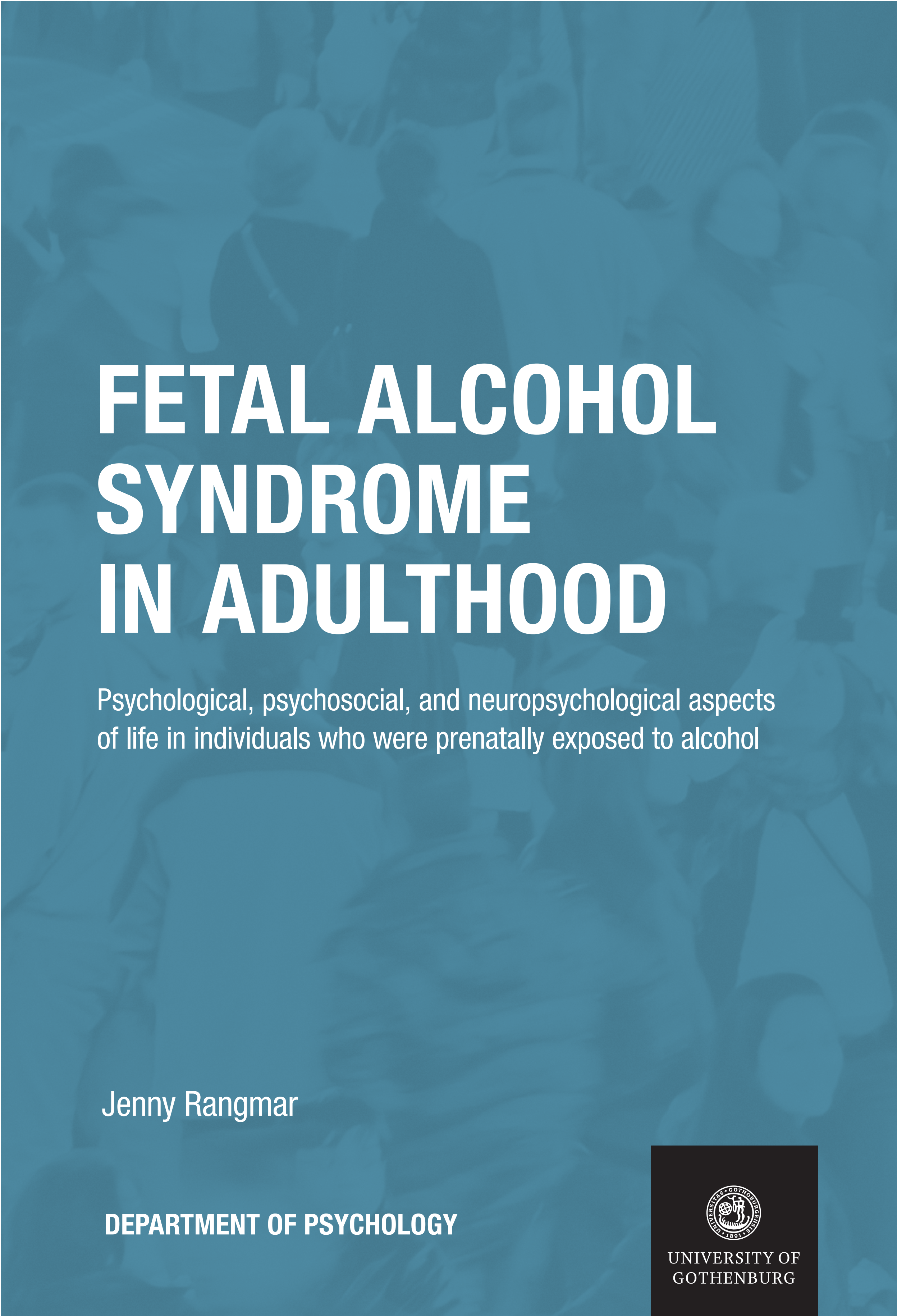


FETAL ALCOHOL SYNDROME IN ADULTHOOD

Psychological, psychosocial, and neuropsychological aspects of life in individuals who were prenatally exposed to alcohol

Jenny Rangmar

DEPARTMENT OF PSYCHOLOGY

UNIVERSITY OF
GOTHENBURG

FETAL ALCOHOL SYNDROME IN ADULTHOOD

Psychological, psychosocial, and neuropsychological aspects of life in individuals who were prenatally exposed to alcohol

Jenny Rangmar

UNIVERSITY OF
GOTHENBURG

Printed in Gothenburg Sweden, 2016
Department of Psychology
University of Gothenburg

ISSN: 1101-718X
ISRN: GU/PSYK/AVH--340--SE
ISBN: 978-91-628-9862-5
ISBN: 978-91-628-9863-2

Abstract

Rangmar, J (2016). *Fetal Alcohol Syndrome in adulthood – psychological, psychosocial, and neuropsychological aspects of life in individuals who were prenatally exposed to alcohol.* Department of Psychology, University of Gothenburg, Sweden.

Alcohol's teratogenic effect on the developing fetal brain is devastating, resulting in, for instance, structural abnormalities as well as behavioral and neuropsychological impairments in the child. The umbrella term Fetal Alcohol Spectrum Disorders (FASD) is used to describe the range of effects, from neuropsychological dysfunctions to complete Fetal Alcohol Syndrome (FAS). The disabilities associated with FASD have a major impact on life for children, and perhaps even in adulthood. However, only a few studies have addressed the long-term outcome in adults prenatally exposed to alcohol, especially with a diagnosis of FAS, from a psychological perspective. The main aim of this thesis was to investigate the psychological, psychosocial and neuropsychological consequences of FAS in adulthood. Participants in the studies in this thesis consisted of 79 adults (mean age: 32 years) with an FAS diagnosis. In **Study I**, data on the adults with FAS and a gender- and age-matched comparison group were obtained from national registers. The results showed that 25 % of the FAS group had attended special education. The adults with FAS were less often employed (49.2 % vs. 85.3 %) but had a low rate of criminal offenses, comparable to that of the comparison group (*ns*). Those in the FAS group had higher hospital admission rates due to psychiatric disorders, and were more often prescribed psychotropic drugs (57 % vs. 26.5 %). In **Study II**, data from childhood medical records on environmental conditions were related to adult psychosocial outcomes in adulthood. No significant differences related to childhood conditions in the adult outcomes were found. The results were suggested to show that, due to the heterogeneity in the FAS group, interventions should be functional-need-oriented to each individual. Data in **Studies III and IV** were obtained through face-to-face data collection. Participants were 20 adults with FAS (mean age: 30 years) and a comparison group consisting of healthy individuals matched on gender and age. The results in **Study III** showed that the FAS group displayed deficits in the neuropsychological tests sensitive to cognitive and executive functions and social cognition. The results in **Study IV**, using the Addiction Severity Index interview, showed that the adults with FAS had problems with depression and suicidal ideation, which were common among them; but problems with substance use were not more common in the FAS group. The crime conviction rate was low, but many in the FAS group had been victims of crime. Based on the results in the empirical studies in this thesis, it was concluded that: 1) The psychological consequences were depression and anxiety, brought on by negative experiences throughout life; 2) The psychosocial consequences of importance were that criminality was uncommon among the adults with FAS who were studied. This could be explained by the fact that they had access to social, educational and financial support during childhood; and 3) The neuropsychological consequences entailed that impaired cognitive functions may be found in individuals with FAS even in adulthood. The conclusions indicate that FAS is associated with a complex chain of causes and consequences that interrelate from early childhood to adulthood. To ameliorate adverse adult outcomes, children with FAS need efficient interventions from welfare authorities. FASD is caused by maternal consumption of alcohol, and is therefore completely preventable.

Key words: Fetal Alcohol Syndrome, adulthood, psychological, psychosocial and neuropsychological consequences, prenatal alcohol exposure

Jenny Rangmar, Department of Psychology, University of Gothenburg,
Box 500, S-405 30 Gothenburg, Sweden, jenny.rangmar@psy.gu.se, +46 31 786 1629

Svensk sammanfattning

Om en gravid kvinna dricker alkohol kan det leda till att barnet föds med skador. Alkohol är ett teratogent ämne som kan störa utvecklingen av fostrets hjärna under hela graviditeten och kan orsaka fysiska avvikelser, beteendestörningar och funktionsnedsättningar hos barnet. Den engelska paraplytermen *Fetal Alcohol Spectrum Disorders* (FASD) används för att beskriva det spektrum av skador som alkoholexponering under graviditet kan ge, allt från neuropsykologiska funktionsnedsättningar till fullständigt fetalt alkoholsyndrom (FAS). De funktionsnedsättningar som hjärnskadorna av alkoholexponeringen vanligtvis innebär kan få stor inverkan på det dagliga livet för det drabbade barnet. Utöver detta kan barnet i relation till omgivningen utveckla olika psykosociala problem såsom svårigheter i skolan, kriminalitet och missbruk av alkohol. Både de funktionsnedsättningar som är följden av hjärnskadorna av alkoholexponeringen och de senare utvecklade svårigheterna kan ha en stor inverkan på det dagliga livet i vuxen ålder. Det finns dock endast ett fåtal studier som beskriver hur det går för vuxna med FASD, framförallt med diagnosen FAS, ur ett psykologiskt perspektiv. Huvudsyftet med den här avhandlingen var därför att undersöka hur det går för vuxna med FAS ur ett psykologiskt, psykosocialt och neuropsykologiskt perspektiv.

Syftet med **studie I** var att undersöka den psykosociala situationen hos vuxna med FAS. Uppgifter om utbildning, social anpassning och psykiska problem om 79 vuxna med FAS inhämtades från nationella register. Deltagarna jämfördes med en grupp matchad på ålder och kön. Resultaten från studien visade att de flesta i FAS-gruppen inte hade vuxit upp med sina biologiska föräldrar utan i samhällsvård, såsom exempelvis i familjehem. Som vuxna var hälften av de vuxna med FAS självförsörjande. Resten av personerna i gruppen försörjdes genom sjukpension och socialbidrag, vilket var signifikant fler än i den åldersmatchade jämförelsegruppen. Resultaten visade också att det var få i FAS-gruppen som hade behandlats för alkoholrelaterade sjukdomar eller narkotikamissbruk. De flesta av de vuxna med

FAS hade inte heller begått brott. En stor andel av de vuxna med FAS hade behandlats på sjukhus för psykiatrisk sjukdom, vilket var betydligt vanligare bland dem än i jämförelsegruppen. Många i FAS-gruppen hade också ordinerats sömnmedel, ångestdämpande eller antidepressiva mediciner. Eftersom de flesta av de vuxna med FAS hade varit placerade i samhällsvård gjordes en ytterligare analys där FAS-gruppen jämfördes med de som hade varit placerade i samhällsvård ifrån jämförelsegruppen. Resultaten visade att både kriminalitet och alkohol- eller narkotikamissbruk var mindre vanligt i FAS-gruppen. Dessa fynd tyder på att placering i samhällsvård kan vara en skyddsfaktor för barn med FAS.

Syftet med **studie II** var att relatera barndomsdata till utfall i vuxen ålder för 51 av de 79 vuxna med FAS som deltog i studie I. Från medicinska journaler från barndomen inhämtades uppgifter om huruvida barnen hade vuxit upp med biologiska föräldrar eller i samhällsvård. Data om psykosociala utfall i vuxen ålder (t.ex. högsta avslutade utbildning, ekonomisk ställning, vård på grund av alkohol eller narkotikamissbruk, psykisk hälsa och kriminalitet) inhämtades från nationella register. Majoriteten av de vuxna med FAS hade inte vuxit upp med sina biologiska föräldrar och bland dem som placerades i samhällsvård var det många som blev omplacerade innan de hamnade i det hem där de sedan växte upp. Resultaten visade att grov brottslighet i vuxen ålder var generellt ovanligt, men det var något vanligare bland de som hade placerats i samhällsvård efter tre års ålder än de som hade placerats vid yngre ålder. Det fanns inga signifikanta skillnader mellan de psykosociala utfallen i vuxen ålder relaterat till uppväxtförhållanden. Resultaten i studie II föreslås därför visa att för individer med FAS kan såväl en uppväxt i samhällsvård som i det biologiska hemmet ha för- och nackdelar. Det som avgör hur den psykosociala situationen blir för dem i vuxen ålder kan vara socioekonomiska faktorer och kvaliteten på miljöförhållandena och relationerna under barndomen.

Syftet med **studie III** var att undersöka intellektuell förmåga och exekutiva funktioner hos vuxna med FAS. Med testerna Raven's coloured progressive matrices, Digit span, Berg's card sorting test-64 och Tower of Hanoi undersöktes 20 vuxna med FAS-diagnos och en jämförelsegrupp matchad på ålder och kön. Resultaten visade att FAS-gruppen hade låg intellektuell förmåga och nedsatt minnesfunktion. Dessa funktionsnedsättningar i vuxen ålder kan påverka det dagliga livet och göra flera situationer svåra att förstå och hantera. FAS-gruppens resultat från testerna av exekutiva funktioner visade att de hade svårt att lösa uppgifter som man möter i vardagslivet; att kunna planera, förmåga att hitta strategier, kognitiv flexibilitet, och förmåga att resonera om vad som är den mest effektiva lösningen på ett problem. Ett test som undersöker Theory of Mind (ToM) genomfördes också. ToM innebär en förståelse för att andra har önskningar, avsikter och perspektiv som skiljer sig från de egna. Resultaten från testet visade att de vuxna med FAS var osäkra på sociala koder och vad som anses lämpligt i sociala interaktioner. När en vuxen har svårigheter av detta slag är det inte ovanligt att det leder till uteslutning från sociala grupper på arbetsplatser och i privatlivet. Resultaten visade även att de vuxna med FAS hade en svag Känsla Av Sammanhang (KASAM). KASAM är ett sätt att beskriva en känsla av meningsfullhet, hanterbarhet och begriplighet i livet. Stark KASAM innebär en upplevelse av att livet är strukturerat och förutsägbart och att den egna förmågan att planera, lösa problem och anpassa sig till förändrade förhållanden är tillräcklig. Dessa förmågor kräver en viss nivå av exekutiva funktioner och social kognition och eftersom dessa var nedsatta hos de vuxna med FAS kan det ha bidragit till deras svaga KASAM.

Syftet med **studie IV** var att undersöka den självskattade svårighetsgraden på problem inom områdena alkohol, narkotika, utbildning och sysselsättning, familj och sociala relationer, kriminalitet, fysisk och psykisk hälsa. För att studera det användes den strukturerade intervjun Addiction Severity Index (ASI). Samma deltagare som i studie III: 20 vuxna med FAS-diagnos och en ålder- och könsmatchad jämförelsegrupp deltog i studien. Resultaten visade att depression och självmordstankar var vanligt förekommande hos de vuxna med FAS. Däremot var problem med missbruk av alkohol och narkotika ovanligt i FAS-gruppen, lika ovanligt som i jämförelsegruppen. Fysiska hälsoproblem rapporterades lika ofta i FAS-gruppen, men antal dagar med sjukfrånvaro på grund av fysiska hälsoproblem var fler bland de vuxna med FAS. En majoritet av deltagarna med FAS hade erfarenheter av att vara brottsoffer, men att ha begått brott var ovanligt både i FAS-gruppen och i jämförelsegruppen. Alla i studiegruppen hade en FAS-diagnos, vilket kan ha inneburit tillgång till stöd och insatser från sociala myndigheter genom livet för dem. De insatserna kan vara en av förklaringarna till den låga förekomsten av kriminalitet.

Utifrån resultaten i de fyra empiriska studierna kan följande tre slutsatser dras:

1) Neuropsykologiska konsekvenser: Även i vuxen ålder kan personer med FAS ha nedsatta kognitiva funktioner. Denna funktionsnedsättning kan antas ha en stor inverkan på livet, i synnerhet på en vuxens liv som kan ställa höga krav på individens fungerande. Många vardagliga situationer kräver exekutiva funktioner, såsom förmåga att planera, lösa problem och

att vara flexibel. Brister man i dessa förmågor kan man ha svårt att klara av en utbildning, att vara förälder eller att sköta ett arbete.

2) Psykologiska konsekvenser: Psykiska problem, framförallt ångest och depression, var vanligt förekommande bland de vuxna med FAS, men de hade inte problem med missbruk av alkohol eller narkotika. En individ med FAS kan ha upplevt en eller flera tidiga separationer från anknytningspersoner, inlärningssvårigheter och problem att få kamrater under barndomen. Senare i livet kan en vuxen med FAS ha upplevt problem med att delta i sociala sammanhang, svårigheter att få anställning eller att klara av sitt föräldraskap. Slutsatsen att psykiska problem var vanligt förekommande hos de vuxna med FAS kan förklaras av sådana negativa erfarenheter under hela livet.

3) Psykosociala konsekvenser: Kriminalitet var ovanligt bland de vuxna med FAS. De har alla fått pedagogiskt och ekonomiskt stöd och haft nära kontakt med socialarbetare under barndomen och det kan ha fungerat som skyddsfaktorer. Senare i vuxen ålder var de självförsörjande eller hade ekonomiskt bistånd, vilket också kan ha bidragit till att kriminalitet var ovanligt.

De empiriska studierna som ingår i den här avhandlingen visar inte om varje negativ psykologisk, psykosocial, och neuropsykologisk konsekvens i sig orsakades av de medfödda skadorna av alkohol. Prenatal alkoholexponering föreslås snarare leda till en komplex kedja av orsaker och konsekvenser som är sammankopplade och påverkar varandra från tidig barndom till vuxen ålder genom ett utbyte mellan individ och miljö. Trots att en individ med FAS de neuropsykologiska funktionsnedsättningarna är följden av en medfödd hjärnskada måste inte det betyda att de är bestående i vuxen ålder, utan de kan påverkas genom livet av psykologiska och psykosociala faktorer. En stimulerande miljö där barnet med FAS ges möjlighet att knyta an till en stabil vårdgivare kan förbättra barnets neuropsykologiska funktioner. Däremot kan försummelse och en eller flera separationer från anknytningspersoner ge sämre förutsättningar för förbättring av barnets neuropsykologiska funktioner. Dessutom kan en negativ psykosocial miljö och upplevelser av negativa händelser även få psykologiska konsekvenser som depression och ångest hos individen senare i livet. Både de neuropsykologiska och de psykologiska aspekterna kan i vuxen ålder ha betydelse för individens möjlighet att fullfölja en utbildning och att få och behålla ett arbete. Enligt detta resonemang innebär det att de psykologiska, psykosociala och neuropsykologiska aspekterna påverkar varandra och blir på samma gång orsaker och konsekvenser i livet för vuxna med FAS.

Eftersom FASD orsakas av alkoholexponering under fostertiden vore det möjligt att helt förhindra att tillståndet uppstår. Insatser på samhällsnivå med syfte att förhindra FASD är av yttersta vikt för att skydda det ofödda barnet. I Sverige rekommenderar Socialstyrelsen gravida kvinnor att avstå från att konsumera alkohol under graviditeten. Samtidigt är det viktigt att betona att FASD inte bara beror på den enskilda kvinnans val. Det kan finnas flera olika anledningar till varför en kvinna inte avstår från att konsumera alkohol under graviditeten. Hon kan vara omedveten om att hon är gravid och fortsätta dricka alkohol enligt invanda mönster, och hon kan vara alkoholberoende och därför ha svårt att avstå från att dricka alkohol under graviditeten. Hon kan också befinna sig i en miljö där sociala normer och relationer gör att det är svårt att inte dricka alkohol. I diskussioner om hur preventiva insatser mot FASD bör utformas är det därför viktigt att tänka på att ansvaret inte enbart är den enskilda kvinnans. På det sättet kan det förebyggande arbetet göras på ett etiskt sätt.

Sammanfattningsvis bidrar den här avhandlingen med kunskap om alkoholexponering under fostertiden och de långsiktiga konsekvenser det kan ge. Framför allt visar den att tidig upptäckt av FAS hos barn, följt av insatser från samhället kan förhindra kriminalitet och alkoholmissbruk i vuxen ålder. Den visar även de psykologiska, psykosociala och neuropsykologiska svårigheter det kan innebära för en individ med FAS att leva ett fungerande vuxenliv.

Acknowledgements

First of all I want to thank my supervisor, Professor Claudia Fahlke, for encouraging me to do this research, and for your ability to never give up and always focus on solutions. I also want to thank my second supervisor, Professor Emerita Annika Dahlgren Sandberg, not only for the practical help but also because you constantly remind me of the importance of trusting myself. I would also like to thank my co-authors, Dr. Marita Aronson and Professor Emerita Kerstin Strömland, for the confidence you gave me to follow up your data on the children whose mothers consumed alcohol during pregnancy, an assignment that demanded a great deal of responsibility. Thank you, Claudia, Annika, Marita and Kerstin, for your excellent guidance and support, and for generously sharing your wisdom and insights with me.

Others of importance are Professor Anders Hjern and Professor Bo Vinnerljung, also my co-authors. Thank you for sharing your great knowledge of record-linkage studies and for encouraging me to aim high. I would also like to thank all my colleagues and friends at the Department of Psychology, particularly Research Assistant Maja Jansson and my examiner, Professor Anders Broberg.

I wish to thank Professor Sarah Mattson and Professor Ed Riley at San Diego State University, and Professor Ken Jones and Professor Christina Chambers at the University of California, for generously welcoming me in October 2015. Our conversations about research and the effects of prenatal exposure to alcohol were really inspiring and educational. Thanks to you, my family and I had a wonderful time in San Diego.

I also want to express my gratitude to Ann-Britt Thulin and Marie Nyman at the Swedish National Board of Health and Welfare; the Alcohol Research Conferences at Skarpö; my co-workers in the FASD project at SBU; and my co-workers in the project on FASD in educational activities; all the staff on the maternal and child care team in Haga, Gothenburg; and Chief Physician Ihsan Sarman. Throughout the years you have supported me, and reminded me of the importance of this research. Others who have been important for this research are Katarina Wittgard from FAS-föreningen and, of course, all the enthusiastic study participants. I am truly grateful to all of you.

To all my dear family and friends outside the academic world, of whom many of you also are my co-exercisers at Friskis: Thanks for the support and all the fun moments we have together – you make me strong! Last, but certainly not least, I would like to thank Fredrik, Axel, Molly and My, for constantly reminding me that life is more than research.

The research presented in this thesis was supported by the Alcohol Research Council of the Swedish Alcohol Retailing Monopoly (ref 09-5:1, 09-5:2, 2011-0047, 2012-0065, 2013-0034), the Swedish National Board of Health and Welfare (ref 00-3177/2007), and the Health and Medical Care Committee of the Region Västra Gotaland, Sweden (ref 309161).

Preface

This doctoral thesis is based on the following four studies, referred to in the text by their roman numerals:

I Rangmar, J., Hjern, A., Vinnerljung, B., Strömland, K., Aronson, M., & Fahlke, C. (2015). Psychosocial outcomes of fetal alcohol syndrome in adulthood. *Pediatrics*, *135*(1), e52–e58.

II Rangmar, J., Dahlgren Sandberg, A., Aronson, M., & Fahlke, C. (in press). Placement in out-of-home care in relation to psychosocial outcomes in adults with fetal alcohol syndrome. *European Journal of Public Health.*

III Rangmar, J., Sandberg, A. D., Aronson, M., & Fahlke, C. (2015). Cognitive and executive functions, social cognition and sense of coherence in adults with fetal alcohol syndrome. *Nordic Journal of Psychiatry*, (0), 1–7.

IV Rangmar, J., Dahlgren Sandberg, A., Aronson, M., & Fahlke, C. *Self-reported health, substance use, and criminality among adults with fetal alcohol syndrome*. Manuscript submitted for publication.

Contents

“It’s like, you live with hope and despair, and you swing between them. And it’s like tears and laughter, there’s such a fine line between them. I don’t laugh much. And I laugh as rarely as I cry. And sometimes I think wow, I laughed. I haven’t done that for ages. Or I think like, I’m crying, oh, it’s been a long time since I’ve done that. So, yes, it’s difficult. It’s difficult to look ahead. But of course I have dreams, but it’s like…what’s the point? I’m never going to get anywhere. So life is just a disappointment. And I feel sad about it.”

Anna, adult with Fetal Alcohol Syndrome

Introduction

Alcohol's potential to harm the fetus has been known for at least 3,000 years. Already in the Biblical Book of Judges, in the story of Samson, a pregnant woman is told not to drink wine to protect her child from harm (Abel, 1997). Since then, research in the past 45 years has shown that children prenatally exposed to alcohol may exhibit a wide range of cognitive and behavioral impairments and physical abnormalities (Streissguth, 2007).

Binge drinking during pregnancy, even if it occurs infrequently, is associated with an increased risk of birth defects, and the amount of alcohol that may be safe to consume during pregnancy is not known (Niccols, 2007). The harmful effects of alcohol exposure on the fetus are not only due to the amount of alcohol consumed; other factors of importance include, for example, the timing of the alcohol exposure during the prenatal period and the age of the mother, as well as the fetus's and the mother's respective metabolisms (Niccols, 2007). As alcohol consumption habits differ between women, and since there are individual differences in how sensitive people are to alcohol, the resulting birth defects differ considerably between children. The wide range of disabilities that can result from prenatal alcohol exposure are collectively called Fetal Alcohol Spectrum Disorders (FASD). This umbrella term covers all the possible cognitive, behavioral and physical effects that may result from prenatal alcohol exposure. However, it should be noted that FASD is not a medical or psychiatric diagnosis.

Children with FASD commonly exhibit impaired neurocognitive functioning. They may have intellectual disabilities and impaired executive functioning, such as difficulties with self-regulation, for example in controlling their impulses. Moreover, social communication and interaction might also be difficult for children with FASD because their adaptive functioning may be impaired. In addition, some children with FASD may exhibit physical effects of the prenatal alcohol exposure, such as a characteristic face dysmorphology including short palpebral fissures, a smooth philtrum and a thin upper lip.

Today there is one established medical diagnosis under the umbrella of FASD: the Fetal Alcohol Syndrome (FAS), introduced in 1973 (Jones & Smith, 1973). The FAS diagnosis captures only a small part of the larger spectrum of possible effects of prenatal alcohol exposure. Studies aiming to establish terms to use in distinguishing and identifying more categories under the umbrella of FASD are ongoing (E. Riley & S. Mattson, personal communication, October 22, 2015). These categories are intended to provide the basis for medical diagnoses in the future.

Many children with FAS are born into families in which at least one parent abuses alcohol, which is a disadvantageous environment for any child to grow up in, especially for a child with cognitive dysfunctions. Therefore, it is not unusual for children born into such unfavorable environments to be placed in out-of-home care (Astley, 2010). The placement may give the child a stimulating and nurturing environment, but it also means a separation from his/her biological mother. The child's disabilities caused by the prenatal alcohol exposure, the childhood environment, and separations from caregivers may all be of importance for his/her further psychological development.

Moreover, it is not unusual for children with FAS who have intellectual disabilities to be offered special education, which gives them opportunities for peer relationships within the group and efficient academic support. On the other hand, attending a special school can also lead to isolation and exclusion from certain contexts and peers. These special circumstances may thus also be important for the child's psychological development.

Previous research on FAS has largely been conducted on children. There have been reports of, for example, physical and medical consequences and behavioral deficits in children prenatally exposed to alcohol. However, only a few studies have addressed the long-term outcome of FAS (e.g., Autti-Rämö, 2000; Baer et al., 2003; Spohr et al., 2007; Streissguth et al., 1996; Streissguth et al., 2004). More specifically, there is a need for studies highlighting the psychological, psychosocial and neuropsychological aspects of FAS in adulthood. Thus, this is the main focus in this thesis. Knowledge about whether these adults can manage to live independent lives may be of importance, making it possible to learn more about whether they need support and interventions. In addition, the findings in this thesis can contribute knowledge about what long-term effects can be expected for children diagnosed with FAS.

Previous research has largely been conducted on individuals within the spectrum of FASD overall, rather than specifically on individuals with the FAS diagnosis. This is because the group of individuals within FASD have a neurocognitive development that may differ from the typical development, but that within the group varies in quite a similar way (Hoyme et al., 2005). The participants in the empirical studies in this thesis together constitute a well-defined group due to their FAS diagnoses, but the results are in many ways comparable and generalizable to previous studies on those within the FASD group.

In the 1980s and 90s, Aronson, Olegård and Strömland studied the physical and psychological development in children with FAS (e.g., Aronson et al., 1985, 1997; Aronson & Hagberg, 1993, 1998; Aronson & Olegård, 1986; Olegård et al., 1979; Strömland 1984, 1987; Strömland & Hellström, 1996). These children are now adults, and some of them have participated in the studies in the present thesis. Together they constitute a unique body of material to follow up, since they are a well-defined group that was studied in childhood. In addition, the individuals who participated in this thesis all had a verified FAS diagnosis, which increases the reliability of the study group. Thus, the material – at least 30 years old – offered an opportunity for this follow-up on adult psychological, psychosocial and neuropsychological outcomes for individuals with FAS.

Terminology

Alcohol is a potent physical and behavioral teratogen agent that interferes with normal embryonic development (Riley, Infante & Warren, 2011). Since 2005, the non-diagnostic umbrella term Fetal Alcohol Spectrum Disorders (FASD; Bertrand, Floyd & Weber, 2005) has been used to describe the range of effects of prenatal alcohol exposure, from possible physical, behavioral, cognitive, and psychosocial effects (Kully-Martens, Denys, Treit, Tamana & Rasmussen, 2012) to the full-blown Fetal Alcohol Syndrome (FAS). Previous studies have largely been conducted on individuals with FASD, and not necessarily specifically FAS. The following paragraphs further describe how FASD and FAS are related, and how studies conducted on the somewhat different groups of individuals are comparable and generalizable to each other.

The original FAS diagnosis

FAS is the endpoint of, and currently the only medical diagnosis within, the continuum of FASD. In the diagnostic system International Classification of Diseases (ICD-10) from 2011 (World Health Organization, 2011), the FAS diagnosis has the ICD-10 code Q86.0. The historical background is that in 1968 Lemoine and colleagues published a clinical description of anomalies in children born to alcoholic mothers (Lemoine, Harousseau, Borteyru, & Menuet, 1968). Unfortunately, its impact in the rest of the world was not great. Five years later, however, Jones and colleagues (Jones, Smith, Ulleland, & Streissguth, 1973; Jones & Smith, 1973) published papers in the medical journal *The Lancet*, describing a distinct pattern of malformation in children born to mothers who were chronic alcoholics. The term Fetal Alcohol Syndrome (FAS) was thus introduced and came to be known worldwide. The diagnostic criteria used for FAS at the time were (Jones & Smith, 1973): 1) a documented history of alcohol abuse during pregnancy, 2) characteristic pattern of facial anomalies, 3) growth retardation, and 4) central nervous system neurodevelopmental abnormalities (Jones & Smith, 1973).

Since 1973, research has shown that alcohol causes a broad spectrum of birth defects in addition to the FAS diagnosis. This has led to suggestions for more categories and cut-off values for abnormalities due to prenatal alcohol exposure in the child, as well as to proposed modifications to the criteria for FAS.

Proposed modifications to the criteria for an FAS diagnosis

Today there are four competing, commonly used diagnostic sets of guidelines, which use different criteria for distinguishing and identifying the range of outcomes from prenatal alcohol exposure. The sets of guidelines are:

1) the 4-Digit Diagnostic Code (Astley & Clarren 2000);
2) the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effects (Bertrand et al., 2004; Bertrand et al., 2005);
3) the Canadian Diagnostic Guidelines (Chudley et al., 2005); and
4) the Revised Institute of Medicine Diagnostic Classification System (Hoyme et al., 2005).

These sets of guidelines agree on three criteria for an FAS diagnosis: 1) characteristic pattern of facial anomalies, including short palpebral fissures, a smooth philtrum, and a thin upper vermillion border, 2) prenatal and/or postnatal weight or height at or below the tenth percentile, and 3) central nervous system dysfunction, mostly defined as evidence of structural brain anomaly or head circumference below the tenth percentile. In addition, it should be noted that confirmed maternal alcohol exposure (e.g., substantial regular intake or heavy episodic drinking) is normally required for an FAS diagnosis, although a diagnosis can be made even when maternal alcohol exposure is not confirmed (Riley et al., 2011). The differences between these four commonly used sets of guidelines for diagnosis include various thresholds for particular criteria. This entails, for example, what percentile and millimeter cut-off should be applied to anomalies on the palpebral fissures, the philtrum, and the upper vermillion border. All sets of guidelines do agree, however, that there is a spectrum of adverse outcomes which requires differential diagnoses (May et al., 2009).

FAS is a medical diagnosis and should be assessed by a physician. There may be difficulties involved in diagnosing infants, as their facial features are not yet distinct. Generally, children are diagnosed at an age of three to five years, but adults can be diagnosed as well (Temple, Ives, & Lindsay, 2015). However, in adulthood it might be harder to obtain reliable alcohol exposure histories and assess the physical characteristics (Moore & Riley, 2015). After puberty, the faces of individuals with FAS are not as distinctive as in childhood, and their weight can be close to the mean; however, they still have a shortened stature (Streissguth et al., 1991). Current research suggests that microcephaly, a thin upper lip, and shortened stature are persistent features in adulthood, which can be used in evaluating FASD and diagnosing FAS (Moore & Riley, 2015).

Additional terms under the umbrella of FASD

The FAS diagnosis is quite narrow and captures only a small part of the larger spectrum of the possible effects of prenatal alcohol exposure. The terms partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Birth Defects (ARBD), and Alcohol-Related Neurodevelopmental Disorder (ARND) are meant to capture the effects of prenatal alcohol exposure that do not meet the criteria for full-blown FAS (Astley & Clarren 2000; Bertrand et al., 2004; 2005; Chudley et al., 2005; Hoyme et al., 2005). These terms are not medical diagnoses, but are intended to provide the basis for medical diagnoses in the future. For example, Hoyme and colleagues (Hoyme et al., 2005) used the term partial Fetal Alcohol Syndrome (pFAS) to describe individuals exhibiting some of the symptoms of FAS but not the full syndrome. As for the FAS diagnosis, confirmed maternal alcohol exposure is not required for pFAS. When there is a confirmed history of maternal alcohol exposure, Alcohol-Related Birth Defects (ARBD) describes children with major and/or minor structural anomalies who display normal growth and intellectual development.

An individual under the umbrella of FASD may have a disordered behavior and cognitive development similar to an individual with FAS, but not the facial dysmorphology required for an FAS diagnosis (Hoyme et al., 2005). Approximately 70 % of children with heavy prenatal alcohol exposure are affected neurobehaviorally, even in the absence of FAS (Mattson et al., 2013). The term Alcohol-Related Neurodevelopmental Disorder (ARND) is proposed to describe a specific pattern of disordered behavior and cognitive development among children with normal growth and structural development, when there is a history of maternal alcohol exposure (Hoyme et al., 2005).

Proposed criteria for ND-PAE

Most of what is known about cognitive and behavioral disabilities in individuals with FAS is based on research conducted on children; this is described further below, in the *Children with FASD* section. In summary, the characteristics include impairments in three domains: neurocognitive functioning, self-regulation, and adaptive functioning. The neuropsychological profile in individuals with FAS coincides with the proposed criteria 2–4 for the diagnosis of Neurobehavioral Disorder associated with Prenatal Alcohol Exposure (ND-PAE), which describes the cognitive and behavioral disabilities in both individuals with FAS as well as those without the physical effects of prenatal alcohol exposure (Kable et al., 2015). The criteria are: 1) Confirmed prenatal alcohol exposure, 2) Impaired neurocognitive functioning, for example executive functioning, 3) Impaired self-regulation, such as attention and impulse control, and 4) Impaired adaptive functioning, such as social communication and interaction. For an ND-PAE diagnosis, the symptoms should cause clinically significant impaired functioning, onset should be before 18 years of age, and it should not be possible to better explain the disturbance with any reason other than prenatal alcohol exposure (American Psychiatric Association, 2013). Section III in the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5; American Psychiatric Association, 2013) consists of conditions future research is encouraged to examine, and proposes criteria for ND-PAE. This may lead to ND-PAE being officially recognized and being used for clinical purposes, through placement in forthcoming editions of DSM. It is suggested that ND-PAE replace the term ARND. A recent review (Doyle & Mattson, 2015) emphasizes that a clinical assessment of ND-PAE – based on the individual's impairments in neurocognitive functioning, self-regulation, and adaptive functioning – should be as comprehensive as possible, and that a qualified multidisciplinary team should make the assessment.

Differential diagnoses

Even in cases in which there is confirmed prenatal alcohol exposure, disordered behavioral and cognitive development in the child may be due to other factors. For example, there are similarities between FASD and Attention Deficit Hyperactivity Disorder (ADHD). ADHD is a neurodevelopmental disorder, characterized by symptoms falling into three categories: inattention, hyperactivity, and impulsivity (DSM-5; American Psychiatric Association, 2013). Impairments in these areas can also be found in individuals with FASD, but previous studies have shown that there are differences between the two conditions (e.g., Mattson et al., 2011). In school and clinically, individuals with ADHD and FASD may resemble each other in many ways, but may also be possible to distinguish. Both children with prenatal alcohol exposure and children with ADHD who were not exposed to alcohol have impairments in adaptive function, but the pattern of impairment differs between the groups. Adaptive ability in children with prenatal alcohol exposure is characterized by a lack of improvement in socialization and communication with age. In contrast, children with ADHD have a developmental delay in adaptive ability, which however improves with age (Crocker et al., 2009). The differences in adaptive behavior may be noticed in school and in the clinical presentation of the conditions. To further distinguish the groups it may be necessary to use tests of cognitive functions, which have been shown to be useful. Alcohol-exposed children have difficulty encoding verbal material, whereas non-exposed children with ADHD have deficits in retrieving learned material (Crocker et al., 2011). Studies using tests on attention showed that FASD is associated with deficits in shifting attention and in flexibility in problem-solving, whereas ADHD is characterized by difficulty focusing and sustaining attention. Children with FASD display a specific impairment in basic numerical processing that is not typically found in children with ADHD (Mattson et al., 2011). In addition, FASD and ADHD differ in that FAS is an etiological diagnosis; that is, the cause of the condition is known. ADHD is not an etiological diagnosis, and is rather based on criteria involving clinical symptoms related to motor hyperactivity, impulsivity and concentration difficulties with unknown causes. However, co-occurrence between the two diagnoses is commonly found. Among individuals who were prenatally exposed to alcohol, it is estimated that 50 to 80 % also have ADHD (Mattson et al., 2011). In summary, FASD and ADHD are two conditions that are quite similar in both their behavioral and neuropsychological manifestations. Further research is needed to reveal how they differ and what factors most clearly distinguish them.

FASD in research

All four commonly used diagnostic sets of guidelines agree that FASD is an umbrella term for describing the wide range of outcomes caused by prenatal alcohol exposure (Riley et al., 2011), and that within the group of individuals with FASD the neurocognitive development differs from the typical development in a quite similar way (Hoyme et al., 2005). However, research – both how it is conducted and interpreted – might be complicated by the fact that there is no consensus concerning which of the four diagnostic sets of guidelines should be used (Riley et al., 2011). Because of this, the same terms may have somewhat varying definitions in different studies. In addition, the broad spectrum of disabilities associated with FASD can make research difficult in this group overall, because of the possible heterogeneity within it. All the participants in the empirical studies included in this thesis had full-blown FAS, which from a medical perspective is the most severe result of prenatal alcohol exposure. They received their diagnosis before the term FASD was used (Jones & Smith, 1973; Clarren & Smith, 1978), and at that time the FAS diagnosis required documented alcohol abuse during pregnancy. In this way, the participants in the empirical studies in this thesis together constitute a well-defined group, but are in many ways generalizable to the FASD spectrum.

Prevalence of FASD

As mentioned, the proposed terms to be used for describing effects of prenatal alcohol exposure that do not meet the criteria for FAS (Hoyme et al., 2005) are not yet medical diagnoses, and can therefore not be used clinically. In addition, despite the quite clear diagnostic criteria and classification in ICD-10, the FAS diagnosis is rarely used. These facts taken together could be reasons for the unreliable data on the prevalence and incidence of damages caused by prenatal alcohol exposure, both in Sweden and internationally. In addition, previous prospective international studies have suggested that FAS is grossly underdiagnosed and underreported (Abel & Sokol, 1987; Clarren, Randels, Sanderson, & Fineman, 2001). This might be an explanation for why figures from the Swedish National Board of Health and Welfare indicate that 237 individuals were diagnosed with FAS in Sweden during the period 2006–2013 (Swedish National Board of Health and Welfare, 2013); that is, about 30 individuals per year. The first prevalence study in Sweden, conducted by Olegård and colleagues in 1979 (Olegård et al., 1979), showed a frequency of 1.7 children with FAS per 1,000 births. Given that the prevalence of FAS is 0.17 %, it could be estimated that there are nearly 4,000 individuals aged 0–17 and nearly 12,000 individuals aged 18–64 with FAS in Sweden (Ericson, Hovstadius, & Magnusson, 2015). In the US, the estimated prevalence of FAS is at least 2 to 9 per 1,000 births (May et al., 2009; 2014; 2015). The highest rates of FAS have been reported in a South African community, with a frequency of 59–91 children with FAS per 1,000 aged 5–7 (May et al., 2013).

The prevalence in the world of the broader spectrum, FASD, is also relatively unknown. For the US, prevalence rates of 2.4–4.8 % have been reported (May et al., 2014); for Italy, 2.3–6.3 % (May et al., 2011); and from the South African community, 13.6–20.9 % (May et al., 2013). In addition, it is estimated that 2–5 % in younger school children in some Western European countries have FASD (May et al., 2009). Since 1979 (Olegård et al., 1979), no prevalence studies have been conducted in Sweden. To ascertain the true prevalence of FAS and FASD, more prevalence studies are needed, both in Sweden and internationally.

FAS and Psychological Development

Human psychological development is a complex cognitive and emotional process affected by individual and environmental factors. For individuals with FAS who have neuropsychological disabilities and who may face negative environmental factors, the development into an independent adult individual might be complicated. As a base for understanding this complex process, various theories of psychological development are summarized in the following paragraphs.

Theories of Developmental Psychology

Developmental psychology describes the expected psychological development in human individuals, from birth through infancy and childhood, to the subsequent adolescence and adulthood. From the beginning the infant is strongly dependent on the caregiver and the environment, and will eventually mature and thereby become able to adapt to, but also influence, the environment. Sameroff (2009) has illustrated the human's psychological development with the so-called Transactional Model. The transactions consist of exchanges between two parties who give and take, and enable changes to take place. The exchange then becomes the new base, and over time makes new exchanges possible. For example, during the prenatal period the child's genome is determined, and already at this point the transactions start. Through an exchange between the fetus and the environment in the uterus due to, for example, exposure to teratogens and the mother's nutritional level, the child is affected. The early characteristics of the child's traits and states will then be reflected in the parents' behavior, which in turn will affect the further development of the child's characteristics. Psychological development thereby consists of repeated exchanges and transactions between the child and the environment (Sameroff, 2009). In addition to the Transactional Model, the Ecological Systems Theory (Bronfenbrenner, 1977) further describes the layers transactions are made with and by which the psychological development is shaped. The interactions between different systems of environmental factors constitute layers of context in which human development takes place. For example, the individual with his/her own biology, such as gender, age and health, is in the innermost layer. The next layer is called the Microsystem, which includes the relations between the developing individual and the context closest to the child, such as family, school, and peers. The next layer is called the Mesosystem, which encompasses interactions between the microsystems, for example family, school, and peers. An extension of the Mesosystem is the layer called the Exosystem, which contains the links between those who are closest to the child and those in the social setting that the child is not a direct part of but is influenced by. Examples of these structures are the mass media, authorities, and informal social networks. The outermost layer is the Macrosystem, which consists of the cultural contexts in which the individual lives. It includes, for example, the socioeconomic status, ethnicity, and social and political systems that are current in the individual's context (Bronfenbrenner, 1977). In every layer of the systems of environmental factors, both risk factors (e.g., abuse) and protective factors (e.g., high-quality relations) could be found throughout the model of the Ecological Systems Theory (Bronfenbrenner, 1977).

Another important theory for understanding the complex psychological development of the human being is the Attachment Theory (Bowlby, 1982). This theory proposes that a child's development is dependent on an attachment to a caregiver who can make him/her feel safe. The child needs to have the chance to attach to at least one close caregiver early in life. Children who have had the chance to attach to at least one caregiver would grieve if separated from that person, and could then become attached to others who they have close and continuing contact with. Early separation from the caregiver is actualized for children who are placed in out-of-home care and thereby separated from their biological mother. This might thus be perceived as distressful for a child (Bowlby, 1982). Moreover, whereas the infant from the beginning is wholly dependent on the caregiver, the child matures and eventually becomes more independent with increased age. Because of this, for a child up to the age of approximately three years, a separation from the caregiver might lead to a feeling of insecurity and further to anxiety. After three years of age the child might have a more mature attachment to the caregiver, and a separation can function without the intense anxiety. An individual's possibilities to attach to a caregiver are thus influenced by early experiences of attachment and separation.

Associated with the child's cognitive and emotional development from the early infant years and throughout childhood is the development of the so-called Theory of Mind (ToM) (Wellman, 2010). More specifically, ToM refers to one certain aspect of the social cognition, defined as the processes involved when an individual reasons about the beliefs and intentions of others (Astington & Gopnik, 1991). During development, the child gradually attains the insight that individuals have their own mental states, thoughts, intentions, motives, and emotions. With increasing age, the child will understand that saying or showing what he/she thinks and wants can affect the behavior of others. The development of ToM is also linked to the child's ability to interpret others' behavior (Astington & Edward, 2010).

In summary, the child's biological predispositions are formed at conception; already at this point the transactions start, and continue throughout the individual's subsequent psychological development. From childhood through adulthood, human development is a progressive accommodation between the growing human organism and the changing environments in which it lives and grows, from the family to economic and political structures. Cognitive and emotional development are interdependent, and are affected by both hereditary and environmental factors. Based on the theories summarized above, psychological development is not linear but rather a process whereby the individual transforms – but is also transformed by – different environmental factors. This complex psychological development is, of course, also true for individuals with FAS. However, because of the neuropsychological disabilities associated with FAS they may not follow the expected psychological development. In addition, they may even face additional environmental risk factors that might disrupt and complicate their development into an independent adult individual.

Children with FASD

Throughout pregnancy, alcohol has a teratogenic effect and can interfere with the development of the fetal brain. Factors of importance for what the effects will be include, for example, maternal age, the amount of alcohol consumed, the pattern of consumption (binge drinking vs. steady drinking), and maternal and fetal metabolism (Niccols, 2007). The teratogenic effect of alcohol can result in a congenital biological malformation of the child's brain, for example displayed as microcephaly (Hoyme et al., 2006). The structural anomalies in the brain may be the underlying reasons for the behavioral problems and neuropsychological deficits normally observed in children with FASD (Niccols, 2007; Streissguth, Barr, Kogan & Bookstein, 1996). These types of deficits, usually called primary disabilities, are characterized by reduced cognitive functions, a generally reduced intellectual functioning, deficits in executive functioning, and learning and memory difficulties. Impaired social cognition as well as reduced adaptive functioning are other primary disabilities that can be found in individuals with FASD. The primary disabilities associated with FASD might lead to difficulties in school, both academically (Diamond, 2013) and socially. Moreover, they can have profound effects on the psychological development in children with FASD, influencing how their adult life will be.

Intellectual functioning

Intellectual functioning, an individual's cognitive ability to manage everyday life, is often referred to as intelligence quotient (IQ). A generally reduced intellectual functioning means difficulty coping with the demands of society without support (Tideman, 2000). According to ICD-10 (World Health Organization, 2011), an individual with an overall IQ score at least two standard deviations below the norm is defined as having an intellectual disability. This entails an overall IQ score of < 70 (World Health Organization, 2011). A previous study showed that individuals with FASD aged 6–51 had a median IQ of 86, ranging between 29 and 126 (Streissguth et al., 2004). This wide range in IQ indicates that intellectual functioning varies widely among individuals with FASD. Characteristic of individuals diagnosed with FAS is that they may have a generally reduced intellectual functioning as part of the neurocognitive impairments. However, the majority of individuals with FAS do not have an IQ below 70, and thus do not have an intellectual disability (Mattson, Crocker & Nguyen, 2011).

Executive functioning

Executive functions are defined as higher-order psychological processes involved in goal-oriented behavior under conscious control (Welsh, Pennington & Groisser, 1991). This term includes such processes as inhibitory control, working memory and cognitive flexibility. Inhibitory control is the ability to control one's attention and behavior to resist external stimuli and instead do what is more appropriate. This includes the abilities of self-control and selective attention. Working memory, closely related to inhibitory control, is the ability to keep information in mind and mentally work with it. Moreover, cognitive flexibility involves the abilities to change perspectives and to adjust to changed demands (Diamond, 2013). The executive functions are commonly linked to the prefrontal cortex of the brain. Previous research (Sowell et al., 2002) using Magnetic Resonance Imaging (MRI) to explore brain abnormalities showed reduced brain growth in the orbitofrontal lobe in children with FASD. Deficits in this brain area have been linked to reduced executive functions, which are commonly observed in children with FASD. This may manifest as, for example, poor working memory, deficits in cognitive flexibility, set shifting, abstraction, and impaired behavioral inhibition (Mattson et al., 2013).

Learning and memory

Children with FASD may have impaired memory and difficulty encoding new information, causing deficits in learning (Doyle & Mattson, 2015). Impaired memory is manifested as difficulty remembering information learned previously and long verbal instructions. The impairments in overall intellectual performance, as well as the learning and memory deficits, in children with FASD have been linked to structural anomalies in the corpus callosum (Mattson, Crocker & Nguyen, 2011). This structure is important for transferring and integrating visuospatial information between the two hemispheres of the brain. It has been found to be vulnerable to prenatal alcohol exposure (Wacha & Obrzut, 2007), resulting in great variance in its volume, ranging from a thinning to complete agenesis of this brain structure in children with FASD (Riley et al., 1995). An additional structure in the brain that is associated with the learning and memory deficits in children prenatally exposed to alcohol is the hippocampus, part of the limbic system. A study using MRI found a reduction in size of this brain structure in children with FASD (Davis et al., 2011). Previous studies have shown that the impairments in memory and learning may persist even after general intellectual functioning is controlled for (Doyle & Mattson, 2015).

Social cognition

Social cognition involves processes related both to cognitive and executive functions as well as to perceptual and emotional processing (Astington & Gopnik, 1991). It has been proposed that social cognitive processes are controlled by a neural network, and the brain regions forming this network have been shown to be particularly vulnerable to prenatal alcohol exposure (Stevens, 2012). The amygdala, for example, is essential in the social cognitive network because it is engaged in processing and recognizing emotions. The temporal parietal junction is involved in ToM, the processes associated with the individual's reasoning about the beliefs and intentions of others (Astington & Gopnik, 1991), which is important for perspective-taking (Stevens, 2012). A recently published study showed that children with FASD may have difficulty solving tasks that require complex social cognition (Stevens et al., 2015), and Rasmussen and colleagues (2009) reported that children with FASD had difficulty with ToM tasks. Impaired social cognition is associated with social skills problems, which are commonly observed in children with FASD (Rasmussen, Wyper & Talwar, 2009; Stevens, 2012). Problems with social skills include not having the adaptive behavior needed to interact socially and get along with other people (Kully-Martens et al., 2012).

Adaptive functioning

Adaptive functioning encompasses the ability to monitor and adjust one's behavior in changing environments (Sparrow, Cicchetti & Balla, 1989), which requires a cognitive capacity that enables one to integrate information from the environment, select appropriate responses and exhibit adequate behavior (Carr, Agnihotri, & Keightley, 2010). Adaptive functioning deficits are examples of primary disabilities commonly observed in children with FASD (Davis, Desrocher & Moore, 2011). These may manifest as deficits in communication, social and motor abilities, and an impairment in daily living (Doyle & Mattson, 2015). The adaptive dysfunctions may cause social skills difficulties and behavioral disorders, such as hyperactivity and attention deficits. In fact, behavioral disorders are also frequently observed in children with FASD (Mattson, Crocker & Nguyen, 2011) and commonly result in a diagnosis of ADHD (Davis et al., 2011).

Environmental factors of importance

In addition to the primary disabilities, some environmental factors during childhood may be of importance for the individual's psychological development. For example, children with FASD are at risk of being born into a disadvantageous environment because their parents abuse alcohol. In such cases the children can receive care from social services, for example being placed in out-of-home care (Astley, 2010). The intervention is meant to give the child a stable and nurturing environment that is non-abusive, which could favor a positive psychological development (Koponen, Kalland & Autti-Rämö, 2009). On the other hand, in a related research area (although not conducted on individuals with FAS), a previous register study showed that placement in out-of-home care can itself sometimes entail a risk for adverse outcomes (Vinnerljung & Sallnäs, 2008). For example, the findings showed that people at age 25 who had been placed in care for behavioral problems when they were 13–16 years old had high rates of premature death, serious involvement in crime, hospitalization for mental-health problems, teenage parenthood, self-supporting problems, and low education attainment. Youths who were placed for other reasons had better outcomes, but still worse than those of their non-care peers. It was more common among children who had experienced foster care to have the nine-year mandatory education as their highest completed education than among their majority population peers with low-educated mothers (Vinnerljung, Öman & Gunnarson, 2005). Children with FASD may grow up with parents who abuse alcohol, or they may be placed in out-of-home care. Placement in out-of-home care always implies a separation from the primary caregiver, which might be perceived as distressful for the child (Bowlby, 1982). Factors contributing to how the child will react to the separation and the new placement may be his/her previous experiences of attachment to a caregiver, in combination with what opportunities the placement in out-of-home care provides for new attachment to a caregiver. However, these environmental factors may be important for the child's further development and how his/her adult life will be (Bowlby, 1982); further research is needed to determine how these factors during childhood influence the psychological development in children with FASD.

Special education

It is not unusual for individuals with FAS to receive special education. Sometimes this is due to intellectual disabilities, and sometimes to concentration and attention problems. Several of the participants included in the studies in this thesis attended primary school in 1970–80, and during this period in Sweden there were also special schools for individuals with intellectual disabilities. The aim of the special schools was to provide efficient support based on the individual's needs and ability to learn. The special schools offered academic support, but also an opportunity to be included in a group of individuals with similar disabilities. On the other hand, attending special school could also lead to isolation from other groups in society, as well as a lack of formal access to activities and higher education requiring ordinary school competence (Szönyi, 2005).

Previous Swedish studies on children and adolescents with FAS

Some of the participants included in the studies in this thesis participated in previous studies on FAS in the 1980s and 90s by Aronson, Olegård and Strömland (Aronson et al., 1985, 1997; Aronson & Hagberg, 1993, 1998; Aronson & Olegård, 1986; Olegård et al., 1979; Strömland 1984, 1987; Strömland & Hellström, 1996). The inclusion criterion for the original studies was that the children had an FAS diagnosis (Jones & Smith, 1973; Clarren & Smith, 1978).

The previous Swedish studies showed that most of the children with FAS had developmental disabilities, and needed special schooling due to various psychological problems (Aronson, 1984). For example, a retrospective study by Aronson and colleagues (1985) showed that at age five, the children born to alcoholic mothers had growth deficiencies, and significantly delayed psychomotor development compared to healthy controls. The delay of mental development persisted even when the children had been placed in foster homes at an early age. A follow-up study was conducted when the children were 12–13 years old (Aronson & Hagberg, 1993). Most of the children had been placed in foster homes, and several were in normal education with special support or assistance. The children whose mothers had consumed alcohol throughout pregnancy were those who needed the most support from social authorities and who had the poorest academic achievements. These children also had the lowest scores on tests of logical thinking, visual perception and short-term memory. The children whose mothers had stopped consuming alcohol in the middle of pregnancy (pregnancy weeks 20–25) had slightly better education outcomes. The main difficulties were language (Swedish) and mathematics. Many of the children were hyperactive and had difficulty concentrating and realizing the consequences of their actions, as well as problems with inhibitory control and managing aggressive behavior. The results from another follow-up study by Strömland and Hellström (1996) on children with FAS (median 11 years old) showed that only 16 % of the biological mothers had been able to take care of their children while they were growing up. About 50 % of the children also met the diagnostic criteria for ADHD. A strong correlation was also found between the severity of neuropsychiatric symptoms and the mothers' consumption of alcohol (Aronson et al., 1997).

Due to the psychological, psychosocial and neuropsychological problems already seen in childhood and adolescence in this group, it is important to investigate what difficulties individuals with FAS face in adulthood.

Emerging Adulthood

For a person developing in the typical manner, becoming an adult means leaving one's family and being expected to take care of oneself. One way of conceptualizing the lives of individuals from the late teen years through the mid- to late 20s is described in the Theory of Emerging Adulthood (Arnett, 2007). This period in life is characterized by reflecting on one's own identity and what kind of adult life is desired, for example concerning love relationships and forming of a family. During the search for identity the direction of the exploration often changes, resulting in an investigation of different areas. The emerging adulthood is characterized by a gradual development into an adult, including being responsible for oneself as well as being able to make independent decisions and one's own choices. This time in life is also characterized by entering the labor market and becoming financially independent. The emerging adulthood with its many opportunities may give the individual a sense of freedom, but it may also mean a sense of distress and emptiness due to the new demands on the individual's own motivation (Arnett, 2007).

For a person with cognitive and behavioral disabilities, the time in life when he/she is becoming an adult might be extra difficult. Previous studies (Tideman, 2000; Tössebro & Lundeby, 2002) have shown that living conditions for individuals with intellectual disabilities differ significantly from those of the general population, especially in terms of employment and social relationships. Individuals with intellectual disabilities generally have a poor social network, in terms of both close relationships and life partners. Cohabiting and having children is uncommon, and adults with intellectual disabilities live with their parents significantly more often than the general population does (Tideman, 2000; Tössebro & Lundeby, 2002). The prevalence of mental health problems among adults with intellectual disabilities is significantly higher than in the general population, and they are more often in need of mental health care and treatment for their behavioral and mental health problems (Gustafsson, 2003). Thus, low intellectual functioning and low academic achievements due to learning disabilities are examples of what could make the period of becoming an adult a difficult time, because of its high demands on functioning.

Adults with FAS

For an individual with FAS the transition into adulthood may be a particularly difficult time, as one is expected to become independent and make one's own choices (Arnett, 2007). The new demands on the individual's own motivation and capacity may be a source of distress for an individual with FAS, who may not have the abilities needed to cope with them. For individuals living with the primary disabilities associated with FAS, and for whom transactions are made with different environmental factors (Sameroff, 2009), the consequences may be both psychological and psychosocial. The psychological consequences concern, for example, the individual's mental health and sense of well-being, while the psychosocial consequences concern aspects like the individual's education and financial opportunities. If the outcome is adverse in individuals with primary disabilities due to prenatal alcohol exposure, these additional disabilities are usually called secondary disabilities (Chudley, Kilgour, Cranston, & Edwards, 2007). An example of the psychological secondary disabilities in individuals with FASD is poor mental health (Famy et al., 1998). Unemployment and dependent living (Spohr, Willms, & Steinhausen, 2007) are examples of psychosocial secondary disabilities in individuals with FASD. With efficient support and interventions, so-called protective factors, the secondary disabilities might be ameliorated. Protective factors previously reported include receiving a diagnosis of FAS before age six, and being raised in stable and nurturing environments (Streissguth et al., 2004). Based on the Transactional Model (Sameroff, 2009), throughout childhood and during the transition into adulthood, individuals with FAS will exchange and develop through transactions with environmental factors; this may have both psychological and psychosocial consequences.

Psychological aspects

Previous studies have reported that problems with the use of alcohol or illicit drugs are common psychological secondary disabilities in individuals with FASD (Baer, Sampson, Barr, Connor, & Streissguth, 2003; Famy et al., 1998). Streissguth and colleagues (Streissguth et al., 2004) have reported a life span prevalence of 35 % for individuals with FASD for problems with substance use. Psychiatric problems such as an increased risk of suicide (Huggins, Grant, O'Malley & Streissguth, 2008), psychotic symptoms, current or past depression, and anxiety or bipolar disorder have also been shown to commonly occur in adults with FASD (Famy et al., 1998).

In adulthood, the demands on coping with stress increase. It is therefore assumed that for adults with FASD the primary disabilities may affect their well-being and sense of coherence (SoC; Antonovsky, 1993); that is, the extent to which they perceive their lives as meaningful, manageable and comprehensible. SoC is a salutogenic model (*salus*=health, *genesis*=origin), focusing on factors that support well-being in humans, rather than factors that cause disease. SoC is more than merely the opposite of depression but rather a multifaceted concept, and covers a wide perspective of health (Olsson, Hansson, Lundblad & Cederblad, 2006). More specifically, this salutogenic model deals with the relationship between health, stress, and coping. SoC consists of three components – meaningfulness, manageability and comprehensibility – and is an expression of the extent to which the individual: 1) is confident in his/her life being structured and predictable, 2) perceives his/her resources as being sufficient, and 3) perceives his/her life as worth the necessary engagement. In the measurement of SoC the individual reports some of the conditions and circumstances of life, but also the perceived feeling of being in control of the situation. As the third component, the individual reports the perceived extent of meaningfulness under the given circumstances (Antonovsky, 1993). SoC may thus provide a measure of individuals' own images of themselves from a psychological perspective.

Psychosocial aspects

Previous studies have reported that problematic school experiences are one of the common psychosocial secondary disabilities in individuals with FASD (Clarke & Gibbard, 2003). A life span prevalence of 61 % has been reported for individuals with FASD for disrupted school experiences (Streissguth et al., 2004). A previous study on psychosocial outcomes in adults with FASD (Spohr, Willms, & Steinhausen, 2007) showed that 86.5 % were unemployed, and that only 29.5 % lived independent lives while 70.5 % lived under dependent or supervised circumstances.

Studies have shown that people with FASD have a behavior that may increase the risk of criminality (Brown et al., 2015; Streissguth et al., 2004). A previous Brazilian study (Momino et al., 2012) found prenatal alcohol exposure among adolescents with criminal behavior. Moreover, a previous Canadian study reported an estimate of youths with FASD being 19 times more likely to be imprisoned compared with those without FASD, and that the number of undiagnosed persons in correctional facilities is high (Popova, Lange, Bekmuradov, Mihic & Rehm, 2011). Many of these individuals had never been diagnosed because they lack the facial abnormalities that would have facilitated identification and diagnosis in childhood. Because of this, Brown and colleagues propose screening for prenatal alcohol exposure in correctional facilities (Brown et al., 2015). Individuals with FASD may thus have primary disabilities leading to a behavior that could increase the risk of criminality (Brown et al., 2015; Streissguth et al., 2004). However, whether or not they become criminal in adulthood is only partly influenced by their primary disabilities; it is also affected by various risk and protective environmental factors through transactions throughout life (Sameroff, 2009).

Neuropsychological aspects

Most of what is known about the neuropsychological impairments in FAS is based on research conducted in children. Less is known about whether the impairments last into adulthood (Moore & Riley, 2015), and if so, whether they deteriorate, stay unchanged, or improve throughout life. One of the few neuropsychological studies reported deficits in memory (Coles, Lynch, Kable, Johnson & Goldstein, 2010) as well as in the ability to hold and manipulate information in working memory in young adults with FASD (Connor, Sampson, Bookstein, Barr & Streissguth, 2001). Another neuropsychological study conducted on adults with FASD (Kerns, Don, Mateer & Streissguth, 1997) showed that they had low results on measures sensitive to complex attention, verbal learning, and executive functions. Executive functions include inhibitory control, working memory and cognitive flexibility, and impaired executive functions may mean difficulties in achieving set objectives, as well as problems with planning and organizing and being flexible in problem-solving (Diamond, 2013). Having these disabilities in adulthood may thus be a source of distress for the adult individual, who may need efficient support to help him/her manage stress, daily life, work and education, and social relations. Impaired executive functions are assumed to be primary disabilities, due to the alcohol's teratogenic effect on the brain (Niccols, 2007). They are therefore likely to persist in adulthood, but may have been modified through transactions with various environmental factors (Sameroff, 2009).

Previous research on FASD has largely been conducted on children (Moore & Riley, 2015), while only a few studies have addressed the long-term outcome of FASD. Because there is little research on FASD in adulthood in general, and particularly as there are no Swedish studies at all, there is a need for more studies to contribute knowledge about the neuropsychological consequences of FAS in adulthood.

Aims

The main aim of this thesis was to investigate the psychological, psychosocial and neuropsychological consequences of Fetal Alcohol Syndrome in adulthood. Psychological and psychosocial consequences were investigated in all of the four empirical studies in the thesis, and the neuropsychological consequences were investigated in Study III. Data were obtained from national registers, childhood medical records, neuropsychological tests, self-rating scales, and self-reporting interviews. The specific aims were the following:

1. Study I aimed to investigate the psychosocial situation in adults with FAS concerning education, employment, family constellation, mental health, alcohol-related disorders, use of illicit drugs, and criminal acts.
2. Study II aimed to investigate whether age at placement in out-of-home care and number of early separations from caregivers during childhood were related to the adult psychosocial situation.
3. Study III aimed to investigate sense of coherence, cognitive and executive functions, and social cognition in adults with FAS.
4. Study IV aimed to investigate self-reported physical and psychiatric health, use of alcohol and illicit drugs, and conviction and being the victim of crime in adults with FAS.

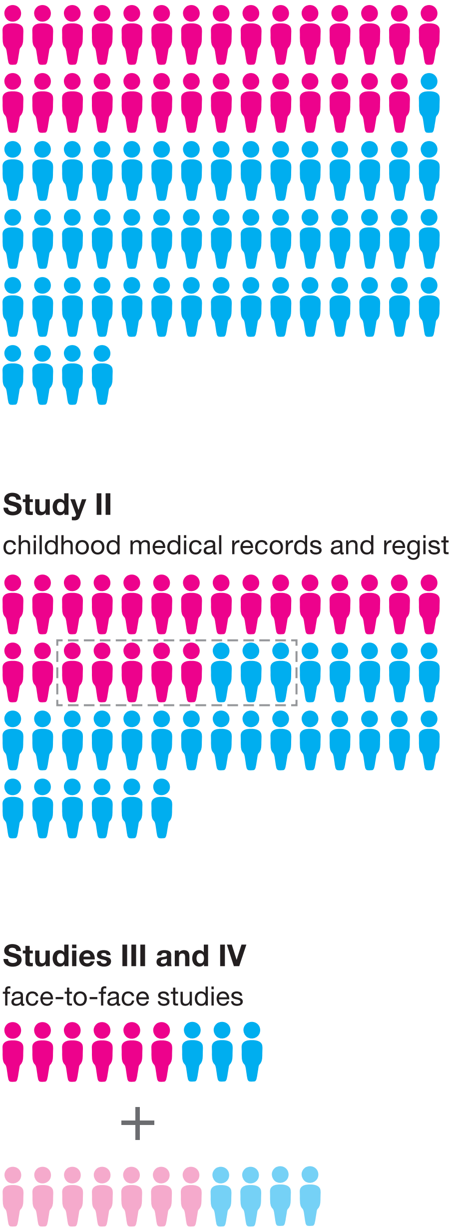
Methods and Materials

Participants

The participants in the studies in this thesis had an FAS diagnosis – Q86.0, according to ICD-10 (World Health Organization, 2011). The study group consisted of 79 adults – 29 women (37 %) and 50 men (63 %) – aged between 18 and 47 years (mean age: 32), all diagnosed with FAS at the Children's Hospital in Gothenburg, Sweden, when they were infants or children, some of whom had participated in various studies (Aronson et al., 1985, 1997; Aronson & Hagberg, 1993, 1998; Aronson & Olegård, 1986; Olegård et al., 1979; Strömland 1984, 1987; Strömland & Hellström, 1996). In Study I, a record-linkage study, all individuals with FAS (*n* = 79) participated. In Study II, the participants were excluded if the linkage between data from their childhood (medical records) and adulthood (register data) was missing on an individual level. Due to this, the study group in Study II consisted of 51 participants. In eight of these 51 individuals, further analyses were done on additional data from childhood as well as adulthood. This subgroup (*n* = 8) consisted of the same individuals also included in Studies I, III and IV.

Data in Studies III and IV were collected at the same occasion, and tests and interviews were conducted through face-to-face data collection. The inclusion criteria for Studies III and IV were that participants must: be at least 18 years old, be aware of their FAS diagnosis, and have a medical record certifying it. Based on these criteria, the participants in Studies III and IV (*n* = 20) were partly the same individuals as in Study I (*n* = 8). The remaining individuals in Studies III and IV (*n* = 12) were recruited from the Swedish national organization for FAS. For further description of the individuals' participation in the studies, see Figure 1.

Figure 1. The illustration shows the individuals' participation in the studies.



Study I

register study

79 adults with FAS
29 women (37 %)
50 men (63 %)
mean age: 32 (18–47 years)

Study II

childhood medical records and register study

51 of the adults from Study I
22 women (43 %)
29 men (57 %)
mean age: 32 years (20–47 years)

⬚ additional analyses were performed on eight individuals

Studies III and IV

face-to-face studies

20 adults with FAS:
8 from Study I
plus 12 from the Swedish national organization of FAS
13 women (65 %)
7 men (35 %)
mean age: 30 years (18–41 years)

Comparison groups

In Study I, data were obtained for 3,160 individuals matched on age, gender, and place of birth. This comparison group was constructed by Statistics Sweden using the Register of the Total Population. In addition, a subgroup of 122 subjects from the comparison group, who had been placed in state care as children, was used for further analyses of the psychosocial outcome variables.

In Studies III and IV, the comparison group consisted of healthy adult men and women without an FAS diagnosis (*n* = 20). They were individually matched to the participants in the study group on age and gender. This comparison group was recruited from public settings.

Procedure

Study I utilized data from record linkages between high-quality national registers held by Statistics Sweden (Statistiska centralbyrån), the National Council for Crime Prevention (Brottsförebyggande rådet), and the National Board of Health and Welfare (Socialstyrelsen).

Studies III, IV and partly Study II (data on mental health in adulthood in the subgroup) used data from face-to-face data collection. An experienced test leader conducted all tests and the interview. The participants gave verbal informed consent, and were invited to the data collection. Expenses for travel, accommodation, and food were paid by the research project, and the participants received compensation (two cinema tickets worth approximately 22 euro). The data collection lasted three to four hours (excluding a one-hour lunch break and at least two 15-minute coffee breaks).

Measures

Study I

Table 1 gives a detailed description of the outcome variables created using the information from the national registers used in Study I.

Table 1.

Description of the outcome variables used in Study I, what they indicate, and the national register used as the source. Some of the variables were also used in Study II, as indicated in the table.

Outcome variable	Used in Study II	Indicates	Source
Adult psychiatry	Yes	Psychiatric in-/out-patient care from 18 years of age	National Patient Register
Alcohol-related disorders	Yes	At least one entry in register on alcohol-related medical care in hospitals	National Patient Register
All-cause mortality		Death	Cause of Death Register
Any type of psychotropic drug prescriptions	Yes	At least one prescription in 2005–2011 for either sleeping medicine, anxiolytics, neuroleptics or antidepressant	Prescribed Drug Register
Child and adolescent psychiatry		Psychiatric in-/out-patient care, ages 0–17	National Patient Register
Cohabiting with child		Two adults cohabiting in a household with at least one child	The Longitudinal integration database for health insurance and social studies
Criminal acts and sanctions	Yes	Sanction for the most serious crime	Register of Criminal Offenses

Outcome variable	Used in Study II	Indicates	Source
Disability pension		Lifelong pension because of longstanding working disability	The Longitudinal integration database for health insurance and social studies
Disposable income		The sum of all incomes including societal benefits, minus income tax	The Longitudinal integration database for health insurance and social studies
Education allowance		Has received student grants or loan	The Longitudinal integration database for health insurance and social studies
Employed in November 2011		Has income from employment or own firm in November 2011	The Longitudinal integration database for health insurance and social studies
Has been convicted of severe crime	Yes	Probation or prison as sanction for a severe crime	Register of Criminal Offenses
Has biological child		Has at least one biological child	The Longitudinal integration database for health insurance and social studies
Has record of court conviction	Yes	Has record of any court conviction	Register of Criminal Offenses

Outcome variable	Used in Study II	Indicates	Source
Highest completed education	Yes	Highest completed education as of November 2011	The Longitudinal integration database for health insurance and social studies
Illicit drug abuse	Yes	Medical care in hospital caused by illicit drug abuse as a main or contributory diagnosis, according to ICD-9 and -10 codes	National Patient Register
Income and compensation		Type of income and compensation for those >25 years old in 2011	The Longitudinal integration database for health insurance and social studies
Placed in out-of-home care	Yes	Placement away from one's biological parents, into foster homes or institutions	The Child Welfare Intervention Register
Post-secondary education		Those >24 years old in 2011 who have completed postsecondary studies	The Longitudinal integration database for health insurance and social studies
Primary school	Yes	Compulsory nine years of school	The Longitudinal integration database for health insurance and social studies

Outcome variable	Used in Study II	Indicates	Source
Psychiatric disorders	Yes	Medical care in hospital caused by a main or contributory discharge diagnosis found in the whole psychiatric chapter in ICD-9 with the exclusion of alcohol- and drug-related diagnoses	National Patient Register
Secondary education	Yes	Those >20 years old in 2011 who have completed 2–3 years of high school	The Longitudinal integration database for health insurance and social studies
Self-inflicted injury/poisoning	Yes	Medical care in hospital for self-inflicted injury and/or poisoning	National Patient Register
Self-supporting	Yes	A summarized outcome variable that indicates being employed in November 2011 and not having received disability pension/social welfare	The Longitudinal integration database for health insurance and social studies
Single parent with child		Living in a household as a single parent with at least one child	The Longitudinal integration database for health insurance and social studies

Outcome variable	Used in Study II	Indicates	Source
Social welfare		Has income allowance from local social authorities after a thorough investigation with the purpose of guaranteeing the applicant a minimum standard of living	The Longitudinal integration database for health insurance and social studies
Special education	Yes	Did not attend ordinary primary school	The Longitudinal integration database for health insurance and social studies

Study II

Study II used data from medical records from visits to the Children's Hospital in Gothenburg, Sweden, from birth to six or seven years of age. Data on intellectual functioning in terms of developmental quotients (Griffiths, 1976) in the subgroup (*n* = 8), education, and whether an individual grew up with his/her biological mother or in out-of-home care were obtained from childhood records from the Children's Hospital. Data on age at placement in out-of-home care and number of early separations from caregivers were also obtained from records from the Children's Hospital.

The cut-off age of three years, based on the Attachment Theory (Bowlby, 1982), was used to classify when children had been placed in out-of-home care (i.e. 0–36 months of age = early placement; from 37 months of age = late placement). The variable concerning the number of early separations from caregivers was also categorized based on the Attachment Theory (Bowlby, 1982). If a child is separated from his/her biological mother, placement in out-of-home care might offer the possibility to attach to a new caregiver. If the child is separated from one or more additional caregivers before three years of age, this may disturb the attachments (Bowlby, 1982). The variable was categorized as one or more early separations from caregivers before three years of age.

Data on mental health in adulthood were obtained from the self-rating scales the Beck Anxiety Inventory (BAI; Beck & Steer, 1993) and the Beck Depression Inventory (BDI; Beck et al., 1961), and the Addiction Severity Index structured interview (ASI; McLellan et al., 2006). For further information on the ASI see *Study IV*. The outcome variables constructed with information from national registers were the same as in Study I, and are further described in Table 1.

Study III

The neuropsychological tests used in Study III are presented in Table 2. In addition, the Swedish version of the self-rating scale Antonovsky's SoC-29 (Antonovsky, 1993) was also used. The SoC-29 was conducted as an interview to give the adults with FAS the opportunity to ask for clarification if there was something they had not understood.

Table 2.

Neuropsychological tests and a self-rating scale used in Study III, and what they measure.

Test	Measures	Reference
Raven's Coloured Progressive Matrices	Cognitive functions – general intelligence, non-verbal	Raven, Raven, & Court, 1998
Digit span	Short-term memory and working memory	WAIS-III, Wechsler, 1997
Berg's Card Sorting Test-64	Executive functions, focusing on cognitive flexibility and set-shifting, inhibitory control, and inhibition of perseverative responses	Mueller, 2013
Tower of Hanoi	Executive functions such as cognitive and spatial planning, inhibitory control, and inhibition of perseverative responses	Mueller, 2013
Faux Pas	Theory of mind	Stone & Baron-Cohen, 2010; Söderstrand, 2010
Sense of Coherence	Sense of coherence	Antonovsky, 1993

Study IV

The Addiction Severity Index (ASI; McLellan et al., 2006) was used in Study IV. The ASI is a structured interview assessing self-reported lifetime and recent problem severity in seven life areas: alcohol use, drug use, employment, family and social relationships, legal, physical, and psychiatric problems. It is an established self-report instrument in addiction research, with acceptable validity (Håkansson & Berglund, 2012). Data on depression and anxiety were obtained from the self-rating scales the Beck Anxiety Inventory (BAI; Beck & Steer, 1993) and the Beck Depression Inventory (BDI; Beck et al., 1961). The BAI and BDI were conducted as interviews to give the adults with FAS the opportunity to ask for clarification if there was something they had not understood.

Data Analyses

Categorical variables were analyzed with chi-square test and standardized residuals (R) were used. When the overall chi-square test was significant, the cell with $R > 2.0$ was considered to be a major contributor to the significant result. Fisher's exact test was used when one or more cells in the chi-square test had an expected frequency of five or less. Continuous variables were analyzed using Student's t-test. When data were not normally distributed, the median value differences between the FAS group and the comparison group were tested using the non-parametric Mann-Whitney U-test. Tests were two-tailed, a $p < 0.05$ was regarded as significant, and effect size was calculated. All statistical analyses were performed using the SPSS software package version 22.

Results and Discussion

Study I

The record-linkage study on 79 individuals with FAS aimed to investigate psychosocial outcomes in adulthood. It showed that the FAS group differed from the comparison group ($p < .001$), in that most of those in the former (81 %) had been placed in out-of-home care as children compared to only 4 % in the latter ($p < .001$). Furthermore, the placements in the FAS group were usually in long-term care (61 %). In the FAS group 46 % had secondary school as their highest completed education, a comparable figure to that of the comparison group (51 %, ns). A reason why so many in the FAS group managed to complete their education may be that they attended special education as children. Indeed, it was found that the FAS group differed from the comparison group in that 25 % of those in the former had attended special education ($p < .001$). Noteworthy is that a majority of those in the FAS group who had not attended special education in primary school had still completed secondary education. The data in this thesis do not allow us to trace how the experience of attending special school has contributed to the results in the FAS group. However, previous studies on the present FAS group up to age 13 (Aronson & Hagberg, 1993, 1998; Strömland & Hellström, 1996) have shown that despite interventions from society, the primary disabilities persisted and had a negative impact on academic achievement. The fairly positive figures on education in the FAS group suggest that secondary disabilities may be ameliorated by factors like special education and assistance in school.

It was also found that the FAS group was more dependent on disability pension (31 %) and social welfare (28 %) than the comparison group, in which the corresponding figure for each aspect was 3 % ($p < .001$). Yet it is noteworthy that 49 % in the FAS group were employed, meaning that they were self-supporting. However, the figures on disposable income in the FAS group imply that they were mainly employed in lower-paid jobs, with income for some of them being supplemented with welfare benefits. In this way the FAS group resembles individuals with intellectual disabilities (Tideman, 2000; Tössebro & Lundeby, 2002), who also may have attended special school. Previous studies show that living conditions for individuals with intellectual disabilities differ significantly from those of the general population, especially in terms of employment (Tideman, 2000; Tössebro & Lundeby, 2002).

A minority (13 %) of the FAS group had been treated for alcohol-related disorders or illicit drug abuse, but this was still more than in the comparison group, where the corresponding figure was 3 % ($p < .001$). A majority of the FAS group (72 %) had no criminal record of court conviction, a comparable figure to that of the comparison group (80 %, ns). A previous study (Streissguth et al., 2004) showed that receiving an FAS diagnosis at a younger age can be a protective factor. In the present study all subjects in the study group had been diagnosed with FAS as children, which might explain the results.

In the FAS group, 6 % (5 of 79) compared to 2 % in the comparison group ($p < .001$) had been treated in hospital for suicide attempts, and 33 % for psychiatric disorders, compared to 5 % in the comparison group ($p < .001$). Many in the FAS group had also received prescriptions for psychotropic drug, such as sleeping medicine, anxiolytics, neuroleptics, and/or antidepressants. These findings may imply that mental health problems are common among adults with FAS.

Comparisons between the FAS group and those from the comparison group who had been placed in out-of-home care showed that medical care in hospital because of alcohol or illicit drug abuse was less common in the FAS group. Moreover, criminality was also less common among the individuals with FAS. Unfortunately, we have no data on reasons for placement in out-of-home care, or on what services and support the participants received when they were in care. However, previous results have shown that an adequate FAS diagnosis may help children receive appropriate support (Adams et al., 2002). The FAS diagnosis may have contributed to improved out-of-home care, for instance through support to foster parents from physicians and nurses within health care, and from special education teachers. The findings in this study thus indicate that stable placement in out-of-home care may be a protective factor for children with FAS. However, further studies are needed to determine whether out-of-home care is efficient for children with FAS.

Study II

It is suggested that separations and non-stable placements that may disturb a child's attachments to caregivers are psychological stressors for the child.

This study investigated whether placements in out-of-home care and number of early separations from caregivers were related to adult psychosocial outcomes in individuals with FAS. The results showed that a majority of the adults with FAS, 43 of 51 (84 %), had been placed in out-of-home care as children and that 31 of them (72 %) had been placed in care before the age of three. Twenty-six (65 %) of those who had been placed in out-of-home care had experienced more than one separation from their caregivers before three years of age. The results showed that among those who had been placed in out-of-home care after three years of age, three of nine had been convicted of severe crime, which was a slightly larger proportion than among those who had been placed in out-of-home care before three years of age (*ns*). No significant differences related to the adults' psychosocial outcomes were found. Thus, psychiatric disorders, psychotropic drug prescriptions, and crime convictions were equally common regardless of whether they had been placed in care early or late, and whether they had experienced few or many early separations. The findings indicate that out-of-home care as well as the biological home might offer both high- and low-quality environments and relations to significant adults during childhood for individuals prenatally exposed to alcohol. These results are in line with previous research (Astley, 2010; Streissguth et al., 2004; Victor et al., 2008; Vinnerljung & Sallnäs, 2008) showing that there may be both advantages and disadvantages to growing up in one's biological home as well as in out-of-home care.

Thirty-four adults with FAS (71 %) had attended ordinary education, and 19 (41 %) had secondary school as their highest completed education. Fourteen individuals (29 %) had received special education, and of these 14, two had secondary school as their highest completed education. Two of the 14 who had attended special education were self-supporting. Among those who had attended ordinary education, 15 (44 %) were self-supporting. There were no significant differences in highest completed education and being self-supporting between those who had attended special and ordinary education. In the Western world a majority of children with FASD receive special education (Streissguth et al., 1996), and although it is uncertain whether special education leads to employment and a stable adult life, it may be a way for students with FAS to receive the appropriate support at school. Additional analyses were done in Study II in a subgroup consisting of eight individuals in the study group. Data from the Griffiths Mental Development Scale (Griffiths, 1976) from childhood in this subgroup showed that those with the lowest DQ scores (median DQ 76) had also attended special education. Individuals with FASD may have a neuropsychological profile that entails a need for special services in school, which would offer opportunities for better adult outcomes. Traditionally, an individual's IQ must be below 70 in order to be eligible for special education. Since this is not found among all individuals with FAS, special services could be inaccessible to them, as discussed by Streissguth and colleagues (Streissguth et al., 2004).

Among the 51 individuals in the present study, 28 (58 %) had been prescribed some sort of psychotropic drug and 17 (33 %) had been treated in hospital for a psychiatric disorder. These figures are in line with previous research showing associations between prenatal alcohol exposure and an increased risk of psychiatric problems in adulthood (Famy et al., 1998). This was further confirmed by the outcomes in the eight individuals in the subgroup, who had all been placed in out-of-home care as children, seven of them before the age of three (see Study II). Their adult scores on symptoms of anxiety (BAI) ranged between 0 and 22 (defined as mild to moderate), and the median of 13 was within the span defined as mild (Beck & Steer, 1993). Five of the eight had experienced severe anxiety, at age 23 at the earliest. The adult scores on symptoms of depression (BDI) in the subgroup ranged between 0 and 31 (defined as mild to severe), and the median of 13 was within the span defined as mild (Beck et al., 1961). Six of the eight had experienced severe depression at some point in life, at age 22 at the earliest. It is suggested that these findings show that psychiatric interventions from society are still needed for individuals with FAS who are older than 22 years old.

In summary, what enables a positive psychosocial outcome for an individual with FAS in adulthood may not be whether he/she attended ordinary or special education or grew up in the biological home or in out-of-home care. What may rather be of importance during childhood could be socioeconomic factors, and the quality of the environmental conditions and relationships. Welfare authorities' decisions concerning choice of educational system and placement in care should be tailored specifically to each individual.

Study III

Twenty adults with FAS underwent neuropsychological testing, aiming to investigate cognitive and executive functions and social cognition. The median score in the FAS group was 29 of a maximum 36 on Raven's Coloured Progressive Matrices, which was interpreted as a low level of intellectual function, indicating neurocognitive impairment (Doyle & Mattson, 2015). These results are in line with previous studies in which cognitive disabilities were found in individuals with FAS, although those studies were conducted on children (Mattson et al., 2011; Streissguth et al., 2004). Moreover, studies in young adults with FASD have reported memory deficits (Coles et al., 2010) as well as deficits in the ability to maintain and manipulate information in the working memory (Connor et al., 2001). In this study, the Digit Span Task was used to assess short-term and working memory. On Digit Span forwards the median in the FAS group was 5, significantly lower than the comparison group's median of 7 ($p < .001$). On Digit Span backwards the median in the FAS group was 3, significantly lower than the median of 5 in the comparison group ($p < .001$). The figures implied that Digit Span backwards, which requires more coordination of cognitive functions, was more difficult for them than Digit Span forwards, which is not as complex.

In one of the tests of executive functions used in Study III, Berg's Card Sorting Test, the median number of total correct responses in the FAS group was 33.0 (maximum 64). In the comparison group, the median was 51.5 ($p < .001$). In the FAS group, 64.5 % of the errors were non-perseverative with a median of 20 – significantly higher than in the comparison group, in which the median number of non-perseverative errors was 5.5 ($p < .001$). The median number of perseverative errors, 7 in the FAS group and 6 in the comparison group, did not differ (*ns*). Another test of executive functions used in Study III, Tower of Hanoi, showed that the FAS group required significantly more steps to solve the task than the comparison group ($p = .007$). The adults with FAS had more difficulty solving tasks requiring cognitive and spatial planning, flexibility, set-shifting and inhibitory control than the comparison group. The most common comorbidity with FASD is Attention Deficit Hyperactivity Disorder (ADHD), estimated to occur in between 50 and 80 % of individuals with FASD (Mattson et al., 2011). A previous study on children with ADHD (Yáñez-Téllez et al., 2012), as well as a study on children with FASD (Kodituwakku et al., 1995), showed an increase in perseverative responses in tests of executive functions. Based on these results, we expected perseverative responses to be common among the individuals with FAS even in adulthood. Perseverative responses indicate difficulty in set-shifting and inhibitory control; that is, executive function disabilities. However, non-perseverative errors (i.e., an unspecified failure to solve the task) were the most frequent in this FAS group. This might be because solving the task was too difficult for this group, requiring a higher level of cognitive function, a suggestion that may be supported by their low number of correct responses. Although the FAS group appeared to have understood the instructions they seemed to have difficulty grasping the rules, and consequently failed to reach even the level of making perseverative errors. Their errors were random. In contrast, the comparison group made a low total number of errors, with an equal distribution of non-perseverative and perseverative errors. Importantly, two (10 %) of the adults in the FAS group had diagnosed ADHD; there could have been more in the group, albeit undiagnosed. The results from the tests of executive functions in this study may be related to FAS specifically, and to comorbid attention deficits and impaired inhibitory control.

The adults' social cognition, defined as their Theory of Mind (ToM), was investigated by use of Faux Pas, clear differences were shown between the groups. The median score for identification of Faux Pas in the FAS group was 25 (of maximum 32). The median in the comparison group, 31, was significantly higher ($p < .001$). The comprehension-control scores ranged from 14 to 16 (maximum 16) in the FAS group, and the median score in both groups was 16. The FAS group had difficulty identifying situations that unintentionally caused embarrassment to another person, indicating their uncertainty about social codes and what is considered appropriate in social interaction. A previous review of social skills deficits (Kully-Martens et al., 2012) reported that children with FASD had difficulty understanding social cues. Based on the results in this study, it is suggested that the social difficulties associated with FAS do not improve with age. This could entail problems in real adult life, since ToM is closely related to community functioning.

An additional aim of this study was to investigate the participants' so-called sense of coherence (Antonovsky, 1993). The total scores reflecting global sense of coherence differed between the groups, with the FAS group scoring 112 (of maximum 203), significantly lower than the comparison group ($p = .005$). A strong sense of coherence means being confident that life is structured and predictable, and that one's own resources are sufficient (Antonovsky, 1993). In other words, the individual must rely on his/her own abilities for planning, problem-solving and adapting to changing conditions, abilities requiring a certain level of cognitive and executive functions, as well as of social cognition. A contributing factor to the low total scores on sense of coherence in the FAS group was the manageability subscale. Their median score was 36 (of maximum 70), which was lower than in the comparison group, where the median was 50 ($p < .001$). On the other hand, although there were significant differences between the groups on the manageability subscale, there were no differences between them on the comprehensibility and meaningfulness subscales. A possible interpretation of this is that although the adults with FAS cannot always manage their lives, they nonetheless find life quite comprehensible and meaningful.

Reduced cognitive functions and difficulty understanding what is considered appropriate in social interactions were found in the adults with FAS. Thus, even in adulthood they had some of the primary disabilities commonly found in children with FAS. It is suggested that these have a major impact on their lives, reflected in their weak sense of coherence, with particularly low scores on the manageability scale.

Study IV

Twenty adults with FAS were interviewed using the structured *Addiction Severity Index interview* (ASI; McLellan et al., 2006), with the aim of investigating self-reported physical and psychiatric health, the use of alcohol and illicit drugs, and conviction and being the victim of crime. The results confirmed previous studies (e.g., Famy et al., 1998; Streissguth et al., 2004), reporting on psychiatric problems among individuals with FASD. Data from the ASI interview showed that the groups differed significantly ($p < .01$), with nine (64 %) of the adults with FAS having experienced symptoms of depression within the recent year compared to two (15 %) in the comparison group. Anxiety within the recent year was also significantly more common in the FAS group at nine (75 %) than in the comparison group, at two (25 %; $p < 0.01$). Data from the BAI showed that the median score for the FAS group on symptoms of anxiety the past week was 13 and for the comparison group 6, although the difference was not significant. Neither did the groups differ in their scores on symptoms of depression in the past two weeks (BDI). The median scores were 10 for the FAS group and 4 for the comparison group. The median scores on the BAI and BDI in the FAS group were within the range defined as mild, whereas the comparison group had scores that could be defined as minimal (Beck & Steer, 1993; Beck et al., 1961).

Suicidal ideation was more common, and started earlier, among the adults with FAS. Age at the first occurrence of suicidal ideation was 21±3 in the FAS group and 33±1 in the comparison group ($p < .001$). Fourteen of the adults with FAS (70 %) had experienced problems controlling violent behavior, which was significantly more than the figure of four (20 %) in the comparison group ($p < .01$). The two groups also differed significantly ($p < .01$) with 11 (55 %) of the adults with FAS having been prescribed some sort of psychotropic drug (i.e., sleeping medicine, antidepressants and/or anxiolytics) compared to three (15 %) in the comparison group. Different types of psychiatric problems were more common among adults with FAS than in the comparison group. On the other hand, data from the ASI showed that no one in either group had experienced problems with the use of alcohol or illicit drugs. The figures showed no significant differences between the groups in any of the variables on the use of alcohol and illicit drugs. In this aspect of psychiatric health, the results contradicted the findings in Study I that showed that alcohol problems and/or illicit drug use were more common among adults with FAS than in the general population.

Unlike the research on psychiatric health among individuals with FAS (e.g., Famy et al., 1998; Streissguth et al., 2004), the knowledge about their physical health is still more limited (Moore & Riley, 2015). The results from this study showed that chronic physical problems that continue to interfere with life were equally self-reported in the FAS group as in the comparison group. Prescriptions of medication for a physical problem were also equally common in both groups. However, three (15 %) in the FAS group had a pension for physical disability while no one in the comparison group did (*ns*). Moreover, at a $p < .05$ level, the number of days on sickness leave due to poor physical health in the latest months was significantly higher in the FAS group. These findings suggest that adults with FAS have a poorer physical health condition, which may affect their ability to work. However, this suggestion does not exclude the possibility that the high rate of days on sickness leave in the FAS group could also be explained by their psychiatric problems. Nevertheless, further studies are needed in order to determine what the long-term physical health problems associated with FAS are.

There were no significant differences between the groups in any of the variables on conviction, and being the victim, of crime. The self-reported data from the ASI showed that two (10 %) in the FAS group had been taken into custody or charged with criminal offenses, resulting in fines, compared with one (5 %) in the comparison group (*ns*). No one in either group had been taken into custody or charged for criminal offenses resulting in probation or prison. These results contradict previous studies (Brown et al., 2015; Momino et al., 2012; Popova et al., 2011; Streissguth et al., 2004) showing that individuals with FASD may have an increased risk of criminal behavior. In this study, all individuals in the study group had an FAS diagnosis and the crime conviction rates were low. The different study populations may explain the differing crime conviction rates between countries in individuals with FASD. The fact that the participants had an FAS diagnosis might have given them access to efficient support from social welfare; such things may serve as protective factors and reduce the risk of criminal behavior. An individual under the broader spectrum of FASD without an FAS diagnosis, who has not received interventions from society, may have an increased risk of criminal behavior.

Previous studies (e.g., Brown et al., 2015) have shown that individuals with FASD have impaired self-control and may be gullible. These characteristics could also make a person more vulnerable to being the victim of crime. Even if a majority of the adults with FAS – 14 (70 %) – had been victims of crime, the groups did not differ significantly; 13 (65 %; *ns*) in the comparison group had been victims of crime. Among the 14 in the FAS group who had been victims of crime, it was most common to have been the victim of violence/sexual violence 8 (57 %). In the comparison group, it was most common to have been cheated out of money 6 (46 %, *ns*). Nine (45 %) in the FAS group and four (20 %) in the comparison group had experienced being physically hurt by family or a close friend (*ns*). Most previous studies investigate whether individuals with FASD commit crimes. One of the few previous studies investigating whether individuals with FAS are vulnerable to being the victims of crime (Freunscht & Feldmann, 2011) reported that they actually have an increased risk of this. It was suggested that the results were due to the fact that individuals with FAS might have difficulty understanding others' intentions and the consequences of their own actions. Although the rates of the experience of being a victim of crime did not differ significantly in Study IV between the FAS group and the comparison group, the fact that a majority in the FAS group had experienced this implies that it is an important topic. These results call for further research to provide more knowledge about the risk for individuals with FAS of being the victims of crime.

Limitations

The design and performance of the studies in this thesis were preceded by methodological considerations. However, there are some shortcomings in the studies included here that need to be mentioned.

Comparison groups

Choosing the correct comparison group for studying adults with FAS is difficult. Throughout this thesis healthy individuals were used, matched on gender and age. However, individuals matched on IQ, or with disabilities comparable to those of the FAS group, could have been chosen instead. For example, general intellectual functioning can be important for the results in tests of executive function, and a matching on IQ could have controlled for this. Moreover, the results in tests of general cognitive function and social cognition can be influenced by a stimulating environment during childhood. From this perspective, individuals matched on environmental influences like socioeconomic or educational factors could also have been chosen. On the other hand, this might have led to other design and methodological considerations; for example, how and where to find the participants, and how to interpret and report on counterintuitive findings on neurocognitive function.

Another issue is the comparison group in the literature. Throughout this thesis the empirical findings are compared and discussed in relation to previous research that has used study groups commonly consisting of individuals from the broader spectrum of FASD (e.g., Famy et al., 1998). Such groups, consisting of individuals with FASD, might be quite heterogeneous. The study groups in the empirical studies included in this thesis were somewhat more delimited, with all participants having an FAS diagnosis. However, while neuropsychological disabilities vary within the group of FASD, as well as within the group of FAS, they vary in a similar way, differing from typical neuropsychological development (Hoyme et al., 2005). Individuals with FAS are thus in many ways representative of the broader spectrum of FASD. Comparisons and generalizations between the results from the empirical studies included in this thesis and previous studies on FASD, and not only on FAS, are thus relevant and useful.

Record-linkage studies

Study I utilized data from record linkages between national registers held by Statistics Sweden (Statistiska centralbyrån), the National Council for Crime Prevention (Brottsförebyggande rådet), and the National Board of Health and Welfare (Socialstyrelsen). The strength of the record-linkage studies (Studies I and II) is the possibility they offer to study the entire group and to assess psychosocial outcomes. However, relying only on official records does not make it possible to recapture a complete picture of the adults with FAS. Study I lacks input from the individuals themselves; on the other hand, Studies II, III and IV provided this, giving a more nuanced picture of the adults with FAS.

Validity of measures

The tests, self-rating scales and interview used in Studies II, III and IV are not validated for adults with FASD. Measures for individuals with disabilities are lacking, and there is a need for the development of such tests. Level of intellectual function was obtained by use of Raven's Coloured Progressive Matrices (Raven, Court & Raven, 1988). This was considered to be an ethical and respectful choice of test, since adults with FASD may have a low level of intellectual function (Streissguth et al., 2004). Digit Span, BCST-64 and Tower of Hanoi were used. These have been used in previous studies on children with FASD (Crocker, Riley & Mattson, 2015; Kodituwakku et al., 2001; McInerney, 2007), and were therefore considered to be useful for adults with FAS. In Faux Pas, the participants' high scores on the comprehension-control questions indicated an appropriate difficulty level. There were no floor or ceiling effects, and the participants understood the instructions, implying that the measures used were appropriate.

Sample size

A shortcoming of Studies III and IV is their relatively small sample size (n = 20). While it would have been preferable to include all 79 participants from Study I, due to ethical considerations only those in the study group in Study I who knew about their FAS diagnosis were contacted about participating in Studies III and IV. Thus many individuals were excluded, which made the sample size smaller. However, it would have been possible to get larger sample sizes by, for example, including individuals prenatally exposed to alcohol who had not had an FAS diagnosis. On the other hand, including such participants might have led to difficulties in drawing conclusions.

Follow-up study

Follow-up studies always entail methodological difficulties. An individual who is prenatally exposed to alcohol and is born with birth defects develops throughout life. The outcomes in adulthood may be influenced by the disabilities caused by the exposure to alcohol during the prenatal period. In addition, they may also be influenced by different environmental circumstances. Investigating this individual in adulthood could thus be problematic, due to uncontrolled ameliorating and confounding factors. To manage this complexity, theoretical models were used in this thesis. Based on the psychological theories (Bowlby, 1982; Bronfenbrenner, 1977; Sameroff, 2009) the participants' development, from being diagnosed with FAS in childhood to the outcome in adulthood, is discussed in terms of processes whereby the individuals exchange, but also are exchanged by, different environmental factors.

General Discussion and Conclusions

The four empirical studies in this thesis investigated the psychological, psychosocial, and neuropsychological consequences of Fetal Alcohol Syndrome in adulthood. From the results obtained, the following conclusions can be made: 1) Neuropsychological consequences: Individuals with FAS may have impaired cognitive functioning even in adulthood; 2) Psychological consequences: Psychiatric problems were commonly occurring among the adults with FAS, although they did not have problems with the use of alcohol; 3) Psychosocial consequences: Most of the individuals with FAS had been placed in out-of-home care, and several had attended special school. In adulthood, being self-supporting and being dependent on financial support were equally common. However, criminality was uncommon among the adults with FAS.

Neuropsychological Consequences

Individuals with FAS may have cognitive disabilities even in adulthood, manifested as generally reduced intellectual functioning, impaired social cognition, and reduced executive functions. These dysfunctions have previously been defined in children as primary disabilities, suggested to be the result of the alcohol's teratogenic effect (Streissguth, Barr, Kogan & Bookstein, 1996). The findings in the empirical studies included in this thesis showed that the primary disabilities associated with FAS are likely to persist in adulthood, but may have been modified through transactions with various environmental factors (Sameroff, 2009). The disabilities can be assumed to have a major impact on life; especially on an adult's life, which might place high demands on the individual's functioning. Many everyday situations require the executive functions, such as the ability to plan, solve problems, and be flexible. Someone who does not meet these requirements might have difficulty managing an education, employment (Diamond, 2013), or parenthood. The impaired social cognition found among the adults with FAS has previously been observed in children with FASD, and found to be associated with social skills problems (Rasmussen, Wyper & Talwar, 2009; Stevens, 2012). The impaired social cognition in adulthood might lead to problems with social judgments and difficulty understanding social cues, which are needed in order to be part of social contexts; this could be in terms of both close relationships as well as relationships with other adults, such as teachers in school or the parents of other children. The conclusion that individuals with FAS may have impaired cognitive functioning even in adulthood calls for further research on efficient interventions and support that would allow them to live as good adult lives as possible.

Psychological Consequences

Psychiatric problems like depression, anxiety, and the need for psychotropic drugs were commonly occurring among the adults with FAS. Their poor mental health was further illustrated by their weak sense of coherence, showing their own images of themselves from a psychological perspective. These results are in line with previous studies showing that psychiatric problems are commonly occurring in adults with FASD (Famy et al., 1998; Huggins, Grant, O'Malley & Streissguth, 2008). However, only a small number of the adults with FAS in the empirical studies in this thesis had problems with the use of alcohol. This finding is not in line with previous reports showing that individuals with FASD have problems with the use of alcohol or illicit drugs (Streissguth et al., 2004). It is suggested that the current findings show that, although anxiety and depression are commonly occurring among the adults with FAS, they do not use alcohol as self-medication in a problematic manner. Moreover, the findings in Study II showed that psychiatric disorders, psychotropic drug prescriptions, and the use of alcohol or illicit drugs were equally common regardless of whether the adults with FAS had been placed in out-of-home care early or late, and whether they had experienced few or many early separations. Even in this way, the results contradict previous research showing that early placement in a stable environment is a protective factor that can ameliorate secondary disabilities (Streissguth et al., 2004).

The conclusion that psychiatric problems are commonly occurring in adults with FAS might be explained by negative experiences throughout life due to the primary disabilities associated with FAS. For the participants in the empirical studies in this thesis, the primary disabilities associated with

FAS have probably had an influence on their psychological development (Bronfenbrenner, 1977). In addition, some may have had negative experiences of one or more early separations from caregivers, learning disabilities, and problems getting along with peers during childhood. Later in life, an adult with FAS may have experienced problems being part of social contexts, or difficulty finding employment or coping with parenthood. Based on the findings, it is suggested that adults with FAS need psychological support throughout life that may ameliorate the adverse psychiatric consequences.

Psychosocial Consequences

Among the adults with FAS, it was most common to have completed at least mandatory school, occasionally including additional secondary school, and several in the group had attended special school. In adulthood, being self-supporting and being dependent on financial support were equally common. The findings in the empirical studies in this thesis contradict previous reports showing that disrupted school experiences are common psychosocial secondary disabilities in individuals with FASD (Streissguth et al., 2004), and that a majority of the adults with FASD were unemployed (Spohr, Willms, & Steinhausen, 2007). Moreover, the findings in the empirical studies in this thesis showed that criminality was uncommon among the adults with FAS. Even in this way, the results contradict previous reports showing that individuals with FASD have a behavior that may increase their risk of criminality (Brown et al., 2015; Streissguth et al., 2004). In addition, the crime conviction rate was even lower among the adults with FAS studied in the empirical studies in this thesis than in a gender-and-age-matched comparison group who had been in out-of-home care during childhood. It is noteworthy that most of the adults with FAS had also been placed in out-of-home care during childhood. The low rate of criminality among the adults with FAS may be explained by the fact that they were all at the most severe end of the FASD continuum. The fact that they all had an FAS diagnosis, and had gotten it early in life, might have protected them from criminality. The diagnosis might be the reason why they had access to financial support and were in close contact with social workers, and received special education during childhood (Aronson & Olegård, 1987; Aronson et al., 1997; Strömland & Hellström, 1996). These factors, together with being self-supporting in adulthood, could possibly have contributed to the low rates of criminality. This could also be explained by the quality of their relationships with caregivers, socioeconomic factors, and the quality of their environmental conditions in childhood.

Interrelated Causes and Consequences

This thesis provides a complex picture of adult individuals who were diagnosed with FAS in childhood. It is not concluded that the psychological, psychosocial, and neuropsychological consequences found in the adults studied were directly caused by the prenatal alcohol exposure per se. It is suggested that individual, as well as environmental, factors are interrelated and influence each other throughout life, coming to be both causes and consequences (see Figure 2).

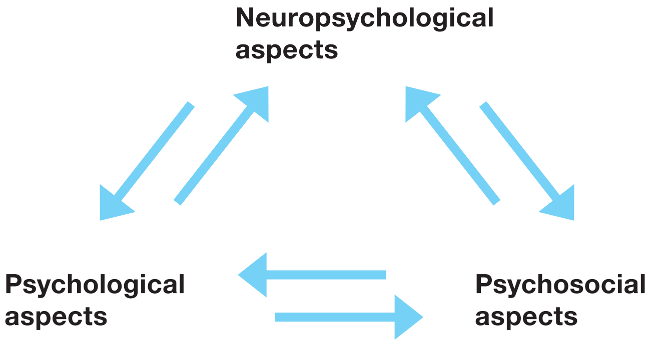
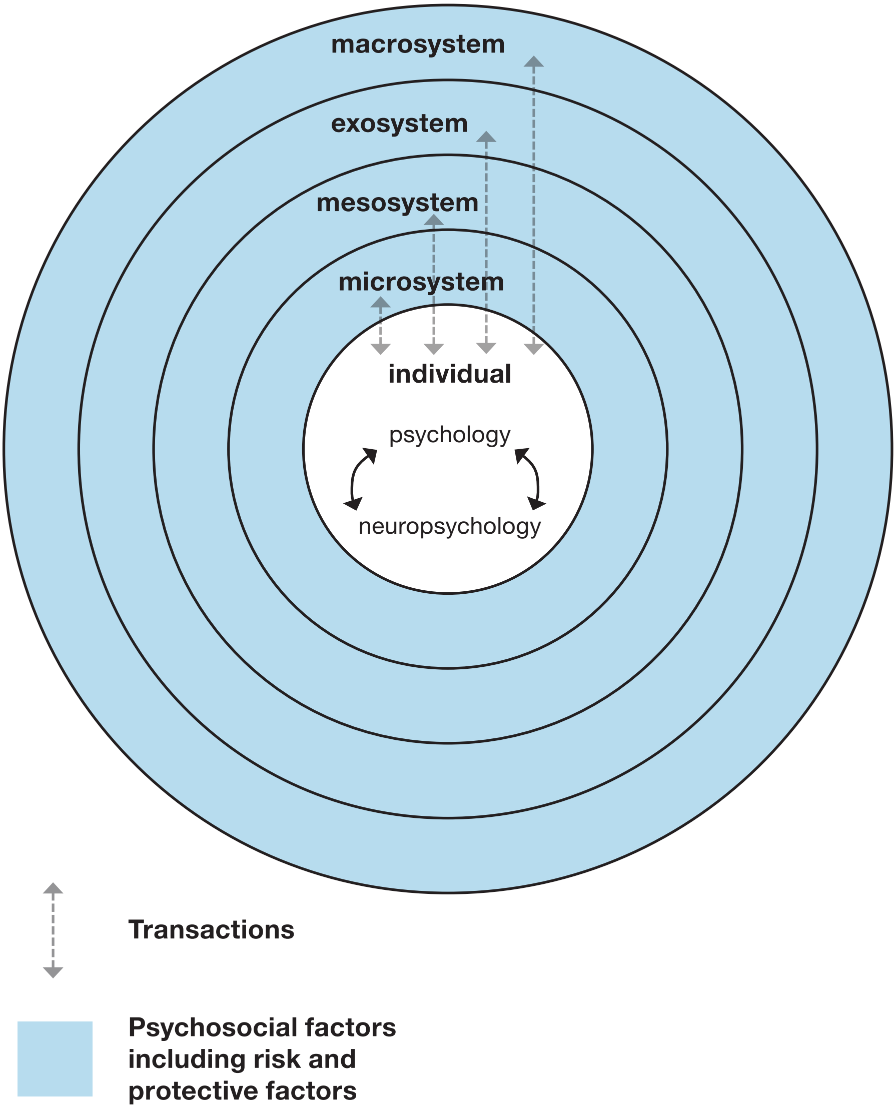


Figure 2. The illustration shows how neuropsychological, psychological and psychosocial aspects can interact, exchange and become interrelated causes and consequences.

The interrelated causes and consequences could be explained by the individual's development through transactions with the surrounding environment, as proposed by Sameroff (Sameroff, 2009). The environment might mean both psychosocial risk and protective factors in all layers of the systems of the environmental factors, as proposed by Bronfenbrenner (1977). This reasoning (see Figure 3) would mean that although neuropsychological disabilities have been shown to be the direct result of the alcohol's teratogenic effect on the fetal brain, psychological and environmental factors could probably interfere with them. A psychosocial situation that stimulates and trains the child's executive functions might be beneficial; while on the other hand, a poor psychosocial situation might have a deleterious effect on the child's executive functions (Diamond, 2013). This implies that some of the primary disabilities can be ameliorated in a child with FAS who is in stable care, attached to a caregiver who stimulates the child's executive functions. This could lead the child's psychological development in a positive direction. However, a child with FAS who experiences neglect and stressors, like one or multiple separations that complicate attachments (Bowlby, 1977), can deteriorate some of the child's primary disabilities and lead the development process in an adverse direction. Thus, psychosocial factors may influence a child neuropsychologically. At the same time, both these aspects may have psychological consequences. Transactions between an individual with FAS whose neuropsychological disabilities have not been ameliorated on the one hand and environmental factors that lead to early negative experiences in life on the other might result in psychological consequences such as depression and anxiety (Sameroff, 2009). Later in life, the psychological aspects may give rise to psychosocial consequences. Poor mental health could affect a person's ability to motivate completing an education or obtaining and keeping a job. Moreover, this influence is reciprocal, since a poor psychosocial situation might have negative psychological consequences for the individual. Thus, the psychological situation for adults with FAS is influenced by the neuropsychological disabilities, but might be modified by psychosocial factors.

According to this reasoning, asserting that it is not only the individual child or the caregiver's abilities that are of importance, but also their contexts, could be useful even when discussing the generalizability of the results from the studies in this thesis. The individuals with FAS and their caregivers are influenced by the extent to which they could receive support from social relationships and efficient interventions from welfare authorities according to their legal rights. The aspects are influenced by cultural factors, and differ between countries. In this way, the individual child is influenced by risk and protective factors in all layers of the systems of environmental factors, even those with which the child is not in direct contact (Bronfenbrenner, 1977). It is suggested that the results from the studies in this thesis have been influenced by the fact that the individuals with FAS grew up in a Swedish context, and might therefore be generalizable to other individuals with FAS living in Sweden. However, the figures on, for example, criminality differ from previous findings from the US (Streissguth et al., 2004), which suggests the importance of the influence of different contexts. For an illustration of the reasoning in this section, see Figure 3.

Figure 3. The illustration shows the reasoning from Figure 2 as applied in a modified model of Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1977).



Preventing FASD

Prenatal alcohol exposure is associated with a complex chain of causes and consequences that interrelate from early childhood to adulthood. It is suggested that the findings from the studies in this thesis show that to ameliorate adverse adult outcomes, children with FAS need health care as well as efficient interventions from welfare authorities involving educational support and social care. In addition, this thesis demonstrates the generally low psychological, psychosocial and neuropsychological functioning that is suggested to have a major impact on daily life for the adults with FAS. This is a source of distress that would have been possible to avoid, considering the fact that FASD is caused by maternal alcohol consumption and is thereby completely preventable.

In Sweden, the National Board of Health and Welfare advises pregnant women to abstain from consuming alcohol throughout pregnancy (Socialstyrelsen, 2007). This recommendation is based on caution, because the amount of alcohol that would be safe to drink without the risk of birth defects is not known. Nearly all pregnant women receive maternity care in Sweden, and the midwives thoroughly inform them about the harmful effects of alcohol and give the recommendation to abstain from consuming alcohol during pregnancy. However, due to shame, and/or fear of the negative attitudes that may exist in maternal care, pregnant women may be reluctant to talk about their alcohol consumption and habits (Kotrla & Martin, 2009). This may lead to an underreporting of alcohol consumption, as well as of perceived alcohol problems. This underreporting may also be due to the women defining their issues as mental health problems rather than alcohol problems (Sydsjö & Wadsby, 2003).

Moreover, although FASD can only occur if the pregnant woman consumes alcohol, it is important to understand that FASD is not only dependent on the individual woman's choice. There can be many different underlying reasons why she does not abstain from consuming alcohol during pregnancy. For instance, she may not know she is pregnant, or she may not know of the risks posed by drinking alcohol during pregnancy. Other reasons may include substance-use disorder, self-medication for anxiety, or social expectations regarding drinking alcohol. The preventive work should therefore be done in an ethical manner, without blaming the individual woman. The responsibility for preventing FASD should be placed on society, social norms, and relationships (Jonsson, 2014).

Concluding Remarks

The findings in this thesis contribute to the general knowledge about prenatal exposure to alcohol, and the long-term persisting consequences. Particularly, it shows that early detection of FAS in children, followed by a broad spectrum of interventions from social welfare authorities, might prevent criminality and substance abuse. It also demonstrates some of the psychological, psychosocial and neuropsychological difficulties an individual with FAS might face in adult life. Thus, seen from a societal perspective, interventions to prevent FASD are of utmost importance.

References

Abel, E. L. (1997). Was the fetal alcohol syndrome recognized in the ancient Near East?. *Alcohol and Alcoholism*, *32*(1), 3–8. doi: 10.1093/oxfordjournals.alcalc.a008231

Abel, E. L., & Sokol, R. J. (1987). Incidence of fetal alcohol syndrome and economic impact of FAS-related anomalies. *Drug and Alcohol Dependence*, *19*(1), 51–70. doi: 10.1016/0376-8716(87)90087-1

Adams, J., Bittner, P., Buttar, H. S., Chambers, C. D., Collins, T. F., Daston, G. P. & Polifka, J. E. (2002). Statement of the public affairs committee of the teratology society on the fetal alcohol syndrome. *Teratology*, *66*(6), 344–347. doi: 10.1002/tera.10118

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*. American Psychiatric Pub.

Antonovsky, A. (1993). The structure and properties of the sense of coherence scale. *Social Science & Medicine, 36*(6), 725–733. doi: 10.1016/0277-9536(93)90033-Z

Arnett, J. J. (2007). Emerging adulthood: What is it, and what is it good for?. *Child Development Perspectives*, *1*(2), 68–73. doi: 10.1111/j.1750-8606.2007.00016.x

Aronson, M. (1984). *Children of alcoholic mothers*. Doctoral Thesis, University of Gothenburg (ISBN 91-7222-697-8)

Aronson, M., & Hagberg, B. (1993). Hur har det gått för de alkoholskadade barnen? Uppföljningsstudie av barn till alkoholiserade mödrar. *Läkartidningen, 90*, 2214–2219

Aronson, M. & Hagberg, B. (1998). Neuropsychological disorders in children exposed to alcohol during pregnancy: a follow-up study of 24 children to alcoholic mothers in Göteborg, Sweden. Alcoholism: Clinical and Experimental Research, 22:321–324. doi: 10.1111/j.1530-0277.1998.tb03655.x

Aronson, M., Hagberg, B., & Gillberg, C. (1997). Attention deficits and autistic spectrum problems in children exposed to alcohol during gestation. *Developmental Medicine and Child Neurology, 39,* 583–587. doi: 10.1111/j.1469-8749.1997.tb07493.x

Aronson, M., Kyllerman, M., Sabel, K.G., Sandin, B., & Olegård R. (1985). Children of alcoholic mothers. Developmental, perceptual and behavioural characteristics as compared to matched controls. *Acta Paediatrica Scandinavica, 74(1)*, 27–35. doi: 10.1111/j.1651-2227.1985.tb10916.x

Aronson, M., & Olegård, R. (1986). Children of alcoholic mothers. *Pediatrician*, *14*(1–2), 57–61.

Astington, J. W., & Edward, M. J. (2010). The development of theory of mind in early childhood. *Social Cognition in Infancy 5*, 16.

Astington, W. J., & Gopnik, A. (1991). Theoretical explanations of children's understanding of the mind. *British Journal of Developmental Psychology, 9,* 7–31. doi: 10.1111/j.2044-835X.1991.tb00859.x

Astley, S. J. (2010). Profile of the first 1,400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorder at the Washington State Fetal Alcohol Syndrome Diagnostic & Prevention Network. *Canadian Journal of Clinical Pharmacology, 17*(1) e132–e164.

Astley, S. J., & Clarren, S. K. (2000). Diagnosing the full spectrum of fetal alcohol-exposed individuals: introducing the 4-digit diagnostic code. *Alcohol and Alcoholism, 35*(4), 400–410. doi: 10.1093/alcalc/35.4.400

Autti-Rämö, I. (2000). Twelve-year follow-up of children exposed to alcohol in utero. *Developmental Medicine & Child Neurology, 42*(6), 406–411. doi: 10.1017/S0012162200000748

Baer, J. S., Sampson, P. D., Barr, H. M., Connor, P. D., & Streissguth, A. P. (2003). A 21-year longitudinal analysis of the effects of prenatal alcohol exposure on young adult drinking. *Archives of General Psychiatry, 60*(4), 377–385. doi: 10.1001/archpsyc.60.4.377

Beck, A. T., & Steer, R. A. (1993). Beck anxiety inventory manual. San Antonio, TX: The psychological corporation.

Beck, A. T., Ward, C., & Mendelson, M. (1961). Beck depression inventory (BDI). *Archives of General Psychiatry, 4*(6), 561–571. doi: 10.1001/archpsyc.1961.01710120031004

Bertrand, J., Floyd, L. L., & Weber, M. K. (2005). *Fetal alcohol syndrome. Guidelines for identifying and referring persons with fetal alcohol syndrome.* US Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention, 2005.

Bertrand, J., Floyd, L. L., Weber, M. K., O'Connor, M., Riley, E. P., Johnson, K. A., et al., (2004). *Fetal alcohol syndrome: Guidelines for referral and diagnosis.* Atlanta, GA: Centers for Disease Control and Prevention.

Bowlby, J. (1982). Attachment and loss: retrospect and prospect. *American Journal of Orthopsychiatry*, *52*(4), 664. doi: 10.1111/j.1939-0025.1982.tb01456.x

Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513. doi: 10.1037/0003-066X.32.7.513

Brown, N. N., Burd, L., Grant, T., Edwards, W., Adler, R., & Streissguth, A. (2015). Prenatal alcohol exposure: An assessment strategy for the legal context. *International Journal of Law and Psychiatry, 42*, 144–148. doi: 10.1016/j.ijlp.2015.08.019

Burd, L., Carlson, C., & Kerbeshian, J. (2007). Fetal alcohol spectrum disorders and mental illness. *International Journal on Disability and Human Development, 6*(4), 383–396. doi: 10.1515/IJDHD.2007.6.4.383

Carr, J. L., Agnihotri, S., & Keightley, M. (2010). Sensory processing and adaptive behavior deficits of children across the fetal alcohol spectrum disorder continuum. *Alcoholism: Clinical and Experimental Research, 34*(6), 1022–1032. doi: 10.1111/j.1530-0277.2010.01177.x

Chelune, G. J., Talley, J. L., Kay, G. G., & Curtiss, G. (1993). *Wisconsin card sorting test manual.* Odessa, FL: Psychological Assessment Resources.

Chudley, A. E., Conry, J., Cook, J. L., Loock, C., Rosales, T., & LeBlanc, N. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal, 172*(5 suppl), 1–21. doi: 10.1503/cmaj.1040302

Chudley, A. E., Kilgour, A. R., Cranston, M. & Edwards, M. (2007). Challenges of diagnosis in fetal alcohol syndrome and fetal alcohol spectrum disorder in the adult. *American Journal of Medical Genetics, 145C*, 261–272. doi: 10.1002/ajmg.c.30140

Clarke, M.E., & Gibbard, W.B., (2003). Overview of fetal alcohol spectrum disorders for mental health professionals. *The Canadian Child and Adolescence Psychiatry Review, 12(3)*, 57–63.

Clarren, S. K., Randels, S. P., Sanderson, M., & Fineman, R. M. (2001). Screening for fetal alcohol syndrome in primary schools: a feasibility study. *Teratology, 63*(1), 3–10. doi: 10.1002/1096-9926(200101)63:1<3::AID-TERA1001>3.0.CO;2-P

Clarren, S. K., & Smith, D. W. (1978). The fetal alcohol syndrome. *The New England Journal of Medicine.* doi: 10.1056/NEJM197805112981906

Coles, C. D., Lynch, M. E., Kable, J. A., Johnson, K. C., & Goldstein, F. C. (2010). Verbal and nonverbal memory in adults prenatally exposed to alcohol. *Alcoholism: Clinical and Experimental Research, 34*(5), 897–906. doi: 10.1111/j.1530-0277.2010.01162.x

Connor, P. D., Sampson, P. D., Bookstein, F. L., Barr, H. M., & Streissguth, A. P. (2001). Direct and indirect effects of prenatal alcohol damage on executive function. *Developmental Neuropsychology, 18*(3), 331–354. doi: 10.1207/S1532694204Connor

Crocker, N., Riley, E. P., & Mattson, S. N. (2015). Visual-spatial abilities relate to mathematics achievement in children with heavy prenatal alcohol exposure. *Neuropsychology*, *29*(1), 108. doi:10.1037/neu0000094

Crocker, N., Vaurio, L., Riley, E. P., & Mattson, S. N. (2009). Comparison of adaptive behavior in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcoholism: Clinical and Experimental Research, 33*(11), 2015–2023. doi: 10.1111/j.1530-0277.2009.01040.x

Crocker, N., Vaurio, L., Riley, E. P., & Mattson, S. N. (2011). Comparison of verbal learning and memory in children with heavy prenatal alcohol exposure or attention-deficit/hyperactivity disorder. *Alcoholism: Clinical and Experimental Research, 35*(6), 1114–1121. doi: 10.1111/j.1530-0277.2011.01444.x

Davis, K., Desrocher, M., & Moore, T. (2011). Fetal alcohol spectrum disorder: A review of neurodevelopmental findings and interventions. *Journal of Developmental and Physical Disabilities, 23*(2), 143–167. doi: 10.1007/s10882-010-9204-2

Diamond, A. (2013). Executive functions. *Annual review of psychology, 64*, 135.

Doig, J., McLennan, J. D., & Gibbard, W. B. (2008). Medication effects on symptoms of attention-deficit/hyperactivity disorder in children with fetal alcohol spectrum disorder. *Journal of Child and Adolescent Psychopharmacology, 18*(4), 365–371. doi: 10.1089/cap.2007.0121

Doyle, L. R., & Mattson, S. N. (2015). Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE): review of evidence and guidelines for assessment. *Current Developmental Disorders Reports, 2*(3), 175–186. doi: 10.1007/s40474-015-0054-6

Ericson, L., Hovstadius, B., & Magnusson, L. (2015) Hälsoekonomisk studie av barn och vuxna med fetalt alkoholsyndrom. (Health economic study of children and adults with fetal alcohol syndrome.) Nka Barn som anhöriga. Kunskapsöversikt 2015:10. Kalmar: Nka, Linnéuniversitetet.

Fagerlund, Å. (2013). Fetal alcohol spectrum disorders in Finnish children and adolescents: Diagnosis, cognition, behavior, adaptation and brain metabolic alterations. (Doctoral dissertation, Turku: University of Turku. Retrieved from: https://www.doria.fi/bitstream/handle/10024/88878/fagerlund_ase.pdf?sequence=2

Famy, C., Streissguth, A. P., & Unis, A. S. (1998). Mental illness in adults with fetal alcohol syndrome or fetal alcohol effects. *American Journal of Psychiatry, 155*(4), 552–554. doi: 10.1176/ajp.155.4.552

Gustafsson, C. (2003). *Intellectual disability and mental health problems. Evolution of two clinical assessment instruments. Occurance of mental health problems and psychiatric care utilisation*. Doctoral thesis. Uppsala: Uppsala University

Griffiths R. (1976) Griffiths mental development scales. Test Agency.

Heaton, R. K. (1993). Wisconsin card sorting test: computer version 2. *Odessa: Psychological Assessment Resources.*

Hoyme, H. E., May, P. A., Kalberg, W. O., Kodituwakku, P., Gossage, J. P., Trujillo, P. M., & Robinson, L. K. (2005). A practical clinical approach to diagnosis of fetal alcohol spectrum disorders: clarification of the 1996 institute of medicine criteria. *Pediatrics, 115*(1), 39–47. doi: 10.1542/peds.2005-0702

Huggins, J. E., Grant, T., O Malley, K., & Streissguth, A. P. (2008). Suicide attempts among adults with fetal alcohol spectrum disorders: Clinical considerations. *Mental Health Aspects of Developmental Disabilities, 11*(2), 33.

Håkansson, A., & Berglund, M. (2012). Risk factors for criminal recidivism–a prospective follow-up study in prisoners with substance abuse. *BMC Psychiatry, 12*(1), 111. doi: 10.1186/1471-244X-12-111

Jones, K.L., & Smith, D.W. (1973). Recognition of the fetal alcohol syndrome in early infancy. *The Lancet, 2,* 999–1012. doi: 10.1016/S0140-6736(73)91092-1

Jones, K., Smith, D., Ulleland, C., & Streissguth, A. (1973). Pattern of malformation in offspring of chronic alcoholic mothers. *The Lancet, 1*, 1267–1271. doi: 10.1016/S0140-6736(73)91291-9

Jonsson, E., Salmon, A., & Warren, K. R. (2014). The international charter on prevention of fetal alcohol spectrum disorder. *The Lancet Global Health, 2*(3), e135–e137. doi: 10.1016/S2214-109X(13)70173-6

Kable, J. A., O'Connor, M. J., Olson, H. C., Paley, B., Mattson, S. N., Anderson, S. M., & Riley, E. P. (2015). Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure (ND-PAE): Proposed DSM-5 Diagnosis. *Child Psychiatry And Human Development.* doi: 10.1007/s10578-015-0566-7

Kerns, K., Don, A., Mateer, C. A., & Streissguth, A. P. (1997). Cognitive deficits in nonretarded adults with fetal alcohol syndrome. *Journal of Learning Disabilities, 30*(6), 685–693. doi: 10.1177/002221949703000612

Kodituwakku, P. W., May, P. A., Clericuzio, C. L., & Weers, D. (2001). Emotion-related learning in individuals prenatally exposed to alcohol: an investigation of the relation between set shifting, extinction of responses, and behavior. *Neuropsychologia, 39*(7), 699–708. doi: 10.1016/S0028-3932(01)00002-1

Koponen, A. M., Kalland, M., & Autti-Rämö, I. (2009). Caregiving environment and socio-emotional development of foster-placed FASD-children. *Children and Youth Services Review, 31*(9), 1049–1056. doi: 10.1016/j.childyouth.2009.05.006

Kotrla, K., & Martin, S. (2009). Fetal Alcohol Spectrum Disorders: A Social Worker's Guide for Prevention and Intervention. *Social Work in Mental Health, 7*(5), 494–507. doi: 10.1080/15332980802466565

Kully-Martens, K., Denys, K., Treit, S., Tamana, S., & Rasmussen, C. (2012). A review of social skills deficits in individuals with fetal alcohol spectrum disorders and prenatal alcohol exposure: Profiles, mechanisms, and interventions. *Alcoholism: Clinical and Experimental Research, 36*(4), 568–576. doi: 10.1111/j.1530-0277.2011.01661.x

Lemoine, P., Harousseau, H., Borteyru, J. P., & Menuet, J. C. (1968). Les enfants de parents alcooliques: Anomalies observees a propos de 127 cas. *Ouest Méd, 21*(2), 476–482.

Mattson, S. N., Crocker, N., & Nguyen, T. T. (2011). Fetal alcohol spectrum disorders: Neuropsychological and behavioral features. *Neuropsychology Review, 21*(2), 81–101. doi: 10.1007/s11065-011-9167-9

Mattson, S. N. and Riley, E. P. (2000), Parent Ratings of Behavior in Children with Heavy Prenatal Alcohol Exposure and IQ-Matched Controls. *Alcoholism: Clinical and Experimental Research, 24*, 226–231. doi: 10.1111/j.1530-0277.2000.tb04595.x

Mattson, S. N., Roesch, S. C., Glass, L., Deweese, B. N., Coles, C. D., Kable, J. A., ... the CIFASD. (2013). Further Development of a Neurobehavioral Profile of Fetal Alcohol Spectrum Disorders. *Alcoholism: Clinical and Experimental Research, 37*(3), 517–528. doi: 10.1111/j.1530-0277.2012.01952.x

May, P. A., Baete, A., Russo, J., Elliott, A. J., Blankenship, J., Kalberg, W. O., ... & Hoyme, H. E. (2014). Prevalence and characteristics of fetal alcohol spectrum disorders. *Pediatrics, 134*(5), 855–866. doi: 10.1542/peds.2013-3319

May, P. A., Blankenship, J., Marais, A. S., Gossage, J. P., Kalberg, W. O., Barnard, R., ... & Seedat, S. (2013). Approaching the Prevalence of the Full Spectrum of Fetal Alcohol Spectrum Disorders in a South African Population-Based Study. *Alcoholism: Clinical And Experimental Research, 37*(5), 818–830. doi: 10.1111/acer.12033

May, P. A., Fiorentino, D., Coriale, G., Kalberg, W. O., Hoyme, H. E., Aragón, A. S., ... & Ceccanti, M. (2011). Prevalence of children with severe fetal alcohol spectrum disorders in communities near Rome, Italy: new estimated rates are higher than previous estimates. *International Journal of Environmental Research and Public Health, 8*(6), 2331–2351. doi: 10.3390/ijerph8062331

May, P. A., Gossage, J. P., Kalberg, W. O., Robinson, L. K., Buckley, D., Manning, M., & Hoyme, H. E. (2009). Prevalence and epidemiologic characteristics of FASD from various research methods with an emphasis on recent in-school studies. *Developmental Disabilities Research Reviews, 15*(3), 176–192. doi: 10.1002/ddrr.68

May, P. A., Keaster, C., Bozeman, R., Goodover, J., Blankenship, J., Kalberg, W. O., ... & Robinson, L. K. (2015). Prevalence and characteristics of fetal alcohol syndrome and partial fetal alcohol syndrome in a Rocky Mountain Region City. *Drug and Alcohol Dependence, 155*, 118–127. doi.org/10.1016/j.drugalcdep.2015.08.006

McInerney, R. J. (2007). *Transfer of learning in children with fetal alcohol spectrum disorder.* ProQuest.

McLellan, A., Cacciola, J. C., Alterman, A. I., Rikoon, S. H., & Carise, D. (2006). The Addiction Severity Index at 25: origins, contributions and transitions. *American Journal on Addictions, 15*(2), 113–124. Swedish version. doi: 10.1080/10550490500528316

Momino, W., Félix, T. M., Abeche, A. M., Zandoná, D. I., Scheibler, G. G., Chambers, C., ... & Schüler-Faccini, L. (2012). Maternal drinking behavior and Fetal Alcohol Spectrum Disorders in adolescents with criminal behavior in southern Brazil. *Genetics and Molecular Biology, 35*(4), 960–965. doi: 10.1590/S1415-47572012000600011

Moore, E. M., & Riley, E. P. (2015). What happens when children with fetal alcohol spectrum disorders become adults?. *Current Developmental Disorders Reports, 2*(3), 219–227. doi: 10.1007/s40474-015-0053-7

Mueller, S. T. (2013). The psychology experiment building language (Version 0.13) (Software). Available at http://pepl.sourceforge.net.

Niccols, A. (2007). Fetal alcohol syndrome and the developing socio-emotional brain. *Brain and Cognition, 65*(1), 135–142. doi: 10.1016/j.bandc.2007.02.009

O'leary, C. M., & Bower, C. (2012). Guidelines for pregnancy: what's an acceptable risk, and how is the evidence (finally) shaping up?. *Drug and Alcohol Review, 31*(2), 170–183. doi: 10.1111/j.1465-3362.2011.00331.x

Olegård, R., Sabel, K.G., Aronson, M, Sandin, B., Johansson, P.R., Carlsson, C., Kylleman, M., Iversen, K., & Hrbeck, A. (1979). Effects on the child of alcohol abuse during pregnancy. *Acta Paediatrica Scandinavica, 275*,112–121. doi: 10.1111/j.1651-2227.1979.tb06170.x

Olsson, M., Hansson, K., Lundblad, A.-M. and Cederblad, M. (2006). Sense of coherence: definition and explanation. International Journal of Social Welfare, 15:219–229. doi: 10.1111/j.1468-2397.2006.00410.x

Popova, S., Lange, S., Bekmuradov, D., Mihic, A., & Rehm, J. (2011). Fetal alcohol spectrum disorder prevalence estimates in correctional systems: a systematic literature review. *Canadian Journal of Public Health/Revue Canadienne de Santé Publique*, 336–340.

Rasmussen, C., Wyper, K., & Talwar, V. (2009). The relation between theory of mind and executive functions in children with fetal alcohol spectrum disorders. *Canadian Journal of Clinical Pharmacology, 16*(2), e370–e380.

Raven, J., Raven, J. C., & Court, J. H. (1998). *Manual for Raven's progressive matrices and vocabulary scales.* Oxford: Oxford Psychologists Press Ltd.

Riley, E. P., Infante, M. A., & Warren, K. R. (2011). Fetal alcohol spectrum disorders: An overview. *Neuropsychology Review, 21*(2), 73–80. doi: 10.1007/s11065-011-9166-x

Sameroff, A. (2009). The transactional model. American Psychological Association.

Socialstyrelsen (2007). Nationella riktlinjer för missbruks- och beroendevård: Vägledning för socialtjänstens och hälso- och sjukvårdens verksamhet för personer med missbruks- och beroendeproblem. Stockholm: Socialstyrelsen.

Sparrow, S. S., Cicchetti, D. V., & Balla, D. A. (1989). The vineland adaptive behavior scales. *Major Psychological Assessment Instruments, 2,* 199–231.

Spohr, H. L., Willms, J., & Steinhausen, H. C. (2007). Fetal alcohol spectrum disorders in young adulthood. *The Journal of Pediatrics, 150*(2),175–179. doi: 10.1016/j.jpeds.2006.11.044

Stevens, S. A. (2012). *Social Cognition: Theory and Neuroscience in Fetal Alcohol Spectrum Disorders* (Doctoral dissertation, University of Toronto).

Stevens, S. A., Dudek, J., Nash, K., Koren, G., & Rovet, J. (2015). Social perspective taking and empathy in children with fetal alcohol spectrum disorders. *Journal of the International Neuropsychological Society, 21*(01), 74–84. doi: 10.1017/S1355617714001088

Stone, V., & Baron-Cohen, S. (2010). Faux Pas recognition test. Adult version.

Streissguth, A. (1993). Fetal alcohol syndrome in older patients. *Alcohol and Alcoholism*, Supplement. 2, 209–12.

Streissguth, A. (2007). Offspring effects of prenatal alcohol exposure from birth to 25 years: The seattle prospective longitudinal study. *Journal of Clinical Psychology in Medical Settings, 14*(2), 81–101. doi: 10.1007/s10880-007-9067-6

Streissguth, A. P., Aase, J. M., Clarren, S. K., Randels, S. P., LaDue, R. A., & Smith, D. F. (1991). Fetal alcohol syndrome in adolescents and adults. *JAMA, 265*(15), 1961–1967. doi: 10.1001/jama.1991.03460150065025

Streissguth, A. P., Bookstein, F. L., Barr, H. M., Sampson, P. D., O'Malley, K., & Young, J. K. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effects. *Journal of Developmental & Behavioral Pediatrics, 25*(4), 228–238. doi: 10.1097/00004703-200408000-00002

Streissguth, A. P., Barr, H. M., Kogan, J., & Bookstein, F. L. (1996). Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE). Final Report to the Centers for Disease Control and Prevention (CDC). Seattle: University of Washington, Fetal Alcohol and Drug Unit.

Strömland, K. (1984). Ocular abnormalities in the fetal alcohol syndrome. *Acta Ophthalmologica. Supplement, 171*, 1–50.

Strömland, K. (1987). Ocular involvement in the fetal alcohol syndrome. *Survey of Ophthalmology, 31*(4), 277–284. doi: 10.1016/0039-6257(87)90028-2

Strömland, K., & Hellström, A. (1996). Fetal alcohol syndrome – an ophthalmologic and socioeducational prospective study. *Pediatrics, 97*, 845–850

Swedish National Board of Health and Welfare. (2013) Record Processing commissioned by the government.

Sydsjö, G., & Wadsby, M. (2003). Period prevalence and types of psychosocial risk factors in pregnant women in an urban Swedish community. *International Journal of Social Welfare, 12*(4), 302–306. doi: 10.1111/1467-9671.00284

Szönyi, K. (2005). *Särskolan som möjlighet och begränsning: elevperspektiv på delaktighet och utanförskap*. Doctoral thesis. Stockholm: Stockholm University

Söderstrand, P. (2010). “Faux Pas” test. Swedish adult version. Retrieved February, 2013, from http://www.autismresearchcentre.com/tests/faux-pas_test_adult.asp.

Temple, V. K., Ives, J., & Lindsay, A. (2015). Diagnosing FASD in adults: the development and operation of an adult FASD clinic in Ontario, Canada. *Journal of population therapeutics and clinical pharmacology = Journal de la thérapeutique des populations et de la pharamcologie clinique, 22*(1), e96.

Tideman, M. (2000). *Normalisering och kategorisering: om handikappideologi och välfärdspolitik i teori och praktik för personer med utvecklingsstörning*. Doctoral thesis. Gothenburg: University of Gothenburg

Tøssebro, J., & Lundeby, H. (2002). *Å vokse opp med funksjonshemming: de første årene*. Gyldendal Akademisk.

Victor, A., Wozniak, J. R., & Chang, P. N. (2008). Environmental correlates of cognition and behavior in children with fetal alcohol spectrum disorders. *Journal of Human Behavior in the Social Environment, 18*(3), 288–300. doi: 10.1080/10911350802427605

Vinnerljung, B., & Sallnäs, M. (2008). Into adulthood: A follow-up study of 718 young people who were placed in out-of-home care during their teens. *Child & Family Social Work, 13*(2), 144–155. doi: 10.1111/j.1365-2206.2007.00527.x

Vinnerljung, B., Öman, M., & Gunnarson, T. (2005). Educational attainments of former child welfare clients – A swedish national cohort study. *International Journal of Social Welfare, 14*(4), 265–276. doi: 10.1111/j.1369-6866.2005.00369.x

Wechsler, D. (1997). *Wechsler Adult Intelligence Scale – revised manual.* New York: Psychological Corporation.

Wellman, H. M. (2010). Developing a theory of mind. *The Wiley-Blackwell handbook of childhood cognitive development, 2*, 258–284.

Welsh, M. C., Pennington, B. F., & Groisser, D. B. (1991). A normative-developmental study of executive function: A window on prefrontal function in children. *Developmental Neuropsychology, 7*(2), 131–149. doi: 10.1080/87565649109540483

World Health Organization. (2011). *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.

Yáñez-Téllez, G., Romero-Romero, H., Rivera-García, L., Prieto-Corona, B., Bernal-Hernández, J., Marosi-Holczberger, E., ... & Rodríguez-Camacho, M. (2012). Funciones cognoscitivas y ejecutivas en el TDAH. *Actas Españolas de Psiquiatría, 40*(6), 293–298.

FETAL ALCOHOL SYNDROME IN ADULTHOOD

Psychological, psychosocial, and neuropsychological aspects of life in individuals who were prenatally exposed to alcohol

Alcohol's teratogenic effect on the developing fetal brain is devastating, resulting in, for instance, structural abnormalities as well as behavioral and neuropsychological impairments in the child. The umbrella term Fetal Alcohol Spectrum Disorders (FASD) is used to describe the range of effects, from neuropsychological dysfunctions to complete Fetal Alcohol Syndrome (FAS). The disabilities associated with FAS have a major impact on life for children, and perhaps even in adulthood. The overall aim of this thesis was to investigate the psychological, psychosocial and neuropsychological consequences of FAS in adulthood. The findings contribute to the general knowledge about prenatal exposure to alcohol, and the long-term persisting consequences. Particularly, it shows that early detection of children with FAS, followed by a broad spectrum of interventions from social welfare authorities, might prevent criminality and substance abuse in adulthood. It also demonstrates some of the psychological, psychosocial, and neuropsychological difficulties it might entail for an individual with FAS living an adult life. Thus, seen from a societal perspective, interventions to prevent FASD are of utmost importance.

Jenny Rangmar

ISSN: 1101-718X
ISRN: GU/PSYK/AVH--340--SE
ISBN: 978-91-628-9862-5
ISBN: 978-91-628-9863-2