
5. De cijfers van uw postcode: ..................................................................
6. Uw geslacht: Man / Vrouw
7. Wilt u het geboorteland van uw ouders aangeven?
   Geboorteland vader: ..............................................................................
   Geboorteland moeder: ...........................................................................
8. Heeft u wel eens meegedaan aan onderzoek van het Nederlands Tweeling Register? : Ja / Nee

B. Gezinssituatie

9. Wat is uw relatie tot uw kind? Ik ben:
   o Biologische moeder
   o Biologische vader
   o Stiefmoeder
   o Stiefvader
   o Pleegmoeder
   o Pleegvader
   o Adoptiemoeder
   o Adoptievader
   o Anders, namelijk .................................................................
Vragen 10 en 11 zijn bestemd voor de biologische ouder. Indien u niet de biologische ouder van het kind bent, kunt u deze vragen overslaan.

10. Woont u samen met de andere biologische ouder van het kind? Ja/nee
11. Indien u niet meer samenwoont met de andere biologische ouder van het kind, hoe oud was het kind toen u uit elkaar ging? ...... jaar en/of ...... maanden
12. Wat beschrijft uw gezinsituatie met het kind het beste?
   o Gezin met biologische vader en biologische moeder
   o Gezin met biologische vader en nieuwe partner
   o Gezin met biologische moeder en nieuwe partner
   o Eén-oudergezin na scheiding, kind woont groterdeel bij moeder
   o Eén-oudergezin na scheiding, kind woont groterdeels bij vader
   o Co-ouderschap na scheiding, kind woont afwisselend bij beide biologische ouders
   o Eén-oudergezin
   o Pleeggezin
   o Adoptiegezin
   o Anders, namelijk ..............................................................................
12. Hoe oud was het kind toen de bij vraag 12 aangegeven gezinsituatie ontstond?
   o Vanaf de geboorte
   o Anders, namelijk vanaf de leeftijd van ……….jaar en/of ………. maanden

14. Woont het kind
   o Voltijds in uw gezin
   o Deels in uw gezin, namelijk gemiddeld ………….. dagen per maand
   o Niet in uw gezin

15. Indien het kind deels of helemaal niet bij u woont, is dit
   o Bij de andere biologische ouder
   o In een pleeggezin
   o In een gezinsvervangend tehuis
   o Anders, namelijk………………………………………………………………………………………………

16. Heeft het kind broers en zussen? Ja / Nee
   Zo ja, geef a.u.b. de kolommen de aantallen weer.
   Ook wanneer deze kinderen (deels) in uw gezin wonen.
   Aantal Aantal
   ……… Zussen met dezelfde vader en moeder ………. wonen in mijn gezin
   ……… Broers met dezelfde vader en moeder ………. wonen in mijn gezin
   ……… Halfzussen met dezelfde vader ………. wonen in mijn gezin
   ……… Halfbroers met dezelfde vader ………. wonen in mijn gezin
   ……… Halfbroers met dezelfde moeder ………. wonen in mijn gezin
   ……… Niet-biologisch verwante zussen ………. wonen in mijn gezin
   ……… Niet-biologisch verwante broers ………. wonen in mijn gezin
   ……… Halfzussen met dezelfde moeder ………. wonen in mijn gezin
   ……… Andere kinderen ………. wonen in mijn gezin

17. Indien er broer(s) en / of zus(sen) niet in uw gezin wonen, verblijven zij
   o Bij de andere biologische ouder
   o In een pleeggezin
   o In een gezinsvervangend tehuis
   o Anders, namelijk …………………………………………………………………………………………………

18. Zijn er verder nog bijzonderheden ten aanzien van uw gezinsituatie waarvan u denkt dat deze belangrijk kunnen zijn? Ja / Nee
   Zo ja, licht a.u.b. toe ……………………………………………………………………………………………..
C. Opleiding en werk

19. Wat is uw hoogst gevolgde opleiding?
   o Lagere school, basisschool
   o Lager beroepsonderwijs (bijv. LTS), VMBO (leerweg beroepsonderwijs)
   o Mulo, MAVO, VMBO (theoretische leerweg)
   o HAVO of VWO (hbs, atheneum, gymnasium)
   o 1-jarig MBO (middelbaar beroepsonderwijs)
   o 2 tot 4-jarig MBO (middelbaar beroepsonderwijs)
   o HBO (hoger beroepsonderwijs)
   o Universiteit of post-HBO onderweg
   o Post-docentaal / tweede fase opleiding of promotie (doctorsgraad)

20. Is deze opleiding met een diploma afgerond?
   o Nee, niet met een diploma afgerond
   o Ja, wel met een diploma afgerond

21. Wat is uw huidige werksituatie?
   o Betaald werk .......... uren per week
   o Vrijwilligerswerk .......... uren per week
   o Scholier / student
   o Huisvrouw / huisman
   o Werkeloos, sinds ..........

D. Gezondheid en medicijngebruik

22. Hoe is in het algemeen uw gezondheid?
   o Slecht
   o Matig
   o Redelijk
   o Goed
   o Uitstekend

23. Gebruikt u medicijnen? Ja/nee
   Zo ja, welke?
   ........................................................................................................................................
   ........................................................................................................................................
   ........................................................................................................................................

24. Ben je ooit onder behandeling geweest voor psychische klachten? Ja/nee
   Zo ja, kunt u aangeven welke diagnose is gesteld of welke klachten u had?
   ........................................................................................................................................
   ........................................................................................................................................
   ........................................................................................................................................