

International Library of Ethics, Law, and the New Medicine 63

Monty Nelson
Marguerite Trussler *Editors*

Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives

An Overview on FASD for Professionals

 Springer

Contents

Part I Ethical Considerations and Implications in FASD

Fetal Alcohol Spectrum Disorder: Ethical, Legal and Moral Implications Associated with the Rights of the Unborn Child	3
Jenny Salmon	
Why People with FASD Fall for Manipulative Ploys: Ethical Limits of Interrogators' Use of Lies	23
Stephen Greenspan and John H. Driscoll	
Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure: Consumer Protection and the Industry's Duty to Warn	39
Susan D. Rich and Laura J. Riley	
Experience in Involuntary Hospitalisation of Drug and Alcohol Addicted Mothers During Their Pregnancies at Borgestadklinikken, Norway	49
Egil Nordlie	
Is It Ethical to Condone Low Levels of Drinking in Pregnancy?	65
Janni Niclasen	
Ethical Challenges When Screening for and Diagnosing FASD in Adults	85
Ilona Autti-Rämö	

Part II Clinical Perspectives on Criminal Behaviour in FASD

Neurocognitive Difficulties Underlying High Risk and Criminal Behaviour in FASD: Clinical Implications	101
Katherine Wyper and Jacqueline Pei	

Medico-Legal Interventions in Management of Offenders with Fetal Alcohol Spectrum Disorders (FASD)	121
Mansfield Mela	

Oral Language and Communication Factors to Consider When Supporting People with FASD Involved with the Legal System	139
Linda Hand, Megan Pickering, Sally Kedge and Clare McCann	

Part III Judicial Perspectives

Evolution of the Diagnosis of Fetal Alcohol Spectrum Disorder from DSM-IV-TR to DSM-5: The Justice System in the United States—Time for a Paradigm Shift!	151
Anthony P. Wartnik, Jerrod Brown and Sarah Herrick	

Smart Justice and FASD in Alaska: From Prevention to Sentence Mitigation	169
Teri Tibbett and Michael I. Jeffery	

FASD & Justice: The Ethical Case for Effective Training and Knowledge Mobilization Practices for Frontline Justice Professionals in Canada	191
Michelle Stewart	

Part IV Social and Policy Issues

Social Care and Fetal Alcohol Spectrum Disorders in the UK	209
Alison McCormick	

FASD in a Canadian Aboriginal Community Context—An Exploration of Some Ethical Issues Involving the Access to FASD Service Delivery	223
Lori Vitale Cox	

FASD and the Concept of “Intellectual Disability Equivalence”	241
Stephen Greenspan, Natalie Novick Brown and William Edwards	

Part V Personal Perspectives and Stories

Minimizing Secondary Disabilities 269
Inger Thormann

The Challenges of Raising an FASD Child in Canada 285

I Did not Take on This Job of Parent in Order to Raise Criminals 293
Dianne O'Connor

Editors and Contributors

About the Editors

Monty Nelson Ph.D. has been a psychologist in Edmonton, Alberta, Canada since 1998. He is also an Adjunct Assistant Professor of Educational Psychology at the University of Alberta. He is in full-time private practice conducting neuropsychological assessments in Edmonton, rural Alberta, and the northern territories. He has been a consultant for various adult FASD clinics since 2008. In collaboration with the Lakeland Centre for FASD he also does training for other clinicians about the FASD diagnostic process. He has presented at provincial, national, and international conferences on assessments of adults with FASD.

Marguerite Trussler B.A., LL.B., LL.M., LL.D. (Hon.), Q.C. was a justice of the Court of Queen's Bench for 20 years. Following her retirement she became the chair of the Alberta Gaming and Liquor Commission where she developed an interest in the issues surrounding FASD. For a number of years, she chaired the Institute of Health Economics' steering committee for the Alberta initiatives on FASD and was the moderator of the Institute's 2013 consensus conference on Legal Issues of FASD. Since May of 2014, she has been the Ethics Commissioner for the Legislature of the Province of Alberta, Canada.

Contributors

Iiona Autti-Rämö is a pediatric neurologist with 30 years of clinical and research experience in FASD. She has been the secretary for the national screening committee and was involved in developing ethical evaluation of screening programs on national and EU level. She is currently the medical director at the Social Insurance Institute of Finland in Helsinki.

Jerrod Brown MA, MS, MS, MS is the Treatment Director for Pathways Counseling Center in St. Paul, Minnesota, USA. Jerrod is also the founder and CEO of the American Institute for the Advancement of Forensic Studies (AIAFS) and is the lead developer and program director of an online graduate degree program in Forensic Mental Health from Concordia University in St. Paul.

Natalie Novick Brown Ph.D. is a clinical and forensic psychologist in Seattle, Washington, USA. She is a founding partner of FASD Experts, through which she has evaluated numerous criminal defendants who have FASD. She has an adjunct appointment at the University of Washington, and is known for her scholarly work on suggestibility and executive functioning in people with FASD.

Lori Vitale Cox Ph.D. is from the Elsipogtog First Nation, NB, Canada. She is the Clinical Coordinator of the Eastern Door Diagnostic Team and the Director of the Nogemag Healing Lodge for Youth at Risk. She is also the author of “Medicine Wheel Tools for Screening, Diagnosis and Intervention of FASD” which was included in the Public Health Agency of Canada FASD Screening Toolbox.

John H. Driscoll Ph.D. is a school psychologist for the Vernon Connecticut (USA) Public Schools, and adjunct assistant professor of educational psychology at the University of Connecticut, where he teaches graduate courses in psychological assessment. He often testifies in civil legal proceedings, and has done research on the cognitive challenges facing youths involved in police interrogations.

William Edwards J.D. is a Deputy Public Defender in Los Angeles County, California, USA, where he spent several years representing people with FASD in the LA Mental Health Court. He served two consecutive terms on the US President's Committee on Intellectual and Developmental Disabilities, and has lectured on FASD to attorneys and judges around the world. He edited a two-issue special volume on FASD for the Journal of Psychiatry and Law.

Stephen Greenspan Ph.D. is emeritus professor of educational psychology at the University of Connecticut, and now resides in Colorado, USA. His writings and testimony on social vulnerabilities of people with intellectual disabilities involved in criminal justice proceedings won recognition from the American Association on Intellectual and Developmental Disabilities, which awarded him its Gunnar and Rosemary Dybwad Award for Humanitarianism.

Dr. Linda Hand is an experienced speech–language therapist in New Zealand. Sally, Linda and Clare have formed the Talking Trouble NZ Project which focuses on language and communication issues for children and young people involved (or at risk of becoming involved) in the legal system. Talking Trouble NZ is developing a range of projects involving research, professional development, speech–language therapy clinical services for children and young people and advocacy. Megan works clinically with children and young people with FASD.

Sarah Herrick MA, LP, LPCC, CCFC has worked with sexual abusers ranging in age from ten to the elderly since 1991, in residential, community mental

health, and secured settings. Currently, she is working with civilly committed sexual abusers and is an adjunct professor with Concordia University's (St. Paul, MN, USA) Forensic Mental Health on-line graduate program.

Michael I. Jeffery J.D. was a Superior Court Judge who retired in 2014 after a 32-year judicial career at Barrow, Alaska, USA. He adapted his court activities for FASD-affected persons. He assisted with Alaska's FASD mitigating factor legislation and is a member of statewide committees dealing with FASD and juvenile justice. He graduated from Stanford University and Yale Law School.

Sally Kedge is an experienced speech–language therapist in New Zealand. Sally, Linda and Clare have formed the Talking Trouble NZ Project which focuses on language and communication issues for children and young people involved (or at risk of becoming involved) in the legal system. Talking Trouble NZ is developing a range of projects involving research, professional development, speech–language therapy clinical services for children and young people and advocacy. Megan works clinically with children and young people with FASD.

Dr. Clare McCann is an experienced speech–language therapist in New Zealand. Sally, Linda and Clare have formed the Talking Trouble NZ Project which focuses on language and communication issues for children and young people involved (or at risk of becoming involved) in the legal system. Talking Trouble NZ is developing a range of projects involving research, professional development, speech–language therapy clinical services for children and young people and advocacy. Megan works clinically with children and young people with FASD.

Alison McCormick (Ali) is a qualified GSCC Registered, Post Graduate Social Work Consultant living in Huntingdonshire, England. Her Social Work experience includes Management, Child Protection and Investigation, Care Management, Bereavement, Adoption and Fostering, Therapy and Behavior Management, as well as writing and training. She also speaks at Conferences and was previously a Children's Guardian advising and advocating for legal rights of children in Care Proceedings. She has also chaired the Birmingham Independent Review Mechanism Panel (IRM) for 8 years.

Dr. Mansfield Mela is an academic forensic psychiatrist in the University of Saskatchewan and a Founder of the forensic subspecialty in Canada. He consults at the Regional Psychiatric Center and the Saskatoon forensic psychiatric outpatient clinic in Saskatoon, Saskatchewan, Canada. He is a member of the Saskatchewan Review Board and is the head of the forensic interdisciplinary research team. His research focuses on the medicolegal implications of cognitive disorders, specifically fetal alcohol spectrum disorder and ADHD.

Janni Niclasen Ph.D. is a psychologist and an assistant professor at the Department of Psychology, University of Copenhagen, Denmark. Janni is a researcher with a particular interest in and knowledge about prenatal exposure to low doses of alcohol and child neurodevelopment.

Egil Nordlie became a Physician in 1972, in Oslo, Norway. Since 1978 he has been the chief physician at Borgestadklinikken, in Skien, Norway, one of the country's largest institutions for patients with alcohol and drug problems. Since the 1990s, he has been responsible for the units for pregnant women with addictions and for involuntarily hospitalized pregnant women. He has done research, written articles, and lectured nationally and internationally about these programs, as well as other topics related to alcohol and drug related problems.

Dianne O'Connor and her husband, Mickey, are the parents of nine children, six of whom have varying degrees of Fetal Alcohol Spectrum Disorders and are now young adults. Dianne is a board member of the NYS Citizen's Coalition for Children and is currently a kinship caregiver for two of her grandchildren.

Jacqueline Pei Ph.D. is an Associate Professor in the Department of Educational Psychology and Assistant Clinical Professor in the Department of Pediatrics at the University of Alberta in Edmonton, Canada. Also a practicing Registered Psychologist, Dr. Pei began her career as a criminologist and has continued in this vein, studying youth at risk, and interventions for those with FASD. Dr Pei currently leads the Intervention Network Action Team (iNAT) for the Canada FASD Research Network.

Megan Pickering is an experienced speech–language therapist in New Zealand. Sally, Linda and Clare have formed the Talking Trouble NZ Project which focuses on language and communication issues for children and young people involved (or at risk of becoming involved) in the legal system. Talking Trouble NZ is developing an a range of projects involving research, professional development, speech–language therapy clinical services for children and young people and advocacy. Megan works clinically with children and young people with FASD.

Susan D. Rich MD, MPH is a board certified psychiatrist specializing in diagnosis and treatment of Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure (ND-PAE) in her clinical and forensic practice in Potomac, Maryland, USA. She has promoted the need for recognition of ND-PAE through psychiatric publications, national conference lectures, and grand rounds at universities.

Laura J. Riley is an attorney working on gender discrimination issues at the California Women's Law Center with a background in disability rights and employment law. She graduated from Columbia University before attending Law School at the University of Southern California where she developed an interest in studying the intersection of Fetal Alcohol Syndrome and the law through a class on Mental Health Law taught by Elyn Saks. She is from Los Angeles, California, USA.

Dr. Jenny Salmon is a social scientist and researcher in the FASD field in Dunedin, New Zealand. She is also a Member of the University of Otago Centre for Research on Children and Families—research cluster.

Michelle Stewart Ph.D. is an Assistant Professor in Justice Studies at the University of Regina, Saskatchewan, Canada. Her research interests center on policing practices with a focus on political anthropology, social justice and science and technology studies. Her current research investigates risk and prevention with attention to FASD, including how risk and diagnostic tools can influence the ways in which FASD is understood in particular communities of practices.

Inger Thormann MA is a psychologist from Copenhagen, Denmark. Since 1973 Inger has worked with neglected and abused children, including the past 30 years at the observation and treatment centre Skodsborg Observations- og Behandlingshjem for infants. Inger has authored books for professionals and children and is active as a film consultant, lecturer and teacher. Inger co-founded the Dansk Institut for Spædbarnsterapi (Danish Institute for Infant Therapy) together with psychotherapist Inger Poulsen; they also recently co-authored the book “Therapy with Infants”.

Teri Tibbett BLA, MFA is a writer living in Juneau, Alaska, USA. She was a legislative aide with the Alaska State Legislature and is the advocacy coordinator for the Alaska Mental Health Board and Advisory Board on Alcoholism and Drug Abuse. She works closely with the Alaska Mental Health Trust Authority and other stakeholders, and serves as the coordinator of the Alaska Fetal Alcohol Spectrum Disorders (FASD) Partnership.

Anthony P. (Tony) Wartnik was a trial judge in the United States for 34 years. He chaired the Washington State Governor’s Advisory Panel on FAS/FAE and conducted training for judges on FASD. Tony is in Seattle, Washington, USA, and is recognized nationally and internationally as an expert on issues involving FASD and the Justice System, and the Law and related issues.

Katherine Wyper M.Ed. is a doctoral student in the Department of Educational Psychology at the University of Alberta, in Edmonton, Canada. Her research and clinical interests focus on the neurocognitive factors that underlie high risk and criminal behaviors in youth and adults, and she has a particular interest in Fetal Alcohol Spectrum Disorder.

Minimizing Secondary Disabilities

Inger Thormann

Primary and Secondary Disabilities Stemming from FASD

While most people understand what a brain injury involves when it occurs after birth, prenatal brain injury is a different matter. There is no before-and-after behavior to compare, and many find it difficult to understand the severe impairments that may occur as a result of FASD. At birth, the symptoms may be vague and diffuse. They may even go unnoticed or be confused with the temporary after-effects of a difficult delivery or the mother's medication prior to the delivery. When the child begins to display more obvious atypical behaviors, the explanation is often not sought in prenatal factors but in postnatal trauma.

Alcohol exposure during pregnancy may disturb normal cell division and the migration of brain cells. This may cause structural anomalies in brain development. Another possible consequence of fetal alcohol exposure is a disturbance of the brain's electrophysiological and neurochemical balance. As a consequence, messages are not conveyed as efficiently and as accurately as they should be and normally are. In some children with fetal alcohol effects, impaired connectivity in the brain causes brain receptors to receive erroneous messages.

It is, however, difficult to measure the structural and functional brain processes in large numbers of individuals with FASD. Instead, researchers and practitioners have relied on psychological testing to measure primary disabilities. This includes IQ tests, performance tests, adaptive behavior tests and behavioral observations as well as interviews with caretakers.

I. Thormann (✉)
Copenhagen, Denmark
e-mail: ingerthormann@yahoo.dk

Studies of Primary and Secondary Disabilities

The Fetal Alcohol and Drug Unit at the University of Washington in Seattle has published three longitudinal studies of children with Fetal Alcohol Syndrome. Although these studies focus on primary disabilities, they also provided a glimpse of what was later termed *secondary disabilities*.

The first study—a ten-year follow-up study (Streissguth et al. 1985)—involved a group of eight children, who were among the first eleven children ever to be diagnosed with what was then termed fetal alcohol syndrome (FAS). Of the remaining three, two had passed away before the study, and one was unavailable for follow-up. The study found that the four persons who had an IQ below 70 were in better and more appropriate educational programs and led more stable lives than the four who had a higher IQ.

The four individuals who had an IQ above 70 were not officially categorized as having an intellectual disability, and they were not seen as having immediate problems or being at risk of developing future problems. However, they all had FAS.

One of the boys dropped out of school for an extended period; he resumed his education when he relocated to another state. One girl dropped out in mid-term and had a baby soon after. Another girl left after 9th grade and became a single mother. Only one of the four stayed in school.

These observations inspired a second study (Streissguth et al. 1991) focusing on adults and adolescents over 12 years of age, the age when children with FASD typically encounter problems, both at home and in school. The subjects were 61 adolescents and adults aged 12–40 years, all with FAS or fetal alcohol effects (FAE). Despite a mean chronological age around 17 years, the mean developmental age (Vineland Adaptive Behavior Scale) was 7 years. Academically, the group performed as expected: although some had reading and spelling skills at a 5th-grade level or slightly higher, the average level was 2nd–4th grade. The group's arithmetic skills lagged even further behind.

The 61 adolescents and adults were tested on three domains:

1. *Daily living skills*, which includes personal hygiene, cooking, cleaning, keeping doctor's and dentist's appointments, managing one's personal budget, personal safety.
2. *Socialization*, which includes appropriate interactions with others, friendships, visitors, contact with family, verbal communication skills.
3. *Communication skills*, which includes shopping, going to the post office, the library and the bank, dealing with public transport, securing positive contacts/neighborly relations.

The group performed best on daily living skills (mean at the nine-year level) and most poorly on socialization skills (mean around the six-year level). A few had age-appropriate daily living skills; none had age-appropriate socialization or communication skills.

As a group, the subset who did *not* have an intellectual disability, according to their IQ score, still had problems with considering the consequences of their actions, displaying appropriate initiative, responding appropriately to subtle social cues and establishing and maintaining reciprocal friendships.

Study Findings and the Development of Secondary Disabilities

Ann Streissguth has carried out numerous studies, and during the 1990s her findings caused her to take a growing interest in secondary disabilities.

She identified the following key challenges typically faced by persons with FASD:

1. *Poor judgment*, which puts them at increased risk of victimization
2. *Attention difficulties*, which causes them to lose focus often and be distracted
3. *Math problems*, which makes it hard for them to handle money
4. *Memory problems*, which makes it hard for them to learn from their experiences
5. *Difficulties with abstract thinking*, which makes it hard for them to consider consequences of their actions
6. *Problems with orientation in time and space*, which makes social interactions challenging
7. *Problems with control/impulsive behavior*, which leads to a low frustration threshold

These seven points describe the link between some of the cognitive impairments in persons with FASD and the resulting everyday challenges.

When these problem behaviors are exhibited by a person who clearly appears to have an intellectual disability, they hardly surprise us. In fact, we might feel sympathy and wish to offer some sort of care or support. However, these behaviors are much harder to accept from a person who otherwise speaks and acts normally, and who does not appear to have an intellectual disability, either to a casual observer or in a formal IQ assessment. Some of the spontaneous reactions might be, “He’s no Einstein!”—“Where does he get off?!”—“What horrible manners,” or “Is this your idea of a joke?!”

Faced with a discrepancy between *how people behave* versus *how we expect them to behave*, we are left to draw our own conclusions. This is an example of the fundamental attribution error or correspondence bias, a term known from social psychology. If the person had recently been in a motor accident, we would probably associate the unexpected behavior with brain injury. But in the absence of a visible explanation, the average person is not likely to consider the presence of a brain injury. Knowledge of the diagnosis or about the manifestations of prenatal alcohol exposure, however, will probably enable the observer to arrive at a correct hypothesis.

It is this discrepancy between *the behavior we expect* of children, youths and adults with fetal alcohol effects and *the behavior we see from them* that shapes the climate for secondary disabilities. Other secondary disabilities may stem more directly from the children's experiences growing up and from their inability to look out for themselves. Ann Streissguth argues that some of the secondary effects could be mitigated if we had a better understanding of the primary effects.

In 1996, Ann Streissguth and her colleagues published a large-scale study of secondary disabilities (Streissguth et al. 1996). The study included 415 persons with FASD aged 6–51 years.

The study examined six secondary disabilities:

1. *Mental health problems*, defined as having received treatment for one or several disorders, for example attention deficit disorder/hyperactivity (ADHD), depression or contemplating or attempting suicide, panic reactions, psychoses (hallucinations), aggressive or obstinate behavior, sexual depravity etc.
2. *Disrupted school experience*, defined as being suspended or expelled or dropping out.
3. *Trouble with the law*, defined as involvement with the police or being charged or convicted of crime.
4. *Confinement*, defined as incarceration in the justice system or inpatient treatment for mental health problems or substance abuse.
5. *Inappropriate sexual behavior*, defined as repeated problematic sexual behaviors, for example sexual advances, sexual touching, promiscuity, exposure, compulsions, voyeurism, masturbation in public or incest, including convictions for sexual offences.
6. *Alcohol and drug problems*, defined as abuse of alcohol or drugs and inpatient treatment for substance abuse.

Mental health problems: More than 90 % of the children, adolescents and adults who took part in the study had mental health problems, and more than 80 % had received treatment. Among the children and adolescents, attention deficit disorder was the dominant issue, while depression was the most prevalent issue among the adults (more than 50 %).

Disrupted school experience: More than 60 % of the adolescents and adults had a disrupted school experience. Surprisingly, the same was true for 14 % of the children. Suspension was the most frequent occurrence across the age groups, but among adults, dropping out was a close second (almost 40 %). Individuals with a disrupted school experience were twice as likely to encounter learning and behavioral problems as the rest of the group. The most common problems across the age groups were failing to pay attention (70 %) and incomplete homework (55–60 %). The most common behavioral problem was being disruptive in class (55–60 %) and not getting along with peers (60 %).

Trouble with the law: 60 % of the young adults and as many as 14 % of the children had had trouble with the law, with shoplifting as the most common offence. Among adolescents and adults above 12 years of age, 60 % were referred to the

juvenile justice system, and more than 40 % were given juvenile prison sentences; 46 % received a suspended sentence, and 39 % were sentenced to community service. The study found a clear correlation between a disrupted school experience and trouble with the law.

Confinement (incarceration or involuntary hospitalization or treatment): 50 % of the adolescents and adults but fewer than 10 % of the children had experienced some sort of confinement.

Inappropriate sexual behavior: 49 % of the adolescents and adults and 39 % of the children displayed inappropriate sexual behavior, which makes this category the second-most common secondary disability for children. The most common inappropriate sexual behaviors were sexual advances (18 %), sexual touching (16 %) and promiscuity (16 %).

Alcohol and drug problems: 35 % of the adolescents and adults (and none of the children) had problems in this area. Many in the surveyed group were completely abstinent. The most common reason stated for abstinence was lack of access to alcohol followed by personal conviction.

Ann Streissguth and her team were greatly surprised by the prevalence of secondary disabilities and the *detrimental effect on the individual person's quality of life*. Undoubtedly, better protection and support for this group of children, adolescents and adults requires increased understanding among teachers, caretakers, social workers and society at large.

As mentioned earlier, the permanent organic brain damage in individuals with FASD is often invisible, and the impairment does *not* automatically lead to special needs education or assistance. Unless the person in question has a severe intellectual disability or a very distinct physical characteristics, any educational or social support requires a presentation of some sort of evidence.

Risk Factors and Protective Factors in Relation to Secondary Disabilities

In order to understand the findings of the study fully, we need to examine the risk factors and the protective factors that affect the severity of the secondary disabilities; *risk factors* being anything that exacerbates the secondary disabilities, and *protective factors* being anything that mitigates the secondary disabilities.

In their analysis, Streissguth, Barr et al. identified five protective factors that had a universal preventive effect on the development of secondary disabilities:

1. a stable home with nurturing parents
2. a minimum of change in home and life environment
3. protection from violence
4. eligibility for special needs services
5. early diagnosis

A clear trend in the study was that those with the *lowest* level of primary impairments—those participants who did not have the full FAS diagnosis and who did not have an intellectual disability—faced the greatest difficulties and were most likely to encounter problems. The study also addressed the key issues of how children with FAE or FAS can develop resilience, and which factors can help reduce their secondary disabilities.

The evidence suggests that *resilience* develops in an environment that is simultaneously *protective* and *stimulating*, and which remains consistent over time. That sort of environment promotes the child's emotional and cognitive development.

A child with FAE/FAS generally has trouble dealing with change. The brain injury impairs the child's ability to understand and handle changes or replacements among key persons such as foster parents, caretakers and teachers.

Even if secondary disabilities cannot be avoided altogether, the risk can be minimized. Inadequate protective measures are the greatest risk factor.

Children and adolescents with less pronounced and obvious presentations of FASD symptoms are especially at risk of missing out on protective measures. Based on "normal" expectations, these children and youths are typically placed in mainstream classrooms rather than in individualized special needs programs. This means that the child/youth misses out on protective factors.

"Normal" expectations are also in play when the young person begins to go out, starts dating or moves away from home. To reduce the risk of secondary disabilities, the responsible caretakers need to use the knowledge that is available. Special needs education should always be a consideration, and specific programs should be explored. Similarly, when the young person moves away from home, both Streissguth's studies and my own study indicate that the demands and stress factors that the young person faces are greater than previously assumed. Therefore, some form of assisted living should be considered.

These aspects were considered for all the participants in the case study (Thormann 2006) reviewed below, including Martin.

Case: Martin

Martin comes to live at the Danish observation and treatment center *Skodsborg Observations- og Behandlingshjem* (SOBH) at the age of 4½ years. Until then he has been living with his alcoholic mother. He comes to the attention of Child Protective Services after he has spent three days alone in the apartment, when a neighbor eventually responds to his crying. At SOBH, Martin undergoes thorough observation and assessment, which concludes that his symptoms stem mainly from profound early neglect.

Martin is restless and hyperactive and has severe concentration problems. Occasionally, he retreats inside himself. He rocks his upper body back and forth, even in his sleep. Enveloped in his own sounds and movements, he sometimes retreats into his own world and is assessed as highly vulnerable. When he

withdraws into his own world he is extremely sensitive to physical touching and easily startled.

In many areas, Martin is assessed to have age-appropriate skills when he receives adult support. He is extremely sensitive to sensory stimuli and unable to block out irrelevant stimuli; as a result, he is easily overstimulated.

Martin stays at SOBH from the age of 4½–6 years. He is found to have a very high anxiety level. Many things frighten him, especially new things and sounds. When he notices an unfamiliar sound he is unable to settle down until he has identified the source of the sound. Martin is wary of unfamiliar people. When he is scared he wraps both hands around his head for protection.

Martin develops an emotional bond with his primary caretaker, and his soft and loving side comes out more and more as he feels more secure. He needs support to stay focused on tasks and requires affirmation and ongoing adult support to complete them. Martin is a big boy with a strong appetite; he eats a lot and has a tendency to “suck” his food down, almost relying on sucking reflexes. He has to be reminded to use his teeth.

Martin receives remedial language training and is prompted to use verbal communication, as he is often quick to resort to kicking and hitting in conflict situations. Martin is profoundly affected by turmoil and noise; he says that it makes him nervous. He attends play therapy targeting his anxiety and his relationship with his mother who repeatedly fails to show up for pre-arranged visits. His rocking continues every night. The night watch soothes him. On one occasion his rocking is so pronounced that his bed collapses.

At the age of 6 years and 3 months, Martin is placed in a foster family. Due to his anxious and nervous character, the placement is preceded by a lengthy transition phase. The family already has one foster child and two children of their own. Martin settles in and thrives as the youngest of four children. From the outset, he is welcomed as a lovely and loving boy, and he develops rapidly. However, he remains an anxious boy, and he still rocks in his sleep, sometimes so much that he has to sleep on a mattress next to his foster parents’ bed. A soothing hand can calm him down. Martin says that when he rocks he is often having violent dreams about being abandoned, as he was in real life as a young child. He improves his ability to express himself verbally when he is upset. But even the slightest change or disruption still triggers intense insecurity and anxiety in Martin. He is still a vulnerable boy.

At the age of 7 years, Martin attends kindergarten. Here, he exhibits concentration problems and insecurity and is referred for assessment. The assessment finds concentration problems, poor fine motor skills, poor body coordination and low muscle tone. Martin has a poor sense of space and direction and a reduced sense of his own body. He has a limited awareness of his own position in space and often bumps into others, which leads to conflicts. He is found to be intellectually age-appropriate with good general knowledge. At home, Martin thrives. He is closely attached to his foster parents and feels secure in the family. His biological mother is very happy with the placement and wants for him to stay with the foster family.

His mother still drinks when she is depressed; it is difficult to make appointments with her, and she often fails to show up for visits.

Martin receives remedial assistance in several areas. He is examined by a physiotherapist specializing in sensorimotor issues, and he sees a psychologist. Martin is not good at handling emotional pressure, and he has difficulty putting his feelings into words. Due to his own vague inner structure he needs a structured environment. He has a tendency toward perseveration: He has difficulty breaking a pattern and initiating a new one and finds it hard to vary his strategy in a given situation, even when his current strategy is not working. He sticks to the ineffective approach and generally needs adult support to change course.

Martin is in a mainstream class. The school describes him as follows:

“Bright student, physically restless. He needs space around him, reacts strongly if others get too close. Hypersensitive to sensory stimuli and fragile. Needs adult support. Inner restlessness, hyperactive, loud. Has difficulty learning from his experiences, often repeats exactly the same sequence of events that he just apologized for. According to speech/hearing therapist Martin has language difficulties as a result of poor oral motor skills and poor coordination of cheeks, lips, tongue, pharynx and palate. In school, Martin benefits most from one-on-one sessions with an adult. (This is possible as he has been granted 7–10 weekly remedial lessons). He is motivated but unable to work on his own.”

Martin attends an after-school program. He likes it there and is well liked by both the other children and the staff. In good periods, he is quite good at putting his actions into words. He is kind toward the other children and receptive to their moods. He is also very polite, sometimes excessively so, as he parrots adult language instead of using his own words. In bad periods, Martin has a low tolerance threshold and he might kick and hit the others. His behavior can be quite unpredictable. He requires adult support to avoid acting out and doing harm to himself and others.

In third through seventh grade his development continues along the same trajectory. His foster family is the secure base, where he thrives, and where there are few problems. He enjoys taking part in practical activities and chores.

Mealtime is a recurring source of conflict; his foster sister especially gives him a hard time. He eats nosily but fails to chew his food properly; instead he relies on something akin to sucking reflexes. Martin wants to eat properly but is physically incapable of doing so.

At the age of 11 years, Martin sees a relaxation therapist and for a while his sleep seems to improve, and he appears to be resting better at night. However, he soon reverts to his old pattern.

His extreme sensitivity to noise continues to inhibit him. For example, he is very good at playing the recorder, but he cannot attend music school because of the loud sounds from the other instruments. At the age of 11 years, Martin is evaluated for fetal alcohol effects. His mother's binge drinking in combination with his many neurological symptoms trigger the suspicion, which has in fact been present ever since his first arrival at SOBH at the age of 4½ years. In a week-long assessment procedure, Martin undergoes educational/psychological observation during the day and is also examined by a physician. He is found to be a likable boy who

appears slightly immature and not quite age-appropriate. His face and appearance reflect his Greenlandic origin. A smooth philtrum is the only facial feature to suggest FAS. He is a big and handsome boy with no signs of growth deficiency.

He does however display many of the neurological symptoms typical of congenital alcohol syndrome. Martin is diagnosed with FAE—Fetal Alcohol Effects. The doctor fears that he will encounter increasing problems in his mainstream classroom as his classmates reach a limit for how much they are willing to tolerate, as both they and Martin get older.

Martin has developed a particularly close relationship with his foster father; they share many activities, including gardening, fishing and washing the car. He also has a couple of close friends.

At the age of 12 years, Martin is tested by a psychologist who concludes that Martin is going to be completely dependent on special needs education for the remainder of his school years.

At the age of 13 years, Martin is afraid of going to the bathroom on his own. He imagines rats coming out of the bathroom floor and up from the toilet. When his anxiety becomes overwhelming he sings a particular tune. Martin says that he sometimes hears voices that tell him to do bad things. He fights these voices, but when he has trouble gaining the upper hand with them he grows very anxious and unfocused and begins to sing his special tune. The foster parents are relieved that Martin shares this with them but are also concerned about his hallucinations.

Martin's social skills develop well. He continues to be kind, friendly and well-behaved; sometimes, however, his politeness seems superficial and studied. He seems to thrive in class and enjoys socializing. Despite his learning difficulties, his ability to pay attention and sustain focus in class improves. He continues to receive special needs education in language arts and math.

When Martin is 14 years old, the adults around him are uncertain about his future. Will he be able to continue in a mainstream setting? What sort of support or program might be appropriate?

He has a variety of problems, but his strength is that he is a very loving and kind boy with emotional resources. He is healthy and creative and still enjoys playing the recorder. He has few but close friends, and he has developed socially; in addition, he is handsome and charming. He has deep roots in his foster family and would prefer to stay there *forever*.

Martin lags far behind his classmates. He is still well-liked by his classmates and teachers, and therefore he stays in the same mainstream setting with ten hours of remedial teaching a week. However, Martin appears to be able to benefit most from a vocational path, and the options are investigated. Eventually, Martin begins to attend a socio-educational program with its own school. The program has a residential component, but Martin attends during the day and continues to live at home. Here he receives two school lessons a day; the rest of the time is occupied with workshop activities, including a mechanic's workshop and farming. According to the staff he thrives here and is well-liked. Martin's own assessment is more mixed:

He likes it when the staff sets a clear agenda, which also offers protection, but he is upset when the staff fails to grasp his particular needs.

At the age of 16 years, Martin visits Greenland together with his foster father. The purpose of the trip is to introduce him to his original culture, and the trip is very successful. It gives him a better understanding of his mother's problems in relation to the culture clash she experiences in Denmark.

When Martin is 16½ years old, the idea of continuation school is brought up, and in the summer when he turns 17 he begins at a continuation school for "youths with delayed development". He is motivated to receive help to learn more, to become more "normal", because that is his ultimate goal. He accepts his disability but feels both grief and anger at his reduced opportunities. He worries about the future.

Before Martin goes away to continuation school he asks for help with his rocking. He is embarrassed because his schoolmates can hear it when he rocks at night. He sees a psychiatrist and receives medication, which helps.

The reports from the continuation school are mainly positive, especially for the first six months. After New Year's Martin's difficulties increase. Martin has more and more conflicts with other students, uses bad language and provokes them. He repeatedly misreads social cues and situations, and combined with a hot temper (lack of impulse control), this creates several dangerous situations. In connection with the Easter break he is expelled from school.

Martin feels that he has been treated unfairly, and his foster parents share this view.

After two months at home, Martin finds a job in a salad factory where he chops and packages salads. He is praised for the quality of his work. The factory keeps him on after he has turned 18 and pays him the full adult rate.

Two weeks after Martin's 18th birthday his mother is found dead of alcohol-related causes. This marks the beginning of a difficult time for Martin and his foster family.

Martin thinks back to his childhood, with all its disappointments. He makes it through this difficult time, however, in part by focusing on positive memories about his mother and her original culture.

After a little more than a year at the factory, Martin experiences stress on the job. The machinery is noisy, the scene before his eyes is a blur, and he makes mistakes and is reprimanded. He works for hours without a break, because the salads have to be in the supermarkets by 11 o'clock. Martin starts work at 5 in the morning. His foster parents back his decision to quit, and his foster father helps him find another job, which he still has when the formal case study is concluded.

The new job offers circumstances that suit Martin well. He works alone but is able to request support and guidance when he needs it. The pace is moderate, and he has regular breaks. There is no noisy machinery, and Martin listens to music, which helps him filter out the normal noises that occur in any workplace. The job procedures are simple and concrete, and the result offers a concrete sense of satisfaction. Thus, he is able to hold a regular full-time job. His job is to cut Oasis floral foam into standardized blocks.

In connection with the completion of the case study Martin, now aged 19 years, undergoes a thorough neuropsychological evaluation. Here is a brief excerpt from the neuropsychologist's report:

"In the present neuropsychological evaluation Martin appears an age-appropriate, handsome, well-dressed and charming young man. He appears polite and trusting but with relevant reservation toward strangers. He seems friendly and happy. He speaks in long, well-formed sentences. He has good insight into his own difficulties. He reports that he has trouble maintaining his concentration for sustained periods and that he has problems remembering things. He also reports that he tires easily when he has to concentrate on something. His working style is characterized by a willingness to cooperate with others. He appears to be good at concentrating over time. There are also no indications that he is easily distracted by irrelevant stimuli. Over time, however, there are slight signs that his mental stamina is less than would be expected.

The psychological testing draws a picture of a young man whose general intellectual level is within the normal range, albeit at the lower end of the scale. However, Martin does have certain cognitive disorders. His attention span is short, which makes unable to handle more than a few elements at a time. Furthermore, his mental pace is slow, which slows down his information processing. These problem areas seem to be the cause of his learning and memory problems, as his learning and memory functions for visual and language content per se appear intact. These problem areas are also deemed to be the source of his math problems.

In addition, Martin's thinking is generally characterized by a certain degree of perseveration and lack of flexibility, which limits the degree of complexity and abstraction he is able to handle. Martin's reading skills are fairly good, but spelling continues to be a challenge. The specific cognitive disorders that were identified are seen to be based on brain dysfunctions caused by FAE. Therefore, in a future job, Martin will require specially adapted conditions. These conditions will need to accommodate his tendency toward mental fatigue as well as his specific cognitive difficulties in the form of his lower mental pace, attention problems (low attention span and problems with shared attention, i.e. difficulty varying his attention focus) and his rigid thinking, which limits his capacity for handling more complex and abstract tasks."

Reflections on Martin's Life and Secondary Disabilities

Martin experienced severe neglect before an adequate intervention was put in place. He is noticed, and many people are concerned, but it is not until his mother physically disappears, and the 4-year-old boy is found alone in the apartment after a third consecutive day, when he is taken into care. Previously, there were concerns that Martin may have suffered the congenital effects of prenatal alcohol exposure, but the obvious signs of neglect during the first four years of his life blur the diagnostic image, and he is not diagnosed with FAE until he is 12 years old.

Martin spends almost 2 years at SOBH, and at the age of 6 years he is placed in the foster family where he still lives at age 19. Thus, the early neglect is replaced by convincing care and protection.

In many ways, Martin is a well-adapted boy and young man, but he has problems that are not visible to the outside world. This puts him at risk. Other people

expect the same of him as they do of his peers. Good behavior and good looks do not exactly lower others' expectations of him—on the contrary. This leads to numerous experiences of failure for Martin, despite the high degree of care and protection he has received, especially from his foster parents. Throughout, a consultant from the association of foster homes has offered advice and support, and for several periods a psychological consultant has also been involved, providing individual therapy to Martin and supervision to the foster parents. Thus, many people have acted as Martin's advocates, and much has been done to minimize any secondary disabilities.

As mentioned earlier, Ann Streissguth argues that the basis for secondary disabilities is the gap between *what we expect* from a person with FASD and *what we see this person actually doing*.

At the age of 15 years, Martin repeatedly finds himself in situations where he is reminded of his shortcomings, and he experiences a series of setbacks. This makes him unhappy, and he sheds many tears about his situation. He realizes that he is unable to meet others' expectations of him, and that he is less capable than his peers. He is especially concerned that his memory is so poor, and that he keeps forgetting things. It is not only in the workshop he is reminded daily of his own shortcomings; in his foster family too, he is needled by his foster sister, who is two years his senior and who excels academically in high school.

A few examples may serve to illustrate how secondary disabilities can emerge:

One day, Martin is assisting a mechanic who is working on a car. Without looking up, the mechanic asks Martin to fetch him a pair of pincers. Martin goes over to the wall-mounted tool board with its large array of different tools, but once he gets there he has forgotten what type of tool he is supposed to get. He therefore grabs three tongs at random and puts them in the pocket of his boiler suit. When he returns, the mechanic holds out his hand, and Martin reluctantly hands him one of the tools. In a less than gentle tone, the mechanic lets him know it is the wrong kind. Martin pulls out another tool and then another, but neither is the right kind. The mechanic gets angry and yells, "Is this your idea of a joke?!" This happens in the presence of a couple of Martin's peers. Martin leaves the workshop and takes the bus home to his foster family where he locks himself in his room, crying.

A few weeks later, Martin is once again assisting a mechanic in the workshop. This time the mechanic needs some oil and hands Martin an oil can to be filled up at the oil pump. At the pump, Martin has to punch in a four-digit code, which has been told to him verbally. At the pump Martin finds that he cannot remember the code. He tries various combinations, initially trying to get it right but eventually he desperately tries random combinations. He feels an inner rage and anger toward the mechanic who asked him to do this. On his way back, he trips on a small set of steps; he has a bad fall and has to go to emergency room with chest pains. It turns out that he has broken two ribs.

For several days following the latter incident, Martin remains sullen and withdrawn. He does not want to go back to the workshop. His sick leave offers a natural break. Martin discusses the two incidents with his therapist. They analyze the incidents. What did Martin actually do, and could he have acted differently? At first, Martin is in low spirits, unhappy and despondent. But as the conversation unfolds, he comes up with ideas for alternative approaches: If the mechanic had had a set of cards with pictures of the various tools, Martin could have taken the

card with him to the tool board and found the right one. And if the mechanic had written the code for the oil pump down he would have been able to handle that task too.

Both suggestions are good, but they require the mechanic to learn about the challenges Martin is facing—and why. Subsequently, a series of lessons are arranged for the program staff. Martin gives his consent for this to happen, albeit reluctantly. After all, he really wants to hide his disabilities. What he wants is to be normal.

Martin explains that he easily becomes stressed and nervous. As soon as he is given a task he is overwhelmed with apprehension that he will not be able to handle it; naturally, that makes it harder for him to carry out the task successfully.

When he works with his foster father, things are different. Over several weekends, Martin helped his foster father fix up an old Volvo. When he was shown how to do a particular task he was subsequently able to do it on his own. The hands-on demonstration works much better for him than the spoken word. When the two go hand in hand he does especially well.

As mentioned previously, Martin has difficulty forming visual imagery. When he hears the word *pincers*, as in the example from the workshop, he does not envision the pincers in his mind, so when he stands in front of the cluttered tool board he cannot compare it to his mental image because it was never formed.

If we consider the 15-year-old Martin and his frustration over being treated “wrong”, compared to his abilities, the demands are too high. He is very vulnerable. After the negative incidents, he receives an extra dose of positive attention in his foster family, he sees a therapist, and his employers learn about FASD, and these protective factors help turn the situation around.

But new disappointments and failures await him.

Considerations about the balance between protective factors and demands are always essential in relation to vulnerable individuals. In Martin’s case they are crucial. Martin needs the protection his foster family offers, but he is determined to be normal and wants independence from his over-protective foster parents. When he is a little over 19 years old he moves to Copenhagen to live in an apartment under “supervision” from a social worker. He distances himself from his foster parents. The specific trigger for his decision to move out is Martin’s discovery that he is sexually attracted to other men. He chats online with guys, and this proves too much for his foster parents. Martin feels that their control is excessive, and he moves out.

Martin pursues his goal of normalcy. He is in a stable and loving relationship and finds a full-time job in a supermarket, although he has been advised to limit his work to 24 hours a week. He wants to be able to buy nice clothes, have a trendy haircut and go out. He spends a lot of money and overdraws his credit card. A repayment plan is drawn up that stretches over several years, which is more than Martin can handle. He is put under administration by the bank, and around the same time he loses his job. He is tired and stressed and makes too many mistakes. As the final straw, his boyfriend breaks up with him. Martin gives up and takes his own life, when he is only 22 years old.

To briefly review the research discussed above, mainly by Ann Streissguth and colleagues, we can observe that

- Martin manages his everyday life well when he is in the familiar environment of his foster family
- Martin exhibits all the seven challenges identified by Streissguth and colleagues (poor judgment and difficulties with attention, math, memory, abstract thinking, orientation in time and space and impulse control)
- Of the six most common secondary disabilities Martin only has one: mental health problems
- Martin enjoys all the five protective factors mentioned on page 6 (stable home, stable life environment, protection from violence, special needs services and a relatively early diagnosis)

When a vulnerable young person like Martin with an invisible disability wants to be independent and experience *freedom*, there is no holding him back. He is no longer a minor, and he has the right to self-determination. The demands were too many and too high, and he lost the protection he had enjoyed when he broke with his foster family.

Closing Remarks

A study by Huggins et al. (2008) found that the suicide rate among adults with FASD aged 21–51 years is 23 %. This is five times the rate in the general U.S. population, which is 4.6 %. The high vulnerability in this group reminds us of the need to evaluate the balance between demands and protection constantly. One of our future challenges will be to create environments where people with disabilities can live independently in a context that offers a high degree of protection, for example in the form of a live-in professional.

Let us never waver in our efforts to overcome the secondary disabilities in vulnerable persons, including those with FASD.

References

- Huggins, J.E., T. Grant, K. O'Malley, and A.P. Streissguth. 2008. Suicide attempts among adults with fetal alcohol spectrum disorders: clinical considerations. *Mental Health Aspects of Developmental Disabilities* 11(2): 33–41.
- Rosett, H.L., and L. Weiner. 1984. *Alcohol and the fetus. A clinical perspective*. Oxford: Oxford University Press.
- Streissguth, A.P. 1997. *Fetal alcohol syndrome. A guide for families and communities*. Baltimore: Paul H. Brookes Publishing Co.
- Streissguth, A.P., J.M. Aase, S.K. Clarren, S.P. Randels, R.A. LaDue, and D.F. Smith. 1991. Fetal alcohol syndrome in adolescents and adults. *Journal of the American Medical Association* 265(15): 1961–1967.

- Streissguth, A.P., S.K. Clarren, and K.L. Jones. 1985. Natural history of the fetal alcohol syndrome: A 10-year follow-up of eleven patients. *The Lancet* 13: 85–91.
- 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 on Grant No. R04/CCR008515 (Tech. Report No. 96-16)*. Seattle: University of Washington, Fetal Alcohol and Drug Unit.
- Streissguth, A.P., and J. Kanter. 1997. *The challenge of fetal alcohol syndrome. Overcoming secondary disabilities*. Seattle and London: University of Washington Press.
- Thormann, I. 2006. *Medfødte Alkoholskader. Omsorg og behandling*. Copenhagen: Hans Reitzels Forlag.