

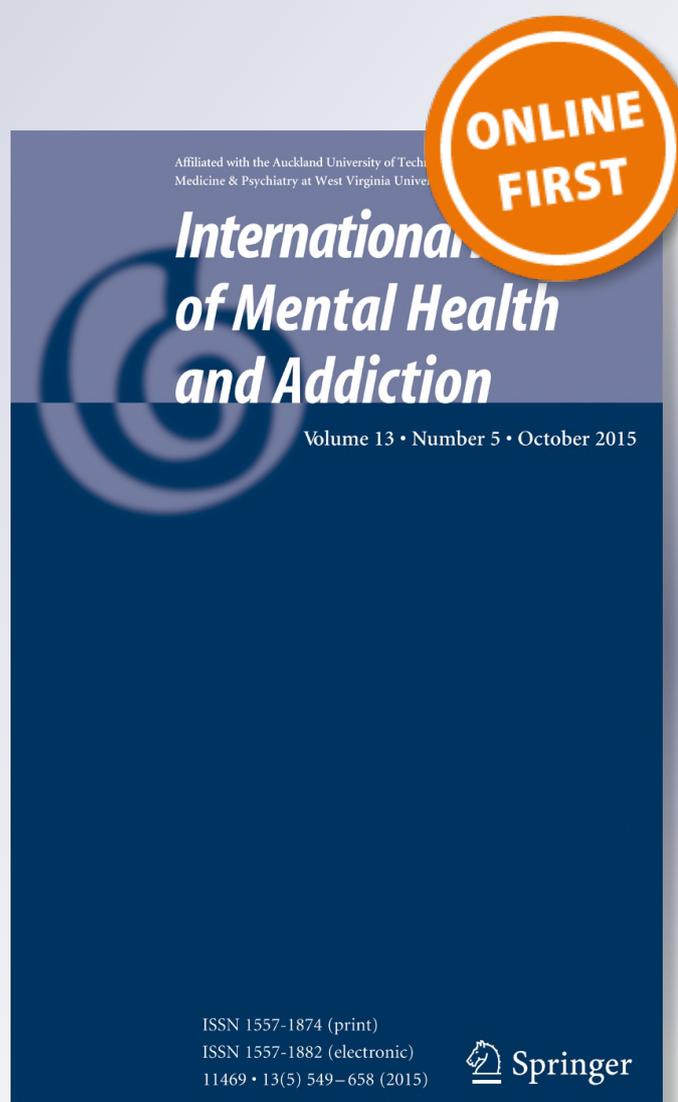
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Developing and Using a Common Framework to Evaluate FASD Programs: Results of a Three-Year Canadian Project

Deborah Rutman^{1,2} · Carol Hubberstey¹ ·
Nancy Poole^{2,3} · Sharon Hume¹ · Marilyn Van Bibber^{1,2}

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Abstract This article discusses a three-year Canadian project that created common Evaluation Frameworks for Fetal Alcohol Spectrum Disorder (FASD) support programs and for FASD prevention programs (i.e., programs serving people living with FASD and programs serving pregnant women and mothers). The project's mixed-methods approach included a comprehensive literature search and consultations across Canada with multi-disciplinary service providers, program funders, researchers, and evaluators. These activities led to development of three visual “maps” depicting evaluation of: a) FASD support programs; b) FASD prevention programs; and c) FASD programming in Aboriginal communities. In addition, the team provided mentoring and evaluation-related support to program staff, funders and/or partners of five community-based FASD-related agencies. Informed by a social determinants of health lens, the maps are comprised of concentric rings showing programs': theoretical foundations; activities; program outcomes; and wholistic participant, community and systemic outcomes. The article also shares findings regarding the applicability and utility of the Frameworks and of evaluation-related mentoring.

Keywords Fetal alcohol spectrum disorder · Program evaluation · Evaluation mentoring · Evaluation framework · FASD support programs · Social determinants of health

In recent years, the research literature and practice evidence are increasingly emphasizing the value of a social determinants of health approach in working to prevent Fetal Alcohol

✉ Deborah Rutman
drutman@uvic.ca

¹ Nota Bene Consulting Group, 1434 Vining St., Victoria, BC V8R 1P8, Canada

² Canada FASD Research Network, Network Action Team on Prevention, Vancouver, BC, Canada

³ British Columbia Centre of Excellence for Women's Health, Vancouver, Canada

Spectrum Disorder (FASD) (Institute of Health Economics 2009; Network Action Team on FASD Prevention from a Women's Health Determinants Perspective 2010). Correspondingly, a growing number of programs in Canada are employing a social determinants of health framework in working with women at risk of having a child with FASD and/or in supporting people living with FASD.

At the same time, there has been very limited independent evaluation of FASD prevention programs or of programs designed to support young people and adults living with Fetal Alcohol Spectrum Disorder. Indeed, systematic evaluations of programs geared to providing support to individuals living with FASD or their families are particularly difficult to find in the literature, although some notable exceptions have been published recently, including evaluations of the Youth Outreach Program in Burns Lake, British Columbia (Hubberstey et al. 2014), the Step by Step program in Alberta (Denys et al. 2011) and the Key Worker program in British Columbia (Rutman et al. 2011).

Similarly, in terms of the evaluation of FASD prevention programs, relatively few comprehensive perinatal support services have been the focus of published evaluation studies though the number is increasing and those that have been published have made an important contribution to the field. For example, the evaluations of the Breaking the Cycle program in Toronto conducted by Motz and colleagues (2006), the Sheway program evaluation in Vancouver conducted by Poole (2000), the New Choices program in Hamilton, Ontario conducted by Niccols and Sword (2005), as well as evaluation of the Parent-Child Assistance Program (PCAP), a parenting mentoring program initially developed, implemented and evaluated in Seattle Washington (Grant et al. 2005) and then adapted for application elsewhere in North America with diverse populations including with women who themselves have the behaviours or characteristics of FASD (Rasmussen et al. 2012) have all been critically important in terms of guiding program development and advancing program evaluation practice.

Still, to date there have been few opportunities for program planners, managers, staff, and funders to come together to discuss the goals and anticipated outcomes of programs that support individuals with FASD or that serve women at risk of having an alcohol-exposed pregnancy. This has meant that in North America and internationally, we lack common evaluation methods, conceptions of appropriate, achievable client outcomes, and indicators of those outcomes. This absence of a common, well-articulated evaluation framework has made it difficult for program staff, planners and funders to identify which aspects of programs contribute to positive client and community outcomes. Moreover, our absence of a common evaluation framework has also hampered efforts to conduct multi-site studies to identify whether or how programs contribute to FASD prevention, improve the health of women living with addiction, trauma and/or mental health issues, and/or those living with FASD.

To address this knowledge gap, the *Toward an Evaluation Framework for Community-based FASD Prevention Programs* project was conceived with the aim of bringing program managers and staff, evaluators, and funders together to identify promising evaluation methods and to create common evaluation frameworks and tools for FASD prevention programs serving pregnant women and mothers, and for FASD supportive intervention programs¹ serving youth and adults living with

¹ In this project, we use the terms "FASD-supportive intervention programs" and "FASD support programs" interchangeably, and we have defined these 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 differ from FASD intervention programs in that they are not primarily focused on addressing or ameliorating the primary effects of FASD (e.g., improving aspects of cognitive functioning known to be particularly affected by prenatal exposure to alcohol).

FASD. As well, in view of the reality that community-based programs face mounting pressure to undertake evaluation, the project aimed to enhance community-based evaluation capacity by providing approximately six months of evaluation-related mentoring to several community agencies in Canada and by creating evaluation materials and bringing together well-regarded tools and resources that exist within the public domain. This article presents the Evaluation Frameworks and other materials developed through the project and also shares findings regarding the applicability and utility of the Frameworks and of evaluation-related mentoring, based on the perspectives of program managers and staff of a community-based organization that provides support, outreach, housing and advocacy for adults and young people living with FASD.

Methodology

The project's five-person team has expertise in FASD prevention and research, in the evaluation of FASD-related programs, and in working with and for Aboriginal communities to address issues related to the social determinants of health and community-based FASD prevention. The project also was informed by participatory approaches and involved a national Advisory Committee comprised of 13 people with expertise in mental health and addiction, FASD prevention and social determinants of health, and evaluation.

Philosophically, the team's starting point has been to view program evaluation as a means to improve learning about: how a particular model works with a given population; how program improvements can be made; and what difference a program is making for participants, providers, communities and service systems. As such, evaluation is a resource to inform evidenced-based decision-making, program development and program refinement (Hutchinson and van der Woerd 2010; Patton 2011).

The project's multi-method process involved a number of integrated and iterative data-collection activities. As an initial step, we contacted program providers, researchers, and evaluators across Canada and internationally in order to identify and gather published and unpublished evaluations of FASD prevention and FASD support programs, including evaluations of pregnancy outreach programs, parent mentoring programs, supportive intervention 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. We then undertook a review of these published and unpublished reports and related materials, guided by the following questions:

- How were FASD prevention and support programs being evaluated? What methodologies and methods of data collection were employed?
- What were identified as key program activities and approaches, and what were the theoretical and/or philosophical underpinnings of the programs?
- What were identified as key participant, program and community outcomes, including both formative and summative, and short-term, intermediate and long-term outcomes?
- What data collection tools were used in the evaluations?

The project team received input on key outcomes, indicators, and respectful and effective approaches and tools for collecting evaluation and outcome data. In our efforts to organize this rich and detailed information, we first created a large matrix of information (i.e., program by program, we endeavoured to lay out programs' anticipated outcomes, indicators of outcomes,

key program activities, and evaluation methods). However, fairly soon into this process, we realized that visual depictions of the information would be more useful, as this would enable “mapping” of a program’s theoretical underpinnings, activities, and anticipated formative and summative outcomes. This realization led us to create three Maps, which depict evaluation of 1) FASD prevention programs; 2) FASD support programs; and 3) FASD programs in Aboriginal communities.

The next key facet of our project process was to obtain feedback on our emerging evaluation frameworks.² Accordingly, in the fall of 2011 and in spring/summer of 2012, the team facilitated day-long consultations with program providers and researchers in five regions of Canada. Participants of the consultations came from a variety of professional disciplines and/or were involved in a number of different types of programming for pregnant/parenting women or for families/youth/children who may have FASD, e.g., Managers of CAP-C (Community Action Program for Children) programs, Managers/Coordinators of Mental Health and Addictions programs, Managers/Coordinators of family serving agencies, staff of Friendship Centres, First Nations services, health care providers (Clinical Nurse Specialists, pediatrician, PHNs), researchers, evaluation and knowledge exchange specialists, government policy makers/program planners within perinatal health, early childhood development and prevention/addictions services. Consultative workshops were also held at conferences such as at the International FASD Prevention Conference in September 2013, with Canada-wide and international participants. All in all, approximately 250 people from all regions in Canada participated in consultations and presentations related to the project.

During the second half of the project, the team further developed the Maps, identifying evaluation indicators and tools that address the layered outcomes of the frameworks, and we launched a website (www.fasd-evaluation.ca) which provides the operational definitions for the philosophical/theoretical approaches, outcomes, indicators, and relevant, publicly available measurement tools.

In addition, the team provided mentoring and evaluation-related support to staff and managers and, in some cases, funders and researchers connected with five Canadian community-based programs/agencies (in British Columbia, Manitoba and the Yukon Territory). Three of the programs were FASD prevention-focused, offering support and services to high-risk pregnant and parenting women and their children; two agencies were FASD supportive intervention-focused, offering support, outreach and advocacy for youth and adults living with FASD; one agency was Aboriginal and another program was rooted in Aboriginal values and perspectives. Many if not the majority of the participants of all five program/agencies struggled with mental health and addictions issues, as well as past and current experiences of violence and trauma.

Evaluation-related mentoring took place over the course of several months, with discussions occurring through teleconferences, web-based technology and face-to-face ‘workshop-style’ meeting(s) that involved program staff, managers, funders, and community partners invited by the community agency. The mentoring focused on helping programs address evaluation-related questions or issues that were of greatest concern to the agencies; our approach was to offer whatever support or guidance was requested by the agency and to work collaboratively and iteratively, jointly building and refining evaluation-related frameworks and materials. In most cases, the evaluation-related mentoring provided community programs with

² Please note that in this discussion and in the Findings section we are using the terms Evaluation Map and Evaluation Framework interchangeably.

opportunities to develop and/or refine their own program-specific evaluation frameworks and identify outcomes, indicators and data collection processes and tools that were most relevant to them.

Finally, as a part of the project's wrap-up and as means to explore agency staffs' experiences of the mentoring process and their perspectives on the relevance and utility of the Evaluation Maps, we gathered feedback via semi-structured phone interviews or face-to-face conversations, from managers of the agencies to which we provided evaluation support. In addition, two of the agency managers shared their perspectives on the project and the maps through participation on a panel discussion session delivered at an International FASD Prevention conference in 2013.

Findings

We begin this section by providing an overview of the FASD Evaluation Maps and their key characteristics; a more detailed description of the Maps is available elsewhere (Rutman et al. 2014). Following this, we share one agency's experience and perspective on its use of Evaluation Maps to strengthen evaluation, program development and reflective practice. For sake of brevity, this article focuses on presenting the Evaluation Map for FASD Support Programs and on the mentoring experiences of an agency that provides support, advocacy and outreach to people living with FASD.³

As shown in Fig. 1, one of the most striking aspects of all three maps' design is their circular structure. This immediately distinguishes them from more typical evaluation frameworks or logic models that tend to use a linear or tabular layout. Indeed, the circular design is congruent with, and has been informed by, Indigenous wheel-based frameworks of well-being that emphasize inter-connections between all dimensions of existence and the centrality of wholistic approaches to healing and understanding (Kryzanowski and McIntyre 2011).

In the innermost ring of the map is "Youth/Adult with FASD". Placing youth/adults with FASD at the heart of our framework reflects and is meant to emphasize appreciation of the degree of heterogeneity that exists amongst people living with FASD and thus the importance of an individualized approach to working with people with FASD. Placing "Youth/Adult with FASD" at the centre of the map also reflects FASD programs' participant-centered approach to service delivery, an element reiterated in the third ring (Philosophical/Theoretical Framework) of our maps. The innermost ring is then surrounded by "Family and Community Support" to reflect the central importance that family and community has or can have in supporting a person living with FASD. As well, the chromatically linked blue tones of the two innermost rings in the map are intended to emphasize the inter-connections between the adult/youth with FASD and family and community support.

The next ring of our Evaluation Map focuses on the elements of a program's philosophy and/or theoretical framework. We believe that identifying key elements of FASD prevention

³ The overall design and the majority of elements of are shared across the three Evaluation Maps. At the same time, there are also some important differences between the Maps. For example, the evaluation map pertaining to FASD programs in Aboriginal communities has "Culture" in the innermost ring, which is then encircled by "Family, Child, Youth, Adult, and Elder" to denote the centrality of culture and extended family in the provision of support leading to wellness and healing. The Evaluation Map for FASD Prevention Programs has "Pregnant woman/mother and child" in the innermost ring to reflect our understanding that FASD prevention programs need to focus on *both* the woman and her child (or fetus).

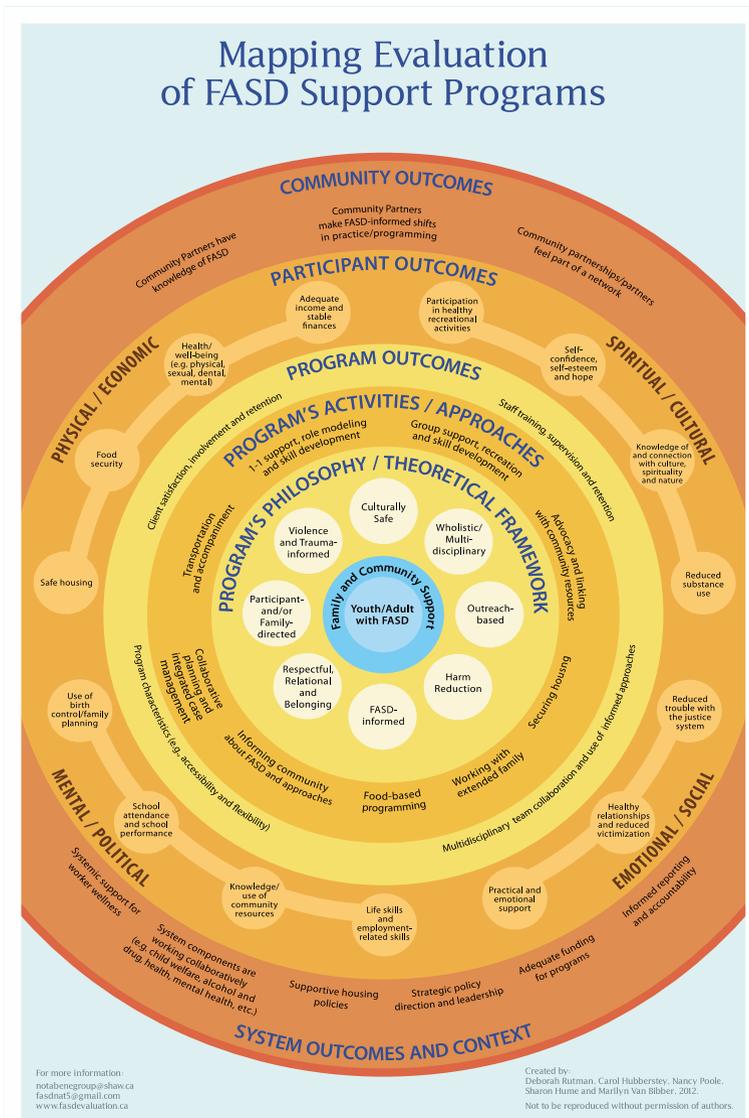


Fig. 1 Evaluation map of fasd support programs

and support programs’ theoretical framework is essential to successful program planning, implementation and evaluation. At the same time, through this project, we learned that evaluation frameworks/logic models typically do not include articulation of the program’s underlying conceptual framework.

In the Evaluation Map for FASD Support Programs, we identify eight elements that may be part of a program’s guiding theoretical framework. We stress that programs need not be guided by all of these elements in their own conceptual map. Rather, we included each of these elements in the Evaluation Map to reflect the fact that Canadian and international FASD support and prevention programs themselves have identified these elements to be important in their service model.

The next ring of the Evaluation Maps is Activities/Approaches, wherein we identify and display the array of activities that can comprise effective FASD support-related programs. As with all rings of the Maps, our intent here is not to be prescriptive and advise that a given program ought to offer all services or activities, but rather to honour the breadth of activities that programs have included in their supportive intervention programming.

Moving to the Program Outcomes ring, we identify four categories of formative/process outcomes that are relevant to FASD support and prevention programs, including outcomes relating to participants' experience of the program, staffs' experience, training and supervision, collaborations and partnerships, and adequacy of program funding and sustainability.

Lastly, summative outcomes for program participants, communities and systems-level outcomes are depicted in the two outermost rings of the Evaluation Maps. A key feature of the Participant Outcomes ring is the suggestive clustering of outcomes by quadrants recognized within Indigenous frameworks (e.g., spiritual, mental, physical and emotional well-being), which underscores our intent to emphasize the value of conceptualizing program delivery and participant needs and outcomes from a wholistic perspective.

In addition, as noted above, to augment the utility of the Evaluation Maps, our project's website (www.fasd-evaluation.ca) provides definitions, potential indicators and publicly accessible, standardized (validated) data collection tools that can assist evaluators and program staff to assess program, participant, community-based and systemic outcomes.

Programs' Experiences of the FASD Evaluation Maps and the Mentoring Process

As noted in the Methodology, an important component of our three-year project was to offer evaluation-related mentoring to five FASD prevention or FASD support programs/agencies in several jurisdictions in Canada. In this section of the findings, we share one FASD support agency's perspective on the Evaluation Maps and the mentoring experience.

The non-profit agency is located in Winnipeg, Manitoba and has been providing individualized support, outreach, advocacy, case management and/or supported housing to youth and adults with FASD (or a similar neurodevelopmental disability) since 2005. In keeping with many social service agencies, comprehensive evaluation of the organization's programs has been limited by lack of organizational resources and also has been undertaken in different ways, depending on the evaluation and monitoring-related requirements of the agency's various program funders. As a result of these realities, the agency had not had an opportunity to conceptualize and create a common evaluation framework for its programs.

When our project team first contacted the Executive Director of the agency, the timing was propitious: the agency's managers and staff had been increasingly expressing a desire to hold focused discussions on evaluation and to create a consolidated evaluation framework and identify relevant and appropriate tools and processes for evaluation-related data collection and reporting. As well, program staff increasingly voiced concerns about an existing evaluation framework/logic model that was being used to monitor and evaluate one of the agency's ongoing programs; this framework had been developed some years ago, and in recent years agency staff had expressed concerns that this logic model and its participant/client outcomes did not sufficiently take into consideration the ways in which FASD affected individuals (i.e., the reality that many people with FASD may not live fully independently, and rather that their living *inter-dependently* with ongoing support would represent a positive outcome) and thus what should be expected as achievable client

outcomes. Fortunately, the agency's principal funder (the provincial government) and other community partners were equally interested in FASD-informed evaluation and thus were keen to participate in our project's mentoring-related activities and discussions.

Our evaluation-related support began with discussions with the agency's managers about what would be most useful and what they hoped to achieve through involvement with our project and its opportunity for mentoring. We also engaged in detailed discussions regarding the elements of the Evaluation Maps and specifically the Evaluation Map for FASD Support Programs. Then, working collaboratively with agency staff and in an iterative fashion, using knowledge of the agency's programs that we gleaned from our initial phone discussions supplemented by program documents (e.g., program flyers, conference presentations made by the agency's Executive Director and program managers, and annual reports), we drafted an overarching Evaluation Framework/logic model for the agency's programs as a whole as well as a specific Evaluation Framework for the program that was soon to undergo its annual review by the program funder.

In drafting these Evaluation Frameworks, we paid particular attention to articulating the agency's underlying assumptions and principles/theoretical framework, using the elements contained within our Program Philosophy ring of the Evaluation Maps as a guide; this was viewed as being particularly important since it often is overlooked in program evaluation. As noted previously, connecting the program's theoretical framework to the program's approaches/activities and then to relevant, achievable participant and community outcomes is a hallmark of the Evaluation Maps.

The Evaluation Maps and the custom-tailored Evaluation Frameworks we developed with the agency were well received by program managers, staff, and the program's funder. For example, commenting on the value of the Evaluation Maps, one senior manager stated:

The Evaluation Maps are now hanging in my office as well as in the offices of the manager and the coordinators of the Men's Outreach program. The Map provides a very nice visual support for the agency's Mission and Values Statement. It puts the Mission and Values Statement into perspective; we can take our agency goals and mission and say, "This is what they look like in action." For example, our goals such as community responsiveness, fostering positive growth, FASD prevention, improving lifelong outcomes through services, responding to the unique needs of youth and adults, community development, and cultural diversity - these are just some of the agency goals that become more visible and alive through the Maps. The Maps capture what we are trying to do.

In addition, reflecting on his experience with the mentoring support provided through the project, the same manager stated that the evaluation-related discussions and use of the Maps as a means to 'visualize' his programs' approaches, activities, and intended participant and community outcomes helped him to appreciate what was missing from the agency's previous evaluations and what was needed to ensure that evaluations were grounded in the agency's goals and values, moving forward. He stated:

When I look at the Evaluation Map I don't think it is all that difficult to create another evaluation framework by using what we did already. Start in the middle and work out. The Map helps with that. I feel I can re-create a framework for other programs based on what we did together and the logic model that was created for [our program]. The consultation was useful, so I feel we can take what we did and re-create it. I feel a lot more comfortable with evaluation now, having gone through the process.

The Evaluation Maps also provided staff with a framework so that they could appreciate how the program or client-related information they had been collecting (i.e., for funder reporting requirements) actually related to the goals and intended outcomes of the program; staff could see “the big picture” and also identify what additional information might still be needed. The manager noted:

The program staff are collecting a lot of data and doing so unobtrusively. However, they don't know why they are collecting this information because they don't have a framework in place. They need to figure out a framework.

In addition, the agency manager also noted that, given the current political climate of fiscal restraint, program evaluation was increasingly a requirement of funding; this meant that non-profit/non-governmental organizations ought to be proactive about having evaluation-related capacity in order to participate in or oversee evaluation processes that were congruent with their organizations. In his words:

Funding is becoming tighter in [our province] so the likelihood of evaluation being imposed on programs is increasing. Thus it is very pertinent and makes sense to get out in front with this framework – to take it upon ourselves to use an evaluation framework that is relevant and makes sense to us.

Lastly, it is noteworthy that in his own consultative program/organizational development work with an Aboriginal non-governmental organization, this manager collaboratively developed a program framework that was closely adapted (with our permission) from the visual elements of the Evaluation Maps. Our project team was pleased that our publicly available Maps could be and had been used to support program development to improve individual and community well-being.

Applications and Conclusion

Feedback received through all of this project's knowledge exchange and mentoring activities demonstrated that the Evaluation Maps are a valuable tool for evaluation planning and implementation. This was reflected in the formal evaluations of these sessions and through discussions with session participants, as well as through the demand for the print version of the Maps and follow up discussions with those requesting the Maps. Moreover, through our knowledge exchange activities and the regional consultations that informed the development of the Maps, we heard time and again that the Maps are useful for program evaluation, program planning and team capacity-building. Indeed, the Maps provide an anchor for practice-based discussions amongst program staff (e.g., “Are we practicing in a way that is trauma-informed? How would we know if we are?” “What could we be doing differently to strengthen our trauma-informed approach?”).

The visually appealing, circular aspect of the Maps resonates for many people, who told us that they can ‘relate’ to them intuitively as well as intellectually. Further, we heard from service providers that the aesthetically-compelling and wholistic nature of the Maps enabled them to “draw people in” and “start a conversation” about FASD with service providers or community members who hitherto were uncomfortable talking about FASD because of perceived lack of safety and stigma associated with women's substance use (during pregnancy). As well, numerous people working in Aboriginal programs and communities have commented that the wholistic aspects of the Maps work well from an Indigenous perspective. Funders and

multi-sectoral program planners working on FASD and/or mental health and addiction initiatives also have expressed interest in the Evaluation Maps and have spoken of the Maps' usefulness in strategic planning, professional development, and identification of wide-ranging client, community and systemic outcomes.

Finally, although the Evaluation Maps and the project overall were designed with FASD prevention and support programs in mind, feedback from service providers, researchers, program planners and funders has shown that our frameworks and the website created through the project are relevant to community-based health and wellness programs more generally – i.e., those without an explicit FASD focus. The broad applicability of the Evaluation Maps will support and enhance community-based programming and evaluation, affirm what programs and communities are already doing well and inspire even more effective work in the area of FASD prevention, supportive interventions and mental health and addictions programming.

Compliance with Ethical Standards

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Conflict of Interest The authors of this article declare that they have no conflict of interest.

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