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Fetal Alcohol Spectrum Disorders and Social Work Practice in Australia: A Narrative Literature Review

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ABSTRACT

In Australia, it has been well documented that the leading preventable cause of nongenetic neurodevelopmental disability (NDD) is Fetal Alcohol Spectrum Disorder (FASD). This review explores literature informing Australian social work in the context of FASD. It highlights the need for increased social work research to inform evidence-based practice (EBP) in FASD diagnosis and management using the biopsychosocial-spiritual-cultural (BPSSC) framework. Social workers are often first to identify children's emotional, behavioural, and learning difficulties that may be a characteristic of FASD. Nonetheless, there is limited knowledge and understanding about how social workers in Australia address FASD. We argue that research about FASD and social work practice can improve social workers' understanding of the BPSSC characteristics and management of FASD across the life course and contribute to EBP development in these areas in Australian social work.

IMPLICATIONS

- Social workers have an emerging role in the holistic assessment, diagnosis, and management of FASD in Australia.
- Social workers are well placed in being first to recognise and identify an individual's emotional, behavioural, sociocultural, and learning difficulties that are characteristics of FASD.
- Social workers can contribute to ongoing care in a tailored FASD management plan that links the caregivers to appropriate local community resources, service provision, and disability supports.

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Prenatal Alcohol Exposure; Fetal Alcohol Spectrum Disorder; Australia; FASD; PAE; Social Work; Mental Health; Biopsychosocial-Spiritual-Cultural Assessment; Child Development; Collaboration; Evidence-Based Practice; Family Social Work; Child Behavioural Problems; Diagnoses; Rural and Remote Health; Disability; Neurodevelopmental; Holistic

Internationally, the known adverse effects of Prenatal Alcohol Exposure (PAE) in utero on a fetus is by no means a recent phenomenon. There has been recognition and acknowledgement of the effects of PAE as early as 1968 (Lemoine et al., 2003) when Fetal Alcohol Syndrome (FAS) was first described, and in 1973 when the first diagnostic criteria were established (Jones et al., 1973). There are many challenges experienced by social work professionals, multidisciplinary teams, educators, and communities in understanding, diagnosing, and managing Fetal Alcohol Spectrum Disorder (FASD).

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There is a clear lack of concise knowledge and deep understanding about the facilitators and barriers social workers, multidisciplinary teams, educators, children, young people, and their caregivers encounter when addressing FASD (Burns et al., 2013; Dudley et al., 2015; Gibbs et al., 2020; Gilbert et al., 2021; Passmore et al., 2018; Payne et al., 2011).

Broadly speaking, the history of FASD in Australia is recent with the first seminal work to inform and guide FASD policy being published in 2009 (Burns et al., 2012). In 2016, the first *Australian Guide to the Diagnosis of Fetal Alcohol Spectrum Disorder* (2016) was introduced and piloted, and in 2018 the *National Fetal Alcohol Spectrum Disorder (FASD) Strategic Action Plan 2018–2028* was released (Department of Health, 2018). As a result, Australian social workers are now expected to quickly catch up to the knowledge base, experience, and skillset of those in Canada, the United States, and the United Kingdom (Bower, 2016; Mukherjee, 2019).

The Australian Guide to FASD (Department of Health, 2016) requires collaborative multidisciplinary assessment, including in-depth physical and developmental assessment, psychometric testing led by specialist paediatricians, neuropsychologists, psychiatrists, and geneticists, and input from occupational therapists (OT) and speech therapists (Bower, 2016). Once assessed, a report is made available to the individual, family, or caregiver outlining the formulated diagnosis. This will include significant biopsychosocial-spiritual-cultural (BPSSC) characteristics and specific recommendations to provide ongoing care in a tailored FASD management plan (Bower, 2016). The BPSSC assessment in social work examines the biological, psychological, social, spiritual, and cultural factors that impact a person's past and present life and is often very useful in uncovering invisible or hidden aspects of the person's life that contribute to a specific problem presentation (AASW, 2013, p. 14). Importantly, social workers undertaking the BPSSC assessment are well trained to sensitively ask questions about past and present biological factors, such as genetics and the history of pregnancy and birth, like in-utero exposure to substances or transgenerational transmission of trauma, which are considered apposite to the context of FASD. Bower (2016) states the value of sharing the diagnosis, management plan, and specialist information including social work, OT, and speech therapist assessments, strategies, or interventions with relevant stakeholders, such as schools. Further, Bower (2016) recommends that this should be a collaborative, open, and ongoing discussion for the individual diagnosed with FASD and their families/caregivers.

In general, there is a fundamental need for more social work research and exploration not only to inform diagnosis using a clinical model, such as the BPSSC assessment, but also to contribute to the evidence-based practice (EBP) of FASD in Australia. Social workers, alongside multidisciplinary professionals in a range of settings like mental health services, schools, and early childhood education, are often first to identify children's emotional, behavioural, and learning difficulties that may be a characteristic of FASD (AASW, 2015; Bower, 2016). Social workers can collaborate and advocate to engage appropriate support for the individual and their families and contribute to the assessment and management of FASD by addressing the BPSSC characteristics related to FASD across the life course. This study, therefore, explores the extant literature informing Australian social work in the context of FASD.

The following sections describe the methodology of this study and discuss BPSSC characteristics of FASD historically and to date in Australia, including First Nations Australian prevalence data to show a comprehensive spread, and the BPSSC risk factors for FASD.

We then detail the importance of providing BPSSC assessment and diagnosis of FASD and the emerging role of Australian social workers in FASD. Finally, we identify the significant practice gaps and future directions for Australian social work research, policy, and practice.

Methodology

This narrative literature review is intended to provide an overview of current literature available to inform social work and multidisciplinary practice in the clinical diagnosis and psychosocial management of FASD in Australia. Within these parameters relevant articles were identified using electronic database searches: Oxford Bibliographies—Social Work, CINAHL EBSCO Publishing: Cumulative Index to Nursing and Allied Health Literature, Informit (Humanities and Social Sciences Collection, and the Health Collection); ProQuest (Academic Research Library, Social Work Journals, Psychology Journals, and Social Sciences Journals); SAGE Journals Online, Social Sciences Review; and the University of New South Wales Library. A range of keywords were combined using Boolean logic including Fetal Alcohol Spectrum Disorder*, FASD*, social work*, Australia*, allied health*, multidisciplinary practice*, neurodevelopmental disability*, diagnosis*, management*, care*, disability*, education*, mental-health*, families*, caregivers*, community*. Searches were not limited to 10 years, as the scholarly field of FASD in Australia is relatively recent and therefore limited, all publications with relevance to Australian social work practice were included, and the search ran from 2019–2020. Subsequently, a general internet search using Google was conducted to identify grey literature, resources provided by peak Australian FASD organisations, and government documents (Trever & Boddy, 2013).

Findings

Study Characteristics

From the initial search, the literature available was limited and it quickly emerged that there are no available papers to date specific to FASD and the role of the social work profession within Australia. A total of 127 articles, books, and grey literature were reviewed. Articles selected for inclusion in the review were based on these criteria: (1) the source focused on FASD and multidisciplinary practice internationally and/or in Australia; (2) the source focused on FASD, and discussed specific information or topics related to areas of social work professional practice e.g., public, mental, and rural health; disability; assessment; diagnosis and management of FASD; and/or provided information that the social work profession can learn from. In total, 41 sources were appropriate, including eight grey literature, two books, and 31 journal articles. Of the 31 journal articles, 10 were quantitative studies, nine were qualitative studies, 11 were mixed-method studies, and one was a conceptual paper. The study location varied: 11 were Australian, three were from New Zealand, six were from the United States, one was from the United Kingdom, two were Canadian, and 11 were from other international countries, including South Africa and Mexico. As none were published in Australian social work journals locally, international literature was deemed appropriate for consideration in the Australian context, as the field of FASD is still emerging in social work practice (Trever & Boddy, 2013).

The BPSSC Characteristics of FASD

FASD is broadly understood as a diagnostic term used to describe the significant functional impairments across multiple central nervous system (CNS) domains caused by PAE (Burns et al., 2013; Coates, 2015). Specifically, in Australia, FASD is defined by the presence of PAE, severe neurodevelopmental impairment, and the identification of FASD with three sentinel facial features (SFF) and FASD without SFF (Dudley et al., 2015).

The primary conditions include alcohol-related birth defects and alcohol-related neurodevelopmental disabilities (NDD). Alcohol-related NDD is described as evidence of CNS disruption, neurodevelopmental and cognitive abnormalities, and/or behaviours that do not meet age-appropriate developmental milestones and are non-attributable to familial background or environmental contexts (Burns et al., 2013).

Secondary outcomes of FASD include adverse BPSSC characteristics including psychosocial and behavioural disabilities, learning difficulties, and mental ill-health that manifest as challenges with schooling, substance misuse, unemployment, and engagement with the criminal justice system (Bagley, 2019; Zizzo et al., 2013). The secondary outcomes of FASD are often “invisible” due to the presentation of co-occurring symptoms and overlapping behaviours that lead to misdiagnosis and a failure to include FASD as a complete diagnosis that encompasses a range of BPSSC characteristics. The overlapping mental health diagnoses and behavioural characteristics that can be displayed in FASD and various conditions have been captured extensively (Bagley & Badry, 2019; Bruer-Thompson, 2010). An example includes the comparable behaviours and characteristics between children with FASD and children presenting with Autism Spectrum Disorder (ASD), Oppositional Defiant Disorder (ODD) and/or Attention Deficit Hyperactivity Disorder (ADHD). The most common challenges that children living with FASD are likely to face include emotional regulation problems, communication difficulties, being perceived as defiant by adults, being sensitive to touch or easily annoyed by others, confabulation, a lack of consequential thinking, and/or impulse control difficulties (Bruer-Thompson, 2010, p. 1).

Moreover, the specific BPSSC characteristics that can lead a young person with FASD to become engaged with the criminal justice system are associated with the primary disabilities of FASD. These include impairment in memory, attention, cognition, language, executive function, and adaptive function that require targeted intervention and prevention in Australia (Passmore et al., 2018). The co-occurrence and complexity of impairments experienced—like factors of NDD, learning difficulties, poor emotion regulation, and complex trauma—can affect an individual’s functional abilities and may lead to early school failure, school absenteeism, school refusal, poor mental health, and, as mentioned above, substance misuse and increased risk of involvement with the criminal justice system (Passmore et al., 2018; Popova et al., 2011; Popova et al., 2016). Social workers remain at the forefront of responding to individuals and families living with FASD in various settings, including, but not limited to, FASD diagnostic clinics, family crisis support services, parenting programs, out-of-home care, early childhood learning, and mental health services in Australia (NOFASD Australia and NDIS, 2022, p. 1). Social workers holistically support individuals with FASD across settings determined by the context in which they work, that is,

by the specific role and social work model or intervention required of their job description.

For example, social workers in child protection, the criminal justice system, or mental health services commonly use a case management, advocacy, psycho-education, or therapeutic model. Such models are often underpinned by systems theory, a person-in-environment lens, and a strengths-based perspective and play a crucial role in co-ordinating services and wrap-around models of support at home, school, NDIS/disability supports, and community (Badry & Choate, 2015; NOFASD Australia and NDIS, 2022, p. 1). Holistic support by social workers includes working with individuals and their families from a person-in-environment lens that looks at the specific needs of the person and their family. Social workers examine the capacity of the support system around them to meet their disability-specific and psychosocial needs, including broader environments like school, social activities, friendships, health, and disability-specific services (Badry & Choate, 2015; NOFASD Australia and NDIS, 2022, p. 1).

FASD in First Nations Australian Communities

Harris and Bucens (2003) found that populations most at risk for FASD are characterised by a high degree of social deprivation and poverty, with FASD continuing to occur among both First Nations Australian populations and the wider Australian population, particularly in rural and remote areas (Bower et al., 2018; Harris & Bucens, 2003). Notably, the Liliwan FASD Prevalence Study in the Fitzroy Valley showed that the prevalence rate of FASD was among the highest in the world and the first to identify exposure to complex trauma as significant to cultural and spiritual understandings of FASD for First Nations Australian communities (Hamilton et al., 2021). The most compelling findings suggest that ongoing trauma can change the brain and the way the individual functions and that the incidence rate for First Nations Australians must be understood in the context of ongoing intergenerational trauma. Williams (2021) maintains that, for First Nations Australians, FASD must be understood within the context of colonisation, Stolen Generations, and systemic racism. Therefore, social workers must be attuned to the importance of cultural and spiritual understandings of FASD, as most First Nations Australians will continue to experience the effects of colonisation and complex trauma.

Prevalence data and knowledge of FASD in First Nations Australian communities continue to be much more developed due to greater surveillance and reporting and, as a result, First Nations Australians are often stigmatised in practice. Data from the Australian Early Development Census Findings (Australian Commonwealth Government, 2018a) indicate that at school entry, six in 10 First Nations Australian children were considered “developmentally vulnerable” at a rate twice that of general population peers. Findings also suggest that the rate is likely to be greater in rural and remote areas in Australia (Australian Government, 2018a). Fitzpatrick et al.’s study (2017) represents the first population-based study that assessed the prevalence and profile of NDD and FASD outcomes of First Nations Australian children living in remote communities in Australia. Findings indicated that one-third of a population-based cohort of school-aged children living in the remote Fitzroy Valley had an NDD (314.8 per 1,000) whether they had been prenatally exposed to alcohol or not (Fitzpatrick et al., 2017). All children diagnosed with

FASD had CNS impairments such as injury and infection, chronic illness, and psychosocial deprivation that were associated with PAE. Similarly, for First Nations Australian children, the leading cause of intellectual disability is PAE (Fitzpatrick et al., 2017). While this information is welcomed to inform research priorities and EBP, the only prevalence data available for school-aged children in remote communities in Australia continues to be in remote First Nations Australian communities in WA (Fitzpatrick et al., 2017). There continues to be the need for more FASD knowledge and EBP research in social work that outlines the BPSSC assessment and risk factors associated with FASD in both First Nations Australian communities and the wider Australian population (Williams, 2021). Social workers must be informed about PAE as a maternal risk factor, and that a range of sociocultural and political barriers prevent women from seeking help for risky patterns of alcohol consumption. Therefore, social work practice must recognise a nonshaming and non-blaming, human rights approach to FASD as crucial to cultural security in service delivery for First Nations Australian communities (Williams, 2021).

BPSSC Assessment and Diagnosis of FASD

In Australia, for FASD to be diagnosed, there must be evidence of Prenatal Alcohol Exposure in utero, severe neurodevelopmental impairment across at least three of ten domains of the central nervous system structure or function, and identification of two specific subcategories within FASD: FASD with three sentinel facial features (SFF) and FASD with less than three SFF (Dudley et al., 2015).

Globally, there is a range of common factors that impact the early identification of PAE-related neurodevelopmental and behavioural deficits that makes them difficult to recognise. For example, in Australia, the USA, and the UK, screening for alcohol use during pregnancy has not been universally implemented through standardised screening questionnaires that ask about usage and/or that screen for ethanol biomarkers to ensure early identification (Garrison et al., 2019). Australia has always opted for targeted screening programs that are deemed to be cost effective in comparison to wider population surveillance, yet this has raised ethical concerns for advocates, social workers, midwives, educators, scholars, caregivers, families, and First Nations Australian communities. Targeted screening programs have failed to reduce the negative impact of stereotyping on families who experience PAE. For instance, marginalised communities, living in rural and remote areas where there are increased psychosocial and cultural-spiritual risk factors associated with substance misuse or where low-socioeconomic-status groups live, continue to be unequally targeted, over-represented, and stigmatised (Basaraba et al., 2016; Zizzo et al., 2013).

Diagnosis begins with multidisciplinary teams both excluding and considering any differential diagnoses that may be proposed as a result of genetics, environmental factors, or originating solely from trauma (Dudley et al., 2015). The process of diagnosis is exclusionary: it requires taking extensive case histories to exclude any other exposures or risk factors and will include a range of investigations that social workers are best placed to undertake using the BPSSC assessment (Dudley et al., 2015). The experience of early life trauma, neglect, and abuse can result in, or compound existing, impairments in language, cognition, and/or behaviour, as can acquired brain injury from trauma, and any infections or metabolic conditions that can present similarly to the

neurodevelopmental profile that is associated with, and seen in, FASD (Lange et al., 2017; Popova et al., 2016). As discussed earlier, social workers must continue to educate themselves on the overlapping diagnoses that are commonly associated with the co-occurrence, or onset, of developmental delays and deficits that may be attributable to other diagnoses such as ADHD, autism spectrum disorders, psychiatric disorders, and/or learning difficulties that co-occur with FASD (Popova et al., 2016). Social workers are best suited to working collaboratively and sensitively with children, families, and caregivers to understand developmental delays using the BPSSC assessment to gather hard-to-reach information, like PAE histories or a family history of mental ill-health, the effects of intergenerational and/or complex trauma, or the impacts of social deprivation as relational to substance misuse in a family system to better inform FASD diagnosis, as a specific and inherent social phenomenon.

The Important Role of Australian Social Workers in FASD

Studies show that the identification of behaviours requiring diagnostic referral where FASD is suspected has been initiated too late by multidisciplinary teams and educators, in terms of early intervention and child development (Petrenko & Alto, 2017; Streissguth et al., 2004). The average age at the point of referral for diagnosis is around nine years of age and it is estimated that one-half of those children who present with a measurable form of NDD deficits are in their first three years of life (Olson et al., 2007). Diagnostic referrals, early intervention, and treatment have not been initiated until around the point of school age, and long after the child has experienced challenges in learning, language, cognition, appropriate behaviours, and forming social relationships (Streissguth et al., 2004). Significantly, among the minority (approximately 10%) of children with full SFF specific to FAS, a diagnosis is only rarely established prior to age four and more often left undiagnosed until a formal school enrolment (Garrison et al., 2019).

Once a child enters the early school years and/or primary school settings, it has been recommended that a diagnosis involve a full multidisciplinary team to ensure the best possible diagnosis is made. The literature suggests that the multidisciplinary team should consist of, but is not limited to, a paediatrician, child development specialist, neuropsychologist/psychologist, OT, speech pathologist, and educators (Dudley et al., 2015). Therefore, we argue that social workers must be involved as part of the multidisciplinary team to recognise and understand the onset of developmental delays or deficits a child may experience because of co-occurring conditions in the context of the child or young person's environment in order to make timely referrals to FASD specialists and implement appropriate early intervention strategies. It is especially important for mental health social workers to understand that a child or young person can be diagnosed with ADHD in the presence of FASD, yet the interventions specifically used to manage ADHD will not produce the expected outcomes or effects in the absence of a combination of treatment strategies that also manage FASD and FASD-related behaviours (Glass & Mattson, 2017). However, significant difficulties in identifying FASD-related issues, alongside the impacts of harmful conditions like neglect and abuse on early childhood development, remain and require further research (Gilbert et al., 2021).

Social workers need increased knowledge to understand and address the linkages between the condition of FASD and the difficulty in managing children with a suspected but unconfirmed diagnosis (Gilbert et al., 2021). Gilbert et al. (2021) found that social workers reported adverse family environment among many children suspected of having FASD, such as parental substance misuse, domestic family violence, mental ill-health, as well as child abuse and neglect. They also suggested that “the combined impact of substance misuse and adverse socio-environment act in concert to complicate the chances of obtaining a FASD diagnosis (p. 168)”. The collaborative relationships between social workers, parents, carers, extended family members, and educators are significant, as these channels of communication can provide crucial information that can add to the development of diagnosis from the BPSSC assessment, and provide sociocultural and relational insight into the development of the FASD management plan that identifies person-in-environment strengths and challenges.

For instance, Chamberlain et al. (2017) suggested that there are gaps in addressing the needs of FASD within the family and home environment. Despite caregivers’ positive perception and experience with services supporting children with FASD, many parents and caregivers continue to report difficulty and strain on the family in raising a child with FASD (Chamberlain et al., 2017). Parents and caregivers reported significant challenges in managing behaviours due to underlying emotion regulation problems and inconsistencies in their own expectations of their child in the home, school, and broader community (Chamberlain et al., 2017).

Here, social workers can support families living with FASD by providing specific family-focused behavioural interventions for children. The goal of such interventions may include supporting the family to access early assessment and diagnosis, specialist behaviour therapy and management, supporting the parents and caregivers through family therapy or parent coaching to use more effective and evidence-based parenting strategies. In addition, identifying problems that could be preventing parents or caregivers from implementing effective strategies, and supporting families and caregivers to build their own capacity in accessing different or additional supports (Badry & Choate, 2015; Gilbert et al., 2021; NOFASD Australia and NDIS, 2022, p. 3). Hence, holistic understandings of FASD using the BPSSC framework should be a priority for social workers as part of the university curriculum and ongoing professional development. Social workers have the capacity to greatly impact the individuals’ and their families’/caregivers’ lived experience of FASD depending on their level of knowledge, understanding, and overall support provided at, during, and long after diagnosis occurs.

In summary, a social worker may be the first point of contact in the early recognition and identification of a child’s CNS dysfunction, FASD deficits, poor mental health, and learning needs because of PAE. Social workers play an influential role in destigmatising and addressing FASD for individuals by identifying unmet needs through BPSSC assessment as a result of PAE rather than, for instance children displaying disruptive school behaviour or wilful disobedience towards teachers and caregivers. Significantly, it is the identification of these unmet needs using the BPSSC assessment which further potentially reduces the risk of mental health deterioration, disruption to school attendance, existing family cohesion patterns, loss of caregiver/parental confidence, sibling conflict, and overall family stressors (Olson et al., 2007).

Future Directions for Australian Social Work in FASD

It is well known that the developmental difficulties of a child with FASD will most likely be identified by social workers and educators as they first become apparent in school settings and more broadly in various social service settings. FASD may present as difficulties in the individual's ability to emotionally regulate, concentrate, learn, and engage in meaningful social participation like education, training, or employment (Bower, 2016; Coates, 2015; Government, 2018, b). Similar to the knowledge gap existing among social workers, international research has identified the needs of professionals working with diagnosed and/or suspected FASD in criminal justice settings (Johnson et al., 2010; Payne et al., 2011). Findings suggest that while criminal justice professionals were aware of "some" aspects of FASD, they both desired and required more education and training to support their work with young people affected by FASD who encounter the criminal justice system more broadly (Johnson et al., 2010; Payne et al., 2011). Findings also suggested that a lack of professional knowledge of FASD not only delayed diagnosis but also acted as a barrier in accessing specialist services (Chamberlain et al., 2017). Generalist social workers are specifically trained in using the BPSSC framework. Therefore, they are well placed to inform the identification, diagnosis, assessment, and ongoing management of FASD across the life course. This is dependent upon increased professional knowledge and development in the field of FASD becoming more readily available and accessible to social workers in a range of first-point-of-contact settings like early intervention, mental health services, child protection, the criminal justice system, and schools rather than limited to specialist, paediatric, and siloed settings.

Conclusion

There is a considerable body of knowledge about the history, prevalence, and risk factors related to FASD in Australia. However, there is a limited amount of research related to how Australian social workers meet the needs of individuals, families/care-givers, and communities living with FASD more broadly. What is known is that individuals presenting with FASD will inevitably come into contact with social workers in a range of contexts like mental health, disability, education, criminal justice, and social services (Bagley & Badry, 2019; Gibbs et al., 2020) with varied unmet needs and difficulties in the level of functioning. Findings from the literature review support the need for social workers to prioritise FASD-specific professional development, training, and education in diagnosis, assessment, management, and brief intervention models that address the BPSSC characteristics of the individual, their families, circle of care, and/or communities (Bagley, 2019; Dudley et al., 2015; Elliott et al., 2008; Gibbs et al., 2020; Payne et al., 2005). A better understanding of how social workers and multidisciplinary teams can collaborate, understand, and address the BPSSC characteristics of individuals with FASD will not only strengthen specialist and mainstream support but also facilitate the innovation and development of Australian FASD EBP in social work and guide future social policy directions on FASD in Australia.

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