Toward an Evaluation Framework for Community-Based FASD Prevention Programs

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Abstract: *This article discusses creation of common evaluation frameworks for FASD-related programs. The project was guided by a social determinants of health perspective and included a literature search and consultations across Canada to help refine and confirm the final product. The end result was development of three visual maps: FASD prevention programs, FASD support programs, and FASD programs in Aboriginal communities. Each map comprises concentric rings showing theoretical foundations; activities and approaches; and formative (program), participant, and community/systemic outcomes. The project website provides tools and indicators. The visual maps have wide-ranging applications that go beyond evaluation of FASD programs.*

Keywords: *Fetal Alcohol Spectrum Disorder, FASD Aboriginal programs, FASD conceptual framework, FASD prevention programs, FASD support programs, program evaluation, social determinants of health*

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Résumé : *Cet article décrit la création de cadres d'évaluation communs pour les programmes de l'ETCAF. Le projet a été guidé par des déterminants sociaux de la santé et comprenait une recherche documentaire ainsi que des consultations à travers le Canada afin d'aider à affiner et à confirmer le produit final. Le résultat final a été la réalisation de trois cartes visuelles comprenant : des programmes de prévention de l'ETCAF, des programmes de soutien de l'ETCAF et des programmes de l'ETCAF chez les communautés autochtones. Chaque carte est composée d'anneaux concentriques indiquant : les fondements théoriques, les activités et les approches ainsi que les résultats programmatiques chez les participants et au sein de la communauté. Le site web du projet propose des outils et des indicateurs. Ces cartes visuelles ont des applications qui vont au-delà des programmes de l'ETCAF.*

Mots clés : *ensemble des troubles causés par l'alcoolisation fœtale, programmes aborigènes de l'ETCAF, cadre conceptuel de l'ETCAF, programmes de prévention de l'ETCAF, programmes de soutien de l'ETCAF, évaluation de programme, déterminants sociaux de santé*

The *Toward an Evaluation Framework for Community-Based FASD Prevention Programs* project grew out of the authors' research in the field of Fetal Alcohol Spectrum Disorder (FASD). As a result of our collective experiences, we were aware that, to date, there have been few focused opportunities for program planners, program staff, funders, and evaluators to identify relevant outcomes, indicators, and evaluation approaches that work best for programs working with women at risk of having an alcohol-exposed pregnancy, and for programs supporting individuals with FASD. The current project was undertaken to address this gap in our knowledge of promising practices in the evaluation of community-based FASD programs.

The project addressed three interrelated challenges in relation to the evaluation of community-based Fetal Alcohol Spectrum Disorder (FASD) programs. First, while an increasing number of programs in Canada are employing a social determinants of health framework, relatively few independent evaluations of FASD programs have been conducted (or reported in the literature). Second, articulation of a conceptual framework that anchors program activities and outcomes is hard to find; and third, many small community-based agencies and programs lack the resources necessary to undertake or respond to funders' expectations with respect to evaluation.

One goal of the project was to develop common evaluation approaches that are responsive to the social, cultural, and geographic diversity evident in programs serving women at risk of having a child with FASD, birth mothers and their children, interventions with families caring for children with FASD, programs for youth and adults with FASD, and FASD programs in Aboriginal communities. Another goal was to support the use of common evaluation measures so that program managers could understand what works and for whom, and thus the types of program outcomes that could be reasonably expected.

WHAT IS FASD?

Fetal Alcohol Spectrum Disorder (FASD) is an umbrella term used to describe the range of disabilities that can be the result of prenatal exposure to alcohol. Research indicates that pregnant women who drink do so in response to issues of poverty, trauma, violence, isolation, peer and partner influences, and cultural discrimination, to name a few (Poole, 2003; Van Bibber, 1997). Consequently FASD is a significant health and social concern in Canada (Institute of Health Economics, 2009) that requires a broad social determinants approach if it is to be prevented (Institute of Health Economics, 2009; Network Action Team on FASD Prevention from a Women's Health Determinants Perspective, 2010; Public Health Agency of Canada, 2005).

EVALUATION OF FASD PROGRAMS

Only a handful of published evaluations of comprehensive perinatal support services exist: they include evaluations of the Sheway program in Vancouver (Poole, 2000), the Breaking the Cycle program in Toronto (Motz, Leslie, Pepler, Moore, & Freeman, 2006), the Healthy, Empowered and Resilient Program in Edmonton (Wodinski, Wanke, & Khan, 2013), the Women's and Children's Healing and Recovery Program in Yellowknife (Four Worlds Centre for Development Learning, 2003), and the New Choices program in Hamilton (Niccols & Sword, 2005). Finding published research related to evaluations of programs providing support to individuals living with FASD or their families is even more difficult. Evaluations of the Step-by-Step program in Alberta (Denys, Rasmussen & Henneveld, 2011), the Key Worker program in British Columbia (Rutman, Hubberstey & Hume, 2011), and the Youth Outreach Program in British Columbia (Hubberstey, Rutman & Hume, 2014) can be found in the literature.

Program managers, policy makers, and funders have had few opportunities to collaboratively discuss anticipated outcomes for programs serving women who are at risk of having an alcohol-exposed pregnancy or programs supporting individuals with FASD or their families. Too often this discussion has been pre-empted by funding organizations with their own requirements for data collection, reporting, and accountability (Liket, Rey-Garcia, & Maas, 2014). Surveys of the nonprofit sector in the United States have found that "funders asking you to report on the wrong data" was a significant challenge for nonprofit agencies; approximately one third of the agencies surveyed reported that most of the data collected was not used (Innovation Network, 2012, p. 12).

The absence of a universal, well-articulated evaluation framework has made it difficult for those wanting to identify program characteristics that contribute to positive client and community outcomes. This leaves program staff, planners, and policy makers without the information they require to know whether or how programs contribute to FASD prevention, to improve the health of women and/or those living with FASD, and to help prevent or reduce secondary and tertiary effects of FASD.

PROJECT APPROACH

Working with an Advisory Committee comprising academics, researchers, and program/agency managers from across Canada, we conducted a jurisdictional scan of existing published and unpublished research and evaluation literature. Finding published evaluations of community-based programs can be challenging; thus the team sought out researchers, evaluators, and program providers in Canada and internationally to ask for outstanding examples of evaluations of FASD prevention and FASD support programs. We reviewed evaluations related to pregnancy outreach programs, parent mentoring programs (e.g., Parent-Child Assistance Program), supportive intervention[1] programs for youth or adults living with FASD, programs focusing on addressing social determinants of health for pregnant and parenting women, and FASD prevention or support programs within Aboriginal communities. Some of the reports received were unpublished or not widely available, a common dilemma when pursuing evaluation literature.

Our review asked the following questions:

- How were FASD prevention and intervention programs being evaluated?
- What methodologies and methods of data collection were employed?
- What were identified as key program activities and approaches?
- What were the theoretical and/or philosophical underpinnings of the programs?
- What were identified as key participant, program, and community outcomes?
- What were markers of success?
- What data collection tools were used in the evaluations?
- What did evaluators identify as being promising approaches to evaluation?

Using these questions as our parameters, the information was synthesized, initially, into two evaluation framework matrices (prevention and support programs) that identified common activities, output indicators, and formative and summative outcomes. The intent was to create a framework that captured key concepts and was easy to understand and use by a range of audiences. The team also wanted to make explicit the interrelationship and factors that influence both programs' and participants' outcomes. However, the matrices were large, complex, visually unsatisfactory, and unwieldy for this purpose. Instead, visual maps were developed that depicted the "big picture" and linked theoretical foundations with program activities and program and participant outcomes, along with community and systemic outcomes.

One-day regional consultations were initially held with key practitioners and researchers in the FASD field in Halifax, Toronto, and Vancouver. Additional regional consultations were later held in Whitehorse and Yellowknife. The focus was to receive feedback on the maps and input on additional resources. These meetings confirmed the need for a framework specific to programs within

Aboriginal communities. The result was three maps showing evaluation of (a) FASD prevention programs, (b) FASD support programs, and (c) FASD programs in Aboriginal communities.

THE MAPS EXPLAINED

The circular structure of the maps (Figure 1) is a unique feature and was a deliberate choice to help to distinguish them from traditional logic models that typically use a matrix and from other visual images that are often a variation on the matrix. The circular design works well with, and was informed by, Indigenous frameworks of well-being that are holistic and place an emphasis on interconnectedness of all aspects of existence (Kryzanowski & McIntyre, 2011).

Although the maps are similar in many respects, there are also some unique features, beginning with the innermost ring. For example, at the heart of the map pertaining to FASD programs in Aboriginal communities is culture, which is then encircled by "family, child, youth, adult, and elder" to signify the centrality of culture and extended family in wellness and healing. For the prevention programs evaluation map, the "pregnant woman/mother and child" is the centre to show that prevention programs need to regard both the woman and child (or fetus) as "clients": for example, the Breaking the Cycle program is built on the notion that the connection between mother and child is the program's "client" (Motz, Leslie, Pepler, Moore, & Freeman, 2006).

At the heart of the support program map is the "youth/adult with FASD," to show the importance of an individualized approach to working with people living with FASD.

Philosophical/Theoretical Framework

The next ring in all of the maps is Philosophical/Theoretical Framework. This is another unique feature of the maps. The philosophical underpinnings of a program are key to understanding its activities and approaches. To illustrate, if a program is designed with a philosophy of being outreach-based, then the program's activities and ways of engaging potential clients should reflect this. Similarly, if harm reduction is a philosophical underpinning, then a strict requirement for abstinence within the program may not be congruent without including some harm reduction strategies as well. Our review of the literature and our own experience told us that fleshing out programs' philosophies is an often-overlooked step.

The philosophies described in these maps reflect the social determinants of health approach and are consistent with information gleaned during consultations with community programs across Canada. It is important to note that FASD programs do not need to be based on all of the elements that are listed within this circle. Rather, the maps depict an array of philosophical/theoretical elements that Canadian and international FASD programs have said are important to the delivery of these types of programs.
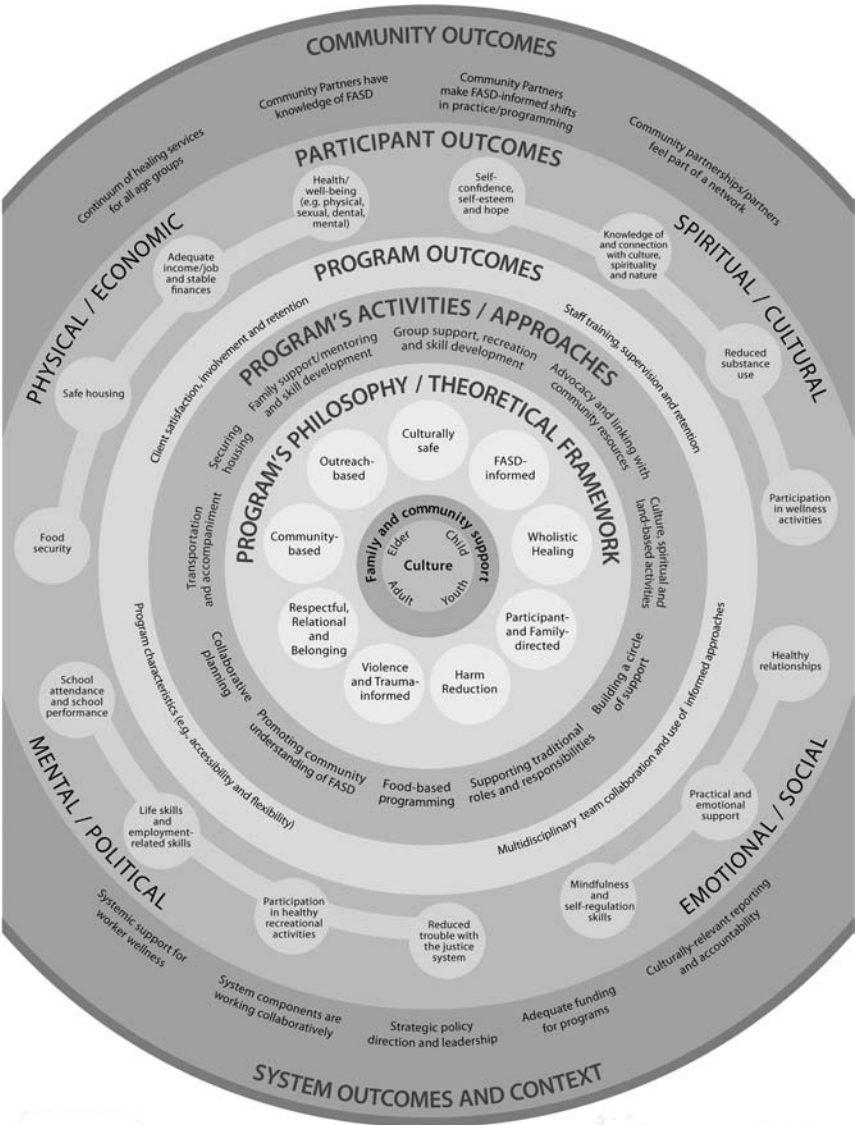
Figure 1. Evaluation Map of FASD Programs in Aboriginal Communities

There are eight philosophical/theoretical framework elements that are common across all maps: FASD-informed; culturally safe; holistic and multi-disciplinary; respectful, relational, belonging; participant/family-directed; violence and trauma-informed; harm reduction; and outreach-based. Mothering and developmental lens is found in the Prevention Map.

The maps and the materials provided on the project website are designed to help individuals working in community programs to be able to clearly describe

the approaches used in the programs and make connections between program philosophy and program activities. For example, during one consultation with a community-based FASD support agency that works with many Aboriginal clients, it became apparent that being culturally safe was important to how service was delivered and was an implicitly held value, but it wasn't something that staff or managers had discussed in terms of how it could or should shape their practice. In posing a question about this, the staff engaged in a constructive discussion about what being culturally safe meant and how that might be more explicitly reflected in the program and in the agency's practices and policies.

Activities/Approaches

The next circle, "Activities/Approaches," identifies the various activities that FASD programs typically undertake. Again, the maps do not depict all of the activities that programs may subscribe to; they are meant to show the number and types of activities that can constitute effective FASD programs. As well, by naming these activities, we also make visible what in some cases are invisible— and unfunded—program activities, such as transportation, accompanying clients to meetings, and providing food. It can also make clearer, to program staff, the importance of all program activities if anticipated program outcomes are to be achieved. We have found, for example, that one-to-one support and role modelling can become a strong focus due to the demands of program participants, while the value of other activities, such as working with extended families, can be overlooked.

Program Outcomes

The next ring of the map, "Program Outcomes," identifies four key categories of formative outcomes and pulls together the elements of the "Philosophical/ Theoretical Framework" ring with outcomes related to participants' and service providers' experience of the program, as well as with systemic outcomes. This category is deliberately broad-based; however, specific program outcomes are named on the project website.

Participant Outcomes/Community and Systemic Outcomes

Finally, the two outermost rings of the evaluation map identify summative outcomes for participants and outcomes at a community and systemic level. The inclusion of community and systemic outcomes, another unique feature of the framework and maps, acknowledge the multiple influences on client outcomes. These are longer-term actions and outcomes that can yield significant results, for example, partnerships that can lead to improved community understanding of FASD, or strategic leadership that can lead to housing policies that better accommodate housing clients with FASD.

It is important to emphasize once again that FASD programs do not need to achieve all the participant outcomes named in the circles of this ring; the maps provide information regarding the array of outcomes that FASD programs

collectively have identified as being desirable and/or achievable. An additional feature of the design of the "Participant Outcomes" ring in our maps is the clustering of outcomes by quadrants recognized within Indigenous frameworks (e.g., spiritual and mental), which again reflects our intent to emphasize the importance of conceptualizing program delivery, and participant needs and outcomes, from a holistic perspective.

The team also developed a website that contains the maps along with examples of evaluation data-collection materials related to each element.

IMPLICATIONS

The evaluation maps developed through this project represent a departure from the more traditional linear or matrix style of evaluation frameworks. They also represented a different approach to building an evaluation framework, starting with input from other evaluators and managers of community-based FASD programs for which there was documented evidence of client and program outcomes.

The holistic approaches, as reflected by the circles and the four aspects of wellness (spiritual, mental, physical, and emotional) are an important foundation of the work. They respect and address the scope of influences on women's drinking and the range of needs of those with FASD.

The evaluation maps have been well received. We have heard from several quarters that the maps enable managers to talk with funders about the types of program activities that work best with participants with FASD, and why. The circular nature of the maps also resonated with participants in the consultation process, some of whom subsequently reported that the evaluation maps have inspired them to reflect on their program philosophy and how they might translate these principles into practice. The maps have also resonated with Aboriginal program managers who appreciate the placement of culture at the centre of program evaluation and have helped others confirm why certain activities are provided, such as transportation or the inclusion of food in program activities, while also revealing areas where there may be gaps.

As well, system planners have expressed interest in moving away from the rather narrow scope of outcomes that have often been imposed, and to look instead at how their work can respect the wide range of outcomes being achieved by programs. Together, the interest and participation of diverse groups in refining the frameworks affirm the multisectoral approach to building a body of knowledge about what contributes to positive outcomes for clients and communities.

CONCLUSIONS

The evaluation framework presented in this article is intended to support a common evaluation language for FASD programs so that they can grow, be sustained, and be shared with other communities. The maps do not remove the need to develop an evaluation framework and evaluation plan when conducting

program evaluation. They do provide a basis for that work and help to make visible the link between various components of a program and its evaluation. As well, it was apparent throughout the project that the maps can be used for programs other than those addressing FASD. Indeed, we have already heard of the maps being used and adapted by communities and agencies in Canada and internationally.

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NOTE

1 We have defined "FASD support programs" and "FASD supportive intervention programs" as programs that aim to support and/or assist people living with FASD and their families and support networks to improve knowledge, skills, and community connections, so as to better address issues associated with day-to-day living. These programs are not primarily focused on addressing the primary effects of FASD (e.g., improving aspects of cognitive functioning known to be particularly affected by prenatal exposure to alcohol), as FASD intervention programs might be.

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