

Foetal alcohol spectrum disorder: Effective helping responses from social workers

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Abstract

Foetal alcohol spectrum disorder (FASD) is a lifelong neurodevelopmental disability that often requires extensive intervention and support from the helping professions, notably social work. This article considers why a social work response to FASD is needed and explores social work frameworks and models that underpin current FASD-informed practice. It illustrates the discussion with three international models used in Canada and New Zealand, the Key Worker model, the Communities of Practice model and an advocacy and mentoring model.

Keywords

Advocacy, Community of Practice, foetal alcohol spectrum disorder, Key Worker Model, social work, systems

Introduction

Foetal alcohol spectrum disorder (FASD) is a health and social issue that impacts individual and family well-being. The dangers of prenatal alcohol exposure have been highlighted in academic publications from the late 1960s (Chudley, 2018). For individuals this can result in lifelong impairments, and, with their families, FASD can be experienced as a disability, gaining both positive and

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negative attention from a diverse range of professionals and systems (Badry and Choate, 2015; Gibbs and Sherwood, 2017). Individuals with FASD and their families access many services where they are likely to come into contact with social workers. This contact includes social workers from health, mental health, social services, corrections, disability and special education contexts (Popova et al., 2011; Streissguth et al., 2004). In some circumstances, social workers with knowledge of FASD have been effective in developing ways of working with individuals and their families, sometimes drawing on theories and frameworks that underpin social work practice in general, while at other times developing ways of working that respond specifically to the challenges posed by FASD. This article articulates why a social work response to FASD is needed and discusses some social work frameworks that underpin current FASD-informed practice. It then explores three international models of effective practice that are used by social workers, drawing on relevant social work frameworks.

The FASD spectrum describes a range of adverse effects that can occur as a result of exposure to alcohol prenatally (Chudley, 2018; Streissguth et al., 2004). This can include birth defects and neuropsychological impairments that result in behaviour challenges and lifelong learning disabilities. The clinical features of FASD vary from individual to individual and diagnostic guidelines and terminology vary internationally; however, common neurological impairments include deficits in memory, complex information processing, learning, social communication, day-to-day living skills or adaptive skills, executive functioning impairments such as poor planning and organizational skills, and understanding cause and effect (Chudley, 2018; Mattson et al., 2011). If not appropriately supported, individuals with FASD are at high risk of developing secondary problems such as disrupted school experience, drug and alcohol addictions and mental illness (Streissguth et al., 2004).

Parents and caregivers of children with FASD have high levels of stress, more so than even parents and caregivers of children with other types of developmental disabilities (Paley et al., 2006; Watson et al., 2013). Existing studies have shown that parents of children with FASD generally use the same sorts of parenting strategies and approaches (positive parenting, consistent and consequential parenting) that seem to be effective in the general population (Olson et al., 2009). However, these do not always work with children affected by FASD, leading to parents and caregivers feeling doubtful and discouraged (Olson et al., 2009; Paley et al., 2006; Watson et al., 2013). This discouragement can be compounded, particularly when support services are unable to provide much direction in the way of additional strategies. All of these factors contribute to the burden of FASD on families and society more broadly (Olson et al., 2009; Popova et al., 2016), and there is an identified need for expanding the range and depth of support available to parents and families of children with FASD (Petrenko and Alto, 2017). This is where social workers and other professionals may play an important role.

However, research into the lived experience of parents and caregivers has revealed a perceived lack of knowledge and understanding of FASD by health and social service professionals, reflected through inadequate support and ineffective service provision (Breen and Burns, 2012; Salmon, 2008). There is a small but growing body of research into clinical interventions that attempt to improve the neurocognitive impairments associated with FASD (see Olson, 2016; Peadon et al., 2009; Pei et al., 2016; Petrenko and Alto, 2017). However, few studies document specific social work and social service interventions and approaches. In a survey of over 1100 human service professionals, including foster parents, over 70% of the participants indicated that they did not feel prepared to care for or manage cases where children had FASD (Caley et al., 2008). In addition, over 80% indicated that they had no training or knowledge about interventions, making referrals or assisting clients. Caley et al. (2008) recommended training on screening, interventions and

support, particularly in relation to secondary problems such as the social and behavioural challenges faced by children with FASD.

While population-based prevalence rates for FASD in the United States and other Western European countries are estimated at between 2% and 5% (May et al., 2014), research on prevalence of FASD in child care (child welfare) settings revealed prevalence rates ranging from 6% to 16.9% (Popova et al., 2016). In a Canadian study, Fuchs et al. (2007) noted that FASD was a diagnosis for one third of children in care with disabilities, approximately 11% of the population in provincial care. Further to this, FASD prevalence rates in correctional systems have been estimated to be from 10% to as high as 22% (Popova et al., 2016), and a recent Australian study in a youth detention centre found that one in three of those assessed had FASD (Bower et al., 2018). These rates indicate concern that children and young people in the care of child protection, and those who have entered the justice system, have disabilities that require workers and caregivers who are informed about FASD (Badry and Choate, 2015). Given the high level of social service system usage by those affected by FASD, and the high prevalence rates of FASD in social work dominated systems such as child protection, youth justice and mental health (Fuchs et al., 2007), it is essential that social workers who come into contact with those affected by FASD (or prenatal alcohol exposure) have some knowledge and training in FASD and are able to apply this to their work.

With a view to advancing this knowledge, we will now outline the importance of a social work response to FASD, highlighting the need for social workers to be able to identify FASD (or suspected FASD) and to employ an FASD lens to their practice. We then discuss relevant theoretical frameworks that inform social work practice with those affected by FASD, before introducing three models of practice that have proved effective in enabling intervention, support, advocacy and casework for individuals and families. The first example is the Key Worker model, which has been used in Canada and New Zealand. The second example explores the development of Communities of Practice in child welfare in Canada, and the third example brings together emerging models of advocacy and mentoring in Canada and New Zealand, focused primarily on peer support for families and individuals.

Why a social work response to FASD is important

There are many reasons why social work practice can be effective in understanding and supporting families where FASD is an issue. Many children with FASD (and their families) come to the attention of social workers because of co-existing issues like poverty, risk-taking behaviour, mental health issues, substance misuse, abuse or neglect. Large numbers of children with FASD are in formal care situations and many are looked after by relatives and/or other caregivers (Badry, 2009; Fuchs et al., 2007; Popova et al., 2016). FASD is too prevalent for social workers to avoid being involved, yet FASD education and training is woefully inadequate for this profession (Badry and Choate, 2015).

Social work's core values, philosophies and practices, which focus on systems, anti-oppression, social justice, human rights and strengths, underpin the core activities of social workers, regardless of where individual professionals are located (Van Heugten and Gibbs, 2015). Social work is able to locate FASD in its economic, social, political, legal and cultural contexts (Badry, 2009; Gibbs and Sherwood, 2017) and take into account factors impacting how those with suspected FASD are assessed, diagnosed, treated and evaluated. In upholding their codes of professional ethics, factors that social workers will consider as relevant to FASD include the influence of addictions, stigma, discrimination, colonization, intergenerational trauma, human rights, disability, and social and economic exclusion. Social work has a long list of core skills and practices associated with its social

justice, anti-oppressive and human rights orientations. These include advocacy, case management, casework, mentoring, ecosystems thinking, critical and radical practices, strength and resilience capacity building, pro-social modelling, collaborative practices and support of service user empowerment, as well as self-determining approaches (Badry, 2009; Van Heugten and Gibbs, 2015). However, to be *effective*, social workers must be trained and knowledgeable in the field in which they are working (Badry and Choate, 2015). Therefore it is imperative that social workers understand the causes of FASD, best practices in relations to supports and interventions, models of disability, protective and risk factors, and wider ecological factors that impact how FASD is viewed. Social workers need to draw on research-based FASD knowledge of what works and apply this alongside their own well-established frameworks and models of social work practice.

Ultimately, social workers practise in multidisciplinary contexts and teams and, like other health and welfare professionals, they need to respond to increasing numbers of those being diagnosed and impacted by FASD (Chudley, 2018). They also work with vulnerable young people and adults who are likely to benefit from social workers who can identify those they need to support in prevention of FASD, as well as those they can assist who are needing help to manage their FASD (Olson et al., 2009).

Frameworks informing social work responses to FASD

In a recent publication, Van Heugten and Gibbs (2015) discuss the use of social work frameworks as a means of embracing theory, perspectives, knowledge, values, ethics and critical concepts. They argue that these frameworks are able to incorporate practice, factual knowledge and experiential knowledge and can be applied in everyday social work situations. There are three well-known frameworks used in social work and other disciplines that have direct relevance for an effective social work response to FASD. These are the developmental or brain-based framework, which focuses on neurodevelopment and FASD; the ecosystems framework, which has a person-in-family-and-environment focus; and a rights-based framework, which is influenced by radical disability and anti-oppressive theories and concepts. Social work can and has drawn on these frameworks to achieve positive outcomes for families and individuals and to advocate for accommodations where FASD is an issue (Gibbs and Eketone, 2018; Malbin, 2009). These frameworks enable social workers to support a 'successful lives' strategy for individuals with FASD to enable them to be self-determining and to achieve success. These frameworks can and have influenced current and emerging models of practice that we outline later in this article.

Developmental/brain-based framework

In social work, developmental theory includes cognitive development, attachment, life stage and theories related to need (Teater, 2015). Malbin (2009) focused on responding to FASD from a developmental or brain-based framework, which positions social work interventions that are informed and understand that FASD is a complex disability that is not readily visible or evident. The impact of alcohol on the developing brain includes altering its structure and contributing to multiple effects, including challenges in cognition, memory, intellectual performance, language, attention and other significant neurobehavioural impacts (Mattson et al., 2011). FASD has been identified as a neurodevelopmental disability that requires appropriate accommodations to support children and families (Malbin, 2009). Malbin, an American social worker, has promoted a neurobehavioural approach to respond to FASD, recognizing that many of the challenges faced by individuals with FASD, their families and caregivers are behavioural in nature and originate in the brain, requiring specific interventions that are FASD informed.

Malbin's account of the brain-based framework has enabled social workers to understand both the difference between primary impairments, leading to behavioural and social interaction challenges, and secondary and tertiary disabilities, which occur when others misinterpret these primary impairments and their symptoms and then blame the child for bad behaviour (or indeed parents for bad parenting responses). Malbin argued that professionals and parents or caregivers need to change their expectations and interpretations and 'get' in line with an understanding of the impact of the primary impairments on young people, as well as the likely negative impact that a 'wrong' response will have on people impacted by FASD. Malbin's work on FASD also incorporated aspects of an ecosystems approach to FASD (see below) by emphasizing the need to take account of the person in their environment and ensure that appropriate changes and accommodations to people's environments were made, rather than expecting people with FASD to constantly have to change their own thinking or behaviours. Olson et al. (2009) also strongly connected a neurodevelopmental or brain-based framework to systems thinking to FASD, and to ecosystems, which we now consider.

Ecosystems framework

Ungar (2012, 2015), in exploring interventions with young people who have complex needs, and Petrenko and colleagues (Petrenko et al., 2014), in targeting the prevention of secondary disabilities for people with FASD, discuss how vital it is to locate FASD within ecological and/or systems-based frameworks. Ungar's social ecological framework takes account of the impacts of social disadvantage, marginalization, exclusion, trauma and disabling systems and argues for interventions that facilitate resilience and strength in young people, alongside the acknowledgement of system exclusion and traumatic experiences (Ungar, 2015). Ungar also argues that using an ecological framework can also help practitioners to develop practices that build positive relationships with young people, facilitate social justice, use advocacy and brokerage to assist young people to gain resources and acknowledge the importance and relevance of culture. This approach is effective, according to Ungar, because it attempts to change the environments and contexts around the young person and build up the resilience of the young person at the same time. Ungar (2012, 2015) has undertaken extensive research on the effectiveness of using this framework and how it enhances the resilience of vulnerable people.

Petrenko et al. (2014) complement Ungar's approach by focusing on the need for comprehensive, coordinated and tailor-made services and supports across systems, throughout a child or young person's lifespan. Petrenko and colleagues specifically developed an ecosystems framework for FASD and argue that it is useful in relation to the prevention of secondary disabilities, such as school exclusion or involvement with mental health systems. An ecosystems framework complements the brain-based framework and points directly to the need for accommodations by, and coordination of, systems, agencies, professionals, families and individuals in their responses to FASD, and across the lifespan (Olson et al., 2009).

Rights-based framework

People with FASD do not choose to be impaired, yet the reality is that they face continued stigmatizing and disabling responses from all sectors of society. For particular populations (especially children [including adopted children], those with impairments and Indigenous peoples), there are more specific rights that focus on factors such as inclusion, protection, participation and cultural heritage that may be relevant to FASD-informed practice. The rights-based framework has developed from a legacy of disability activism, the development of the social model of disability and the

implementation of human rights conventions (Degener, 2016; Oliver, 2009). The United Nations Convention on the Rights of the Child, the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Declaration on the Rights of Indigenous Peoples enshrine core rights (such as freedom of expression, active participation in society, self-determination) that social workers employ in their work with service users and communities. Ife (2012) identifies core traditions of human rights that are critical in social work: human, natural and legal rights. From a rights-based framework, all people have the right to have their basic needs met; to be nurtured, valued and respected; to receive health services and education; and to be free from discrimination (Van Heugten and Gibbs, 2015). In addition, service users who are also academics have strongly advocated for the inclusion of people with disabilities as co-equals in defining disability and in finding solutions to societal oppression of people with impairments (Oliver, 2009).

A rights-based framework promotes critical and radical approaches by professionals to working for and alongside their clients (Degener, 2016; Ife, 2012; Van Heugten and Gibbs, 2015); hence, social workers adopting a rights-based framework will work towards equity, equality, anti-discrimination, participation and social justice for those impacted by FASD. A rights-based framework draws on skills of advocacy, brokerage and mentoring to ensure that FASD is addressed at strategic and micro levels. Using this framework, social workers will challenge systemic barriers that exclude people with FASD and will advocate for diagnostic and intervention services for this group. A rights-based framework values diversity and will help service users build on their successes and positive achievements. Ife (2012) suggests that an approach to social work practice that includes advocating for rights with and for service users is often essential. At times, a practitioner using a rights-based framework may need to be both critical and activist in orientation, in a way that may go against the prevailing political, ideological and medical understandings of FASD, in order to ensure those with FASD can live successful lives (Good et al., 2017).

While these three frameworks are not the only relevant ones to consider for social work and FASD, they do offer the potential to provide social workers with some core concepts that they can draw on in their everyday encounters with individuals, families, services and communities. The weakness of these frameworks is that they do not solve or prevent FASD; they just offer a socially just context for social workers to intervene effectively.

Examples of effective practice models

We now present three models currently being used in Canada and New Zealand that utilize the above frameworks. The first focuses on how a co-ordinated and integrated approach to FASD intervention and support is facilitated by social workers in the Key Worker model, the second on the development of Communities of Practice and the third on advocacy and mentoring initiatives. These models have been influenced by Malbin's (2009) work on primary impairments from physical brain damage, as well as ecosystems frameworks, disability movements and rights-based frameworks (Degener, 2016; Ife, 2012; Rutman et al., 2011).

The Key Worker model, used in Canada and New Zealand

The Canadian Key Worker and Family Support model, originating in British Columbia, was the first comprehensive evidence-informed FASD casework model for FASD (Rutman et al., 2011). The model was developed by specialists from a range of fields, which drew on international research and practice experience in FASD and disability. The model is grounded in ecosystems frameworks and employs a non-judgemental and empathic relational approach that is family

centred, as well as one that emphasizes the importance of all stakeholders involved (including the client, family, professionals and other relevant people) having an understanding of the nature of FASD, which in turn underpins all practice, management and intervention (Petrenko et al., 2014; Rutman et al., 2011). In addition, it applies the neurobehavioural framework to FASD, in which FASD is framed primarily as a brain-based physical disability for which appropriate accommodations are required (Malbin, 2009).

While fundamentally a model of casework, the Key Worker model differs somewhat from traditional casework models of practice, as it has a dual role. One role, which is in line with traditional intensive casework models, is to provide support, education and intervention services to children, youth and families affected by FASD (Rutman et al., 2011). This involves the 'Key Worker' engaging with the family or individual to provide support; psychoeducation to link them to existing services across health, allied health, community and social services; education, justice and other relevant areas. The other role revolves around networking and capacity building. Within this role, the Key Worker, who has specialist training in FASD-informed practice, is able to provide training and consultancy to professionals within generalist pre-existing services who may not have much prior knowledge of FASD, enabling them to apply an FASD-informed lens to their practice. In a review of the model, professionals within the community service sector indicated that it had contributed to an increase in their understanding of FASD as a neurodevelopmental disability, and that it had helped them to modify their practice in keeping with this learning and understanding (Rutman et al., 2011). The dual role of Key Workers – as both family support professionals and consultants to other professionals – helps to ensure a coordinated effective approach to FASD management, which in turn decreases the chance of the duplication of services. This model has been shown to improve knowledge and services for families (Rutman et al., 2011). Importantly, the original Key Worker model was built on a regional service delivery model that was sensitive to regional variation and modifications, to meet local needs and family circumstances. This aspect of the programme design enabled its transferral to the New Zealand context.

Hawkes Bay, New Zealand. Hawkes Bay has a multidisciplinary diagnostic team within the health sector which has specialized in the diagnosis of developmental disabilities since 2003. In 2011, clinical capacity for diagnosing FASD specifically became available, after clinicians had travelled to Canada and the United States to undertake diagnostic training (Gibbs and Sherwood, 2017; Health Promotion Agency, 2015). The diagnostic team clinical coordinator, a social worker, has been instrumental in developing a model of working across disciplines to place the child/youth and family at the centre. This was grounded in the recognition that, ethically and morally, more was required than diagnostic intervention alone. Since 2011, the key focus of the work has been on education and training on the promotion of effective multidisciplinary work, co-creation in planning across sectors, shared resourcing and taking action, all underpinned by the centrality of the family as the recognized expert in their own needs. This approach could be identified as a Key Worker model, as well as growing a Community of Practice (CoP).

The model used in Hawkes Bay aimed to build working relationships on the basis of shared values, beliefs, attitudes and behaviours, and uses a common language for FASD, as well as specific FASD knowledge and skills (Health Promotion Agency, 2015). Resources have been shared and local solutions utilized, and relationships have been underpinned by goodwill and wanting the very best for New Zealand children and young people. The role of the social worker as a change agent has been pivotal in this model. It involves dealing with the challenges of

- service specifications (i.e. how services are contracted and delivered);
- the increasing complexity of families in a world of competing and ever increasing demands;

- children being misunderstood as ‘naughty’ or ‘wilful’ rather than impaired and/or misdiagnosed;
- philosophical differences between sectors;
- FASD not being recognized for inclusion in needs assessment services;
- working with those with power, who are in power, to support FASD initiatives.

Earlier we noted that social work practice is guided by understanding social justice and human rights, which includes an interface with economics and politics (and the values and beliefs that drive these). This has meant applying core social work values, philosophies, frameworks and theories to practice (Teater, 2015; Van Heugten and Gibbs, 2015). The progress in developing a local model of practice that uses a Key Worker approach alongside effective multiagency practice provides a forum to build working relationships, offers a menu of potential interventions and services to families, empowers and recognizes the family as knowledgeable about their needs, and celebrates the collective wisdom to co-create robust plans of action. There is no one expert; rather, the model recognizes that it takes many parts to make a whole, with high expectations for quality and accountability. Communication is with the whole cross-sector team to ensure transparency and to decrease the burden of multiple demands on families. There are agreed written plans that everyone sees, a visual ‘road map’ of services with named individuals who are able to be contacted, and other team-based communication tools. This enables everyone, including the family, to be kept informed of the work being completed from the agreed plan. The Key Worker role keeps the team linked and responding. The dual role of the Key Worker model in Hawkes Bay is similar to that of the Canadian Key Worker model in that, alongside individual casework, there has been provision of education and awareness training through the development and delivery of two education modules on FASD (Health Promotion Agency, 2015). This education and training has now been delivered to over 2000 health, allied health and social service professionals.

Communities of Practice in Alberta, Canada

A Community of Practice (CoP) is a group of people who share an interest, a practice and/or a profession (Lave and Wenger, 1991). The group can evolve naturally because of the members’ common interest in a particular domain or area or around a goal of gaining knowledge related to a specific area, such as FASD. It is through the process of sharing information and experiences with the group that the members learn from each other and have an opportunity to develop themselves personally and professionally.

The FASD CoP developed in Alberta as an innovation in child welfare practice for children and families where FASD was a concern. It began with a small pilot project, identified as the FASD Practice Standards, that took place from 2003 to 2005 in an urban/rural community in southern Alberta and that was positively evaluated (Badry et al., 2005). The initial project was considered successful in terms of supporting a population of children in care with high needs, and this led to the development of a research project funded by Policy Wise for Children from 2009 to 2011 (Pelech et al., 2013). This project focused on measuring the impact of training, both qualitatively and quantitatively, and its effect on child intervention practice for children and youth with FASD, later becoming known as the FASD CoP. Within the context of the project, the Alberta FASD Cross-Ministry Committee and the Alberta Human Services’ Ministry of Children’s Services (formerly Alberta Children and Youth Services) collaborated to provide training from 2009 to 2011 across the province on FASD, which included front-line workers, supervisors, managers and caregivers including foster parents and group care providers. The FASD CoP continued until 2015 with annual training taking place in various sites across the province. At present, a new provincial training framework is under development through the CanFASD Research Network under the

auspices of the Education and Training Advisory Council of the Alberta FASD Cross-Ministry Committee. Two pilot sessions of the revised CoP training were offered in 2018 in Alberta, and more training is planned.

The educational model for the FASD CoP offered basic training on FASD, but primarily focused on child-centred case management and caregiver support. Children with FASD need a team that is functioning in a consistent fashion in its work with the child. The training emphasized that FASD was a brain-based disability, and this supports shifting perceptions around the child's behaviour, often viewed as purposeful. In the training, participants were challenged to see the child as being 'hurt, not bad' and to recognize the effects of prenatal alcohol exposure. The knowledge and value of perceiving FASD as a disability due to the neurological (brain damage) and other impacts of prenatal alcohol exposure can change practice. The need to adapt and shape the environment based on the needs of the child was also critical in practice. It was determined that the FASD CoP training had a positive impact on placement stability for children involved in the research (Pelech et al., 2013).

The FASD CoP entered a new phase in 2013, known as The FASD CoP Initiative: Leading from Within (Badry, 2013). With experience in the previous iterations of the FASD CoP, Workforce Development in Alberta Human Services committed to advanced training on FASD and case management, and additional competency credits were offered through the Alberta College of Social Workers for participants who were registered social workers. The key aspects of this training were solutions through case management, advanced training, team competency and screening, and offering case consultation days. A key aspect of the Workforce Development training was to develop the skills, knowledge and leadership within the organization and to provide opportunities for those emerging leaders to train and consult on cases within their region and within the province. Child intervention/child welfare practice is a highly specialized area with intrinsic aspects of the work embedded within a child protection framework. In the case of FASD, the work is complex and challenging, and that is why specialized training is critical. To the best of our knowledge, there is no specific framework or model of practice in child protection intervention that is specific to FASD that has been published outside the FASD CoP research in Alberta (Badry, 2009, 2013; Badry et al., 2005; Pelech et al., 2013).

Advocacy and mentoring in Canada and New Zealand

While the previous two models have mentioned advocacy, our third example highlights the importance of both advocacy and mentoring from a rights-based and radical disability model standpoint that aims to help young people, as well as their families, to live successful lives and remain connected to their cultures and communities (Good et al., 2017). Advocacy is a skill at the heart of social work and stems from social work's long history of working to reduce disadvantage and oppression (Van Heugten and Gibbs, 2015). Being an advocate and enabling advocacy requires social workers to give up control, power, and support the marginalized group or person to allow them to be heard, to be included, to exercise their rights and to become self-determining. Mentoring is a powerful strategy for social workers to implement and use alongside advocacy. It can be understood as coming alongside someone to teach, model, motivate and facilitate learning and support (Tremblay, 2017). It allows workers, including social workers, to work alongside families and individuals and utilize skills of pro-social modelling, capability building, motivational interviewing and brokerage or negotiation. These two processes together are likely to build resilience, strength, hope and success and send a clear message that there are people out there who both know and care and have trodden the path before.

In Canada and New Zealand there are a number of best practice examples implementing both advocacy and mentoring in peer support situations. The Wellness, Resilience and Partnership (WRaP) Scheme from the province of Alberta (Tremblay, 2017) has had strong social work involvement, both strategically, in co-ordinating the scheme, and in operational terms, by employing trained social workers as Success Coaches. The role of Success Coach has included specific support for students with FASD, to enable them to stay at school and succeed in their school achievements and relationships. Success Coaches also support teachers with awareness training and day-to-day advice about the students in their caseload. This role has also included peer-to-peer support and professional development, whereby more experienced Success Coaches mentor and support the less experienced Coaches. The WRaP Scheme, which has also employed other professionally trained coaches, has been successful in many ways, including helping students with FASD to complete academic courses of study and achieving reduced school exclusions, as well as ensuring that staff and student awareness about FASD has increased (Tremblay, 2017). Unfortunately, WRaP as a specific provincial initiative has recently lost its core funding, but a number of schools in Alberta are continuing to use the Success Coaches to support their students because of their positive impact, and further funding is being sought.

The second example is that of the Parent Support Agency (PSA) in Calgary, which engaged in peer-to-peer support of parents/caregivers, operating specialist FASD parent-to-parent support groups from 2007 to late 2016. The role of the FASD group programme facilitator was undertaken by a social work or human services-trained employee. Their job was to facilitate regular parent-to-parent peer support meetings, as well as run educational and awareness-raising activities, and to help parents know there was support for them. Parents of children with FASD were also mentored and supported to take a role in running the monthly support groups. The work established by the PSA is now spread across three networks in Calgary but the involvement of social work is still considered important. A Coaching Families programme run out of Toronto and Edmonton also uses similar advocacy and mentoring strategies and has been shown to be effective (Leenaars et al., 2012; Pei et al., 2016; Petrenko and Alto, 2017).

In New Zealand there are similar parent-led initiatives using advocacy and mentoring, some with a strong disability rights and social work focus, which are especially important in the South Island of New Zealand where there is a recognized lack of formalized diagnostic or intervention services (Gibbs and Sherwood, 2017). One recent parent-to-parent initiative in Dunedin provides a 7-week 'best practices' course for caregiving and parenting children with FASD, with a clear aim to draw on the three frameworks discussed earlier (Gibbs and Eketone, 2018). This initiative has incorporated effective strategies from a range of sources, including research and expert consensus out of North America (e.g. Calgary Foetal Alcohol Network [CFAN], 2016; Malbin, 2009; Olson et al., 2009; Pei et al., 2016; Petrenko et al., 2014), and material from the lived experience of families. The group takes an empowerment, advocacy and mentoring orientation and aims to assist parents/caregivers who are caring for children with/or suspected to have FASD, to help families develop greater resilience and to develop strategies to live successfully with impairments in a disabling society. The course uses mentoring and advocacy strategies to help parents/caregivers develop specific strategies and interventions for their own families, as well as to use in relationships with professionals and in dealing with systems. Alongside the training course, parents/caregivers are encouraged to join a monthly peer support group. The course (developed for caregivers by caregivers) is in its early days and has had an initial interview-based evaluation, with caregivers reporting increased knowledge about FASD benefitting their parenting strategies (Gibbs and Eketone, 2018). The evidence from other similar initiatives is also promising (CFAN, 2016; Olson et al., 2009; Pei et al., 2016; Petrenko and Alto, 2017).

Discussion and conclusion

All three of the practice models presented in this article share certain characteristics that reflect a social work response, in so far as being systematic, anti-discriminatory, rights-based and concerned with advocacy. Importantly, they all place the individual and their family at the centre of decisions being made about their welfare. A social work response to FASD will almost always involve collaboration with other professionals, as well as with service users and their families. The specific operation of this differs depending on the local circumstances, but the underlying intent towards empowerment is shared.

Social workers can draw on the frameworks and models explored in this article to help people with FASD flourish, thrive and live successful lives. By doing so, social workers would be using effective models with a strong social justice and rights orientation but offering specific types of intervention to suit client need. In drawing on brain-based, ecosystem and rights-based knowledge, social workers will be able to identify the individual challenges that clients (and their families) face, as well as how situational and contextual factors can both help and hinder the lives of their clients. Each of the frameworks, to varying degrees, impacts the uses and applications of the practice models we have presented. These models for FASD-informed practice have some evidence to support them, but more research is required to fully understand how helpful they are when used by social workers specifically to assist clients and their families.

A second important characteristic of all three models is that they include educational elements – for health and social service workers as much as for individuals and their families. The specific education strategies employed in each case differ in terms of formality and structure, but overall the aim is the same: to achieve better welfare outcomes by empowering communities with relevant information and knowledge. Again, this is an area where more research could be undertaken as, although a few examples of excellent education for professionals exist (Badry, 2013; Hayes et al., 2014), more needs to be done to ensure that each professional group has access to appropriate, tailored training to suit their client population. For social workers, who are employed in a vast array of systems, their base training might include more introductory material on FASD. But depending on where they work, they may need more advanced knowledge of the disability and interventions to help families.

The practice models discussed in this article started out as small-scale initiatives, with limited finances and support, often community and parent initiated, and involving concerned individuals who might also have been human service professionals. Some of these models, like the Communities of Practice and the Key Worker model in Canada, received substantive funding to enable capacity building and research, and these initiatives have been shown to be effective as state-wide or country-wide initiatives. Other initiatives, like some of those involving mentoring and advocacy, struggle to get any funding at all, or fall victim to short-termism (as in the case of the WRaP and PSA advocacy initiatives in Alberta). It is logical then for lessons of good practice to be shared globally; after all, much of what has started in New Zealand has its origins in Canadian and other North American research.

The case for FASD knowledge development for social workers cannot be overstated, and the responsibility for the care of children with FASD involves everyone (Badry and Choate, 2015). This is cross-sector work involving many professions, but social work has a key role on the front lines in responding to children and families, and knowledge about FASD is essential for effective intervention and prevention. Children with FASD require understanding, and social work is a critical frontline discipline that is well positioned to make a positive difference in improving the lives of children with FASD and in supporting their families and caregivers.

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