



Fetal Alcohol Spectrum Disorder (FASD) and Problem Fragmentation (Opinion Piece)

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As a social problem and a consequence of the plethora of alcohol caused harms, fetal alcohol spectrum disorder (FASD) is characterised by complexity, ambiguity, and a lack of agreement on definition and solutions. Despite a history of applying a linear policy approach, prevention of FASD continues to be resistant to change. Multiple stakeholders engage (or try to engage) in the problem system, each with their diverse frames of reference and preferred definitions of the problem and its solution. After 40 years, many issues advocated in the late 1990s have not yet been resolved.

The technical complexities of FASD are in contrast with the problems in its social dimensions. Public policy preferences based in authoritative type solutions have emerged and this has fractured the problem of FASD into more problem parts, at least to those parts which can be quantified. There are consequences – the conundrum inherent in the diagnosis, determining the lowest threshold to cause fetal harm, the discretionary choice in respect to target groups and the search for evidence-based interventions. Eliminate the words ‘fetal’ or ‘alcohol’ and conflict can be avoided with the alcohol industry (demonstrated for example in the issue of voluntary labelling alcohol beverages) and the public coffers continue to bulge with collected tax revenues.

Meanwhile, such a focus denies the public the opportunity to bring oppositional pressure (Cobb, Ross & Ross 1976, pp. 126–138) and perpetuates the notion of FASD as a women’s problem, an Aboriginal problem, a problem focused on diagnosis and research attention to marginalised groups. It avoids the true prevalence of FASD ‘hidden’ among those diagnosed with alternatively named conditions, avoids a better understanding of the presentation of FASD across the lifespan and the pervasive use of alcohol in society. It has failed to meet the needs of individuals living with FASD and their families who carry the burden of care. Nor has sufficient attention been given to the lived experience of older adolescents and adults.

Governments rely researchers, and evidence produced from people considered qualified to know and understand the problem. Often there is an assumption that the interests of individuals living with FASD and their families are represented. The lifetime reality of FASD means poorer academic success, economic dependence, mental health diagnoses, alcohol and other drug dependencies, likely imprisonment, and homelessness. Acknowledgement of the long-term time frame needed to address prevention, and the historical, cultural, intellectual, personal and professional obstacles that exist – and including these topics as part of the conversations about FASD prevention – is critical.

Diagnosis, clinical expertise and research are critical components of the FASD issue but cannot meet the lifetime support needs of individuals, their supporters and their families. The consequence of policy decisions based on representations rather than those living with the condition is unfair and unreliable. After 40 years of accumulated knowledge and wisdom, the real guts of this issue are suppressed: love of alcohol, existence of an unregulated alcohol industry, a disability that remains unrecognized, families under incredible stress, uninformed service providers, and, most of all, individuals trying to negotiate a life course in the presence of social and political denial.

Collaborative strategies (Roberts, 2000) offer an alternative way of viewing the problem as a system, and the process of resolution as greater than the tendency to seek solutions to parts of the problem rather than the whole. There seems no alternative than reliance on the widest collaboration and open leadership. Stakeholders are currently missing from national FASD collaborative events. Stories told by pregnant women and those living with FASD, and the wisdom of parents and carers and communities must be heard. Given the different frames of reference evident within each group, accurate representation by spokespersons appointed from a limited pool cannot be assumed. Neither can one-off forums hosted by governments resolve these challenges.

Parents and carers or their representative agents have unilaterally struggled for change to address ‘invisibility’ of the problem. Policy and medical audiences are necessary to facilitate the critical need to raise public awareness, and impart an understanding of the characteristic features of FASD as having a physical brain-based aetiology with behavioural symptoms. These critical factors are commensurate with the implementation of appropriate services in all institutions with which those living with FASD must engage.

The care and support by parents and families for children across the lifespan may be perceived as acquiescent, but it is up to us to empower and listen in a different way. Science cannot speak for lived experience.

Author Biography

Vicki Russell Ph.D. is a Churchill Fellow (2001), has a bachelor's degree in justice, a master's degree in police studies, and diploma in project management. Her research interests are the diverse frames of reference and contested nature of preferred definitions of problems and solutions. Russell has worked in management, sexual assault trauma counselling, community development in alcohol and other drug education, and recently served five years as CEO of the National Organization for Fetal Alcohol Spectrum Disorder (NOFASD Australia). She has a certificate of mastery in the fetal alcohol-neurobehavioral approach through FASCETS Inc. in Portland, Oregon. Russell is trained in narrative practice and for almost 30 years, has developed and delivered education and training programs on trauma and FASD to professional and non-professional groups across all levels of prevention. Russell facilitated weekly group sessions for over three years to all residents in a youth detention aware that FASD is overrepresented among youth offenders. This program grew from participatory research and became grounded in a relational approach and focused on addressing some of the more typical brain-based conditions resulting from fetal alcohol exposure.

References

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