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Introduction: Fetal Alcohol Spectrum Disorders (FASD) are the fastest rising cause of childhood disability and special educational needs, representing a unique 21st century challenge. Although recognised in ancient Greece, the full fetal alcohol syndrome was only described by Jones and Smith in 1973 while the range of FASD was recognised in 2000. Carpenter in 2007 lamented ‘the blank sheet of paper on the educational needs’ of children with FASD. Yet this book describes the development of a robust evidence-base for prevention and intervention for the ‘umbrella’ of disorders that teachers and families face with these children who ‘seem to be wired differently’. Teachers describe “he is not like any other boy I have ever taught before”. These are new children who need new solutions. We are faced with ethical challenge: while we accept the high medical cost of interventions that ensure survival of children with complex needs, we fail to provide adequate service infrastructure to support them and their families in the communities. Similarly, few services exist for children with FASD.

A whole population approach is needed to challenge the community ignorance of alcohol harms and the cultural acceptance of excessive alcohol in young women. It is only in recent years that the full impact of alcohol on the developing fetus has been understood. Only the message that “women who are pregnant or trying to conceive should avoid alcohol” gives a 100% guarantee of no alcohol damage to the fetus. Fathers who are heavy drinkers also produce infants with lower birth weight and increased likelihood of heart defects. FASD prevalence is under-estimated, due to lack of recognition and mechanisms for surveillance, but the rates are likely to be 2-5% in developed countries and even higher in high risk populations (Chapter 22)!

Without diagnosis and support, unrealistic expectations from children themselves, parents and teachers, may lead to serious defensive behaviour and cognitive and secondary psychological disabilities, leading to disrupted school experience, mental health problems, trouble with the law, inappropriate sexual behaviour, addiction, problems with independent living, and attempted suicide. This book is full of first-hand accounts: “I had no clue that I was struggling because parts of my brain didn’t develop...acceptance and knowing brings relief and help.”

Early childhood intervention has developmental and economic benefits (Chapter 9) and is a human rights issue. Families describe the unrelenting battle for services and challenges of parenting (Chapter 17). Politicians need to stand up to the alcohol industry and facilitate changed community attitudes on behalf of thousands of children born each year with this preventable lifelong disability (Chapter 2). Children and young people with FASD are currently the largest group of children being placed in fostering and option services (Chapter 8). These children need high-quality early childhood experiences, yet their social circumstances often give them a double jeopardy (Chapter 10). The Education system has been slow to accommodate the unique learning needs and style of children with FASD, so by the time they reach secondary education they are disenfranchised and may drop out from a demanding and inflexible system (Chapter 11). The emotional roller coaster ride of adolescence often leads them into criminal activities when they fail to realize the consequences of
their actions. They are the largest percentage group of young people entering the criminal justice system, becoming ‘revolving door prisoners’ (Chapter 14 & 16). But, like the education system, the justice system is ill-prepared and ill-equipped. People with FASD face a bleak outcome after spending time in the systems in which we are all involved, and this weighs on our collective conscience. Addressing FASD will require collaboration across health, community, education and justice sectors. Each discipline has its own literature but this book represents an interdisciplinary wealth of knowledge which can lead us to improve the life chances of someone born with FASD. This book celebrates the global FASD community of families, researchers and practitioners as equal partners in developing joint aims, a common language, collaboration and information sharing, not only across disciplines but across social, cultural and global landscapes. Observations from the book’s introduction give an idea of the breadth of the problems and issues associated with FASD and subsequent chapters elaborate, referencing their sources.

Elizabeth Elliott (Chapter 2) presents the international history and challenges of FASD: against the background of 50% of pregnancies being unplanned, the growth of teenage binge drinking is key. Although indigenous populations don’t drink more than non-indigenous, some have higher rates of high risk drinking and therefore increased rates of FASD. Global challenges include: overcoming scepticism about FASD, documenting alcohol use in pregnancy, making an early diagnosis, providing evidenced-based health care and education, educating professionals, supporting parents and carers, developing and disseminating evidence-based alcohol policy for pregnancy, prevention, and a coordinated national approach. Ron Gray describes the causal web from disadvantage to birth defect (Chapter 3), drawing on three high risk populations, their context of social inequity and injustice and the role of partner violence. Moira Plant describes the growth of alcohol misuse in the UK (Chapter 4) and the widespread health consequences.

**II Families:** Chapter 5 (Peter Hepper) describes how behaviour develops in the fetus and that suppression of startle responses results from maternal alcohol use. Simon and Julia Brown described (Chapter 6) how as parents they had to be ‘the experts’, because professionals don’t know what to do. Problems they faced included physical/health issues, motor coordination, communication and emotional and behaviour issues. Other parents from the FASD Trust were a source of support in understanding that these children don’t ‘fit in the box’. For early years they reinforce the need for the 4 ‘R’s: Routine, Rules, Repetition and Relaxation and urge parents to remember to enjoy their child. Sarah Muir-Timmins and John Timmins describe their experience as adoptive parents (Chapter 7): dealing with terrible feeding and sleep difficulties, problems of safety, impulsive hyperactivity, learning, concentration and memory, and lack of understanding of their own or others emotions. These and other case histories (Chapter 8, Good care makes a difference) paint a picture of real life realities.

**III Education:** Kate Frances (Chapter 9) describes the problematic referral pathways for FASD and, based on 2012 research in Western Australia, lack of professional knowledge. Carolyn Blackburn (Chapter 10) looks at the importance of Early Childhood Intervention for FASD and how a developmentally enriched environment can provide cost-effective compensation for intrauterine damage and lay the foundation for later development. She cites the problems of maternal denial of alcohol intake and the failure of professionals to share the diagnosis with parents. FASD charitable organisations play an important supportive role, as do evidence based approaches to intervention e.g. ‘Parents under Pressure’ training and alcohol in pregnancy training for midwives. Barry
Carpenter writes about an evolving pedagogy - the science and art of education - for FASD (chapter 11). He cautions that it is important to be aware of hidden impairment in children with FASD: they may appear physically mature, and have advanced expressive language, although their verbal communication and maths concepts may be compromised and they may have social and emotional maturity at half their developmental age. There may also be problems with memory, visual motor integration, slow information processing, cognitive inflexibility, executive function, attention and impulse control, disorganisation, perseveration, and a range of developmental, emotional and mental health problems. Associated problems include attachment disorder, lack of social reciprocity and perception including self-reflection and insight, gross and fine motor problems and sensory processing. He describes an inquiry and evidence-based approach using the Engagement Profile and Scale (www.complexid.ssatrust.org.uk) bringing an individualised approach. Jo Egerton (Chapter 12) identifies approaches to help with transition to adult roles. Difficulties with impulsiveness, poor judgement, poor self-esteem with a desire for excitement, novelty and friends draws them into law-breaking behaviour. ‘Adapting and extending the external brain’ can be used to enable daily living skills, social relationships, physical and mental health, financial management and accessing disability services and benefits. She includes approaches to preparing for employment and independent accommodation, stressing the need to celebrate small achievements.

**IV Interdisciplinary Perspectives** starts with Chapter 13 from Raja Mukherjee who describes the physical abnormalities of FASD and their differential diagnoses. Free Fatty Ethyl Ester in blood in 2⁰ and 3⁰ trimester will help identify risk, and he suggests a process for diagnosis and information gathering used in UK. Rogan and Crawford (Chapter 14) describe building a community of care for FASD in New Zealand, where the health and social cost of the harm of drinking is $5.3 billion each year. The government there has funded a charity to promote prevention of alcohol-related harm. The first challenge is awareness-raising and educating professionals, followed by building diagnostic and assessment capacity multidisciplinary teams. Susan Fleisher (Chapter 15) adopted a child with a FASD and the challenge of care led her to found NOFAS-UK. This organisation has brought change to Midwife knowledge and practices, so they now enquire and advise pregnant mothers on alcohol consumption, and to provide education to all secondary schools in UK. Julian Killingly (Chapter 16) describes the issues of diminished criminal responsibility and the need for greater awareness of FASD in the criminal legal system. Of juveniles remanded for forensic psychiatric in-patient assessment in British Columbia, 23% had FASD. They were more likely to waive away their rights on arrest, are suggestible and have neurologically based tendency to acquiesce to leading questioning. They made guileless confessions (including false confessions), showed no apparent guilt or remorse and were unable to appreciate the seriousness of their offences. A person with a learning disability or known to have FASD, must only be interviewed when accompanied by an ‘appropriate adult’. The recognition of FASD for mitigation in criminal proceedings is better established in the USA than UK. Although it cannot generally be used for diminished responsibility, it can mitigate the sentencing. However, the cost of forensic assessment of FASD can be $25,000! Alison McCormick (Chapter 17) describes the response to FASD of the social care system in UK, where 70% of looked after children are a result of parental substance abuse. About 250-350,000 children live in families where one or both parents are affected by serious drug problem and 900,000 in families affected by parental alcohol abuse. People affected by alcohol in the family have more chance of rehabilitation but are less likely to succeed. Those receiving social care seldom had proper assessments despite the 2005 legislative requirements, and their foster/adoptive parents had little understanding of the challenges
of FASD. The level of burden of care often leads to secondary abuse and disabilities. Foster families describe unsupportive and hostile relationships with social care services including a lack of respite, allegations of abuse, and other pressures often leading to marital breakdown. Nguyen and Riley describe the teratogenic effects of alcohol in Chapter 18, summarising the findings on neuroimaging and neuropsychological assessment. Microcephaly and other structural abnormalities of the brain may occur and their location determines the type of learning problems. For example, abnormal development of the corpus callosum is related to problems of connectivity, and an abnormal cerebellum results in problems of motor coordination. Neuropsychological testing is described for each of the apparently unrelated problems young people with FASD suffer. Assessing different dimensions of cognitive and learning enables individualised intervention. Kieran O’Malley in Chapter 19 summarises associated developmental psychiatric disorders. Of adults with FASD, 92% had mental health problems including 65% with ADHD, 45% with depression and 21% with panic disorder. Other diagnoses include addictive disorders, regulatory disorders, Autistic Spectrum Disorder, intermittent explosive disorder and mood/affective instability and many of these problems do not respond to standard treatment approaches. He describes the multi-modal approaches needed to address these problems, including constructing a scaffolding containment system, and briefly describes possible interventions supported by illustrative case vignettes.

**V International Perspectives** is the last section. Chapter 20 by Grant and Clare on FASD in North America, focuses on policies, practices, guidelines, screening, public health, prevention and intervention efforts. In 2000 the US Congress recognised FASD and created six FASD Centres of Excellence. In 2012 the American Bar Association urged the justice system to identify and respond to FASD. However there are poor quality data on the problem and a lack of national coordination for advocacy and research. Diane Black reports on European Perspectives (Chapter 21). The WHO reports Europe as having amongst the highest alcohol consumption worldwide. The FASD Alliance Congresses attract significant interest in Europe and a few countries have significant education programs. Viljoen’s Chapter 22 on South Africa describes local epidemiological studies which identify a range of risk factors: both social (including poverty, poor education and diet, and binge patterns of drinking) and genetic, and outlines a novel and effective prevention measure. In South Africa, major problems including FASD stem from provision of alcohol in lieu of payment for farm workers in wine growing regions. He cites Ethyl Oleate in fetal meconium as a useful biomarker. Elliott (Chapter 23) presents on progress in Australia including: establishment of an Intergovernmental Committee on Drugs Working Party on FASD in 2006, a prevalence study in remote Western Australia; and in 2012 a draft national plan of action, submitted to the 2011-12 House of Representatives Inquiry into the prevention of FASD. With the steady rise of alcohol use in women, including some Indigenous women, the Guidelines to Reduce Health Risks from Drinking Alcohol in 2009 were timely. Yet intention to drink is not related to knowledge of the risk, but to attitudes towards drinking. Stresses underpinning alcohol use in Indigenous women include domestic violence, being victims of the stolen generation, dispossession of traditional land, and loss of language and culture. She argues that evidence based strategies to decrease alcohol consumption across society are needed, as implemented in Australia to decrease smoking. Despite developing diagnostic tools, there is still a major need for professional education and for clinical services for FASD. The editors Carpenter, Blackburn and Egerton (Chapter 24) conclude the book with ‘the way forward: diverting bleak outcomes’. Drawing on the rich experience of this multi-author group they note the rapid
development of FASD awareness in the last 10 years and outline what can and should be done in the future to eradicate FASD, a 100% preventable disability.

This ambitious book identifies the multifaceted nature of FASD and highlights the extent and diversity of problems faced by children living with FASD and the challenges for their families and professionals. Internationally, the science, intervention approaches, public health issues and politics are in a rapid stage of development. In this book a growing and diverse literature is cleverly brought together by leaders in the field. It is well written and the novelty of the research reported and the approaches to understanding the real life challenges of FASD are compelling. This books makes one appreciate that FASD is a major concern for all professionals who deal with children and that we must keep up-to-date. It also provides a map of the available evidence for what can be done to help. It is relevant to, and a ‘must-read’ for, all professionals who deal with children with complex neurodevelopmental needs, among whom will be some with FASD, and for professionals who can influence outcomes for the next generation of children.