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Evaluation of a three-year Youth Outreach Program for Aboriginal youth with suspected Fetal Alcohol Spectrum Disorder

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Abstract

Aims: This article discusses the process, findings and lessons learned from the external evaluation of the *Youth Outreach Program* (YOP), a three-year intensive outreach and support program intended for at-risk Aboriginal youth, 13 to 18, with characteristics and/or behaviors associated with Fetal Alcohol Spectrum Disorder (FASD). The overall purpose of the formative and summative evaluation was to document the development and early implementation of the program, in order to make adjustments as the program unfolded; and to assess, describe, and document early outcomes for youth participants and community partners.

Design: The project employed a mixed-method design using qualitative and quantitative data.

Setting: The program and evaluation took place in a small, rural community in British Columbia, Canada.

Participants: Program managers, program staff, program participants, community partners, family members of participants.

Measures and methods: Triangulation, program output data; program-specific data collection tools, such as qualitative interview guides; participant outcome rating scale.

Results: Multiple sources of data revealed that the Youth Outreach Program led to a number of positive outcomes for youth in areas of safety, relationships, school attendance, sexual health, substance use, and knowledge and use of community resources.

Conclusions: The Youth Outreach Program made an important contribution in developing and implementing a program model for promoting positive change for highly marginalized youth who display characteristics of FASD and have limited community and family support.

Many program planners aiming to enhance support and improve daily living outcomes for high-risk youth must consider the effects of Fetal Alcohol Spectrum Disorder (FASD). Seminal research conducted by Streissguth and colleagues in 1996 conceptualized a difference between primary and secondary disabilities associated with FASD. Primary disabilities are characterized as permanent and directly due to prenatal exposure to alcohol, and they include difficulties with memory, abstract thinking, impulsivity, receptive communication, and understanding social cues. Secondary disabilities are not directly due to the prenatal exposure to alcohol and can potentially be reduced or prevented with improved community, professional, and family understanding, as well as appropriate interventions and support; the secondary effects identified by Streissguth, Barr, Kogan, and Bookstein (1996) included mental health problems, involvement with the criminal justice system, dropping out of school, substance use, and employment difficulties. Current research suggests there may be a primary connection between the neuro-behavioral effects of prenatal alcohol exposure and mental health issues such as depression, anxiety, and hyper-reactivity to stressful events (Weinberg, 2009).

Program planners working with high-risk youth typically have little or no diagnostic or assessment data from which to draw. Insufficient personal history (apart from self report), along with few diagnostic resources, mean that many youth, including those who are known within their community to be affected by prenatal alcohol exposure, do not have a diagnosis related to FASD. This is especially true for individuals living in small or remote communities, such as the community in which this program was located, where access to assessment or diagnostic facilities is extremely limited or non-existent. Nevertheless, positive outcomes can and do occur when programs for youth with behaviors or characteristics of FASD are designed with FASD-informed approaches.

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The Youth Outreach Program (YOP) was a three-year intensive and individualized outreach and support program designed for at-risk Aboriginal youth, aged 13 to 18, with characteristics and/or behaviors associated with FASD. The program offered both one-to-one support via two Youth Support Workers (YSW) and weekly after-school groups that provided opportunities for relationship building, skill development and recreational activities. Formal diagnosis was not a goal or an eligibility criterion of the program, due to an eight-year waiting list for diagnostic testing coupled with limited likelihood of family cooperation due to stigmatization associated with FASD and/or perceptions that diagnosis would make little difference to families' lives.

The program was designed to be flexible, available both on- and off-site, and individually tailored to each youth participant based on his or her needs, goals, and abilities. Funded by the (Canadian) National Crime Prevention Centre, the goals of the program were to achieve the following in relation to youth participants:

- Increase in school success and community engagement
- Increase in protective factors and decrease in risk factors
- Increase in community and youth knowledge and engagement on relevant issues, including FASD
- Improvement in positive family relationships
- Decrease in substance use and negative social behaviors
- Reduction and/or prevention of crime and crime-related behaviors

The program was delivered in a small rural community in northern British Columbia (see Table 1 for socio-demographic information about the area). All but one youth enrolled in the YOP was from one of the area's six First Nations. The program's sponsoring organization, the College of New Caledonia (Lakes District Campus), was a post-secondary educational institution that is a recognized leader in FASD interventions; all college staff are encouraged to be knowledgeable about FASD through training and education. Equally as important, the institution was trusted by Aboriginal and non-Aboriginal community members alike, and by other community organizations and service providers.

The YOP arose out of concerns from community agencies and the high school that there were many youth in the community who displayed behaviors and/or characteristics indicative of FASD and who had little to no support in the community. The youth were at high risk of experiencing secondary effects of FASD, specifically drug and alcohol use, unplanned pregnancy, violence, victimization, sexual exploitation, and being in trouble with the law. The youth also had a lot of unstructured time, which could potentially lead to their involvement in high-risk activities. Anecdotal information suggested that many youth were homeless and/or couch-surfing, as there were very few housing options available to youth who were unable remain in their family home. There was also a dearth of affordable recreational facilities. The following illustrates the degree of abuse, pressure and fear that youth can experience.

> *A young girl who was being molested repeatedly in her home by her uncle was reluctant to leave home as she was fearful for her siblings. She felt she needed to be there so that her uncle would not molest her younger sisters* (YOP program manager)

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Table 1

Lakes District statistics as of April 2011

Lakes District Region Demographics	Lakes District	Comparison relative to British Columbia
Population	7,951	
Income		
Family income (2011)	$65,629	$15,000 lower than provincial average
Education		
% of 18-year-olds who did not graduate (2008–2011)	46.4%	64% higher than provincial average
School age reading and math scores—students below standard (2008–2011)	37.9%–45.2%	91%–136% below provincial standard
Crime		
Violent crime rate per 1,000 (2010)	6.3	91% higher than provincial rate
Health/Social		
Infant mortality rate per 1,000 live births (2011)	7.1	92% higher than provincial rate
Children in care, per 1,000, age 0–18 (2011)	32.8	260% higher than provincial rate

(Source: BC Stats, retrieved 2013)

Program transferability was a critical component of initial planning and a factor throughout delivery of the program[1]. The program architects thus saw an external evaluation as the cornerstone for building the program and its portability, and a formative and summative evaluation was implemented from the outset of the YOP. The overall purpose of the evaluation was to document implementation of the program, provide feedback for improvements to the program, and assess early outcomes for youth participants and community partners.

This article shares highlights of the evaluation findings, and their implications for policy, practice and FASD-related evaluation. While some key findings related to the YOP's formative evaluation are presented, more detailed discussion of these will be the focus of forthcoming publications. The article's authors are the YOP's external evaluation team.

Method

The formative evaluation used mixed methods of data collection, such as qualitative interviews with program staff, community partners, and program participants, document review, and monthly output data to obtain a detailed description of the program's development and operation.

The summative evaluation also employed a mixed-method (qualitative and quantitative) design. Data collection methods included individual interviews with program staff and managers, youth program participants, and community partners; two focus groups with youth participants; Intake and Annual Assessments of youth participants, completed by program staff; and participant observation during annual site visits. As well, the evaluation team designed a rating form for the Youth Support Workers to complete (the "Staff Ratings of Youth Outcomes" scale), consisting of a five-point Likert scale indicating whether, and the degree to which, the YOP had made a difference to the youth participants in relation to 21 program outcomes (Appendix A provides a copy of this scale).

In total, 58 people were interviewed for the YOP evaluation:

- 31 youth program participants
- 18 community partners/service providers
- 2 family members of the program participants
- 7 program team members and/or managers of the sponsoring organization

The focus groups and interviews focused on participants' perspectives on program outcomes, impacts, strengths and challenges; youth participants shared what they liked best and what they did not like about the program, and what difference it had made to them. Interviews with community partners focused on impacts of the program for community organizations and service agencies, benefits of the program for the community, and lessons learned about providing service to high-risk, high-needs youth who may have FASD.

[1] Information on staff training, hiring, project support, monitoring processes, reporting formats, forms, data collection, lessons learned, and modifications were recorded by the program. In addition, YOP staff developed a comprehensive manual for activities, projects and objectives for at-risk youth groups, to provide a foundation for other programs wanting to implement effective supports for this population.

Results

The findings presented in this article are primarily based on qualitative interviews with youth participants, family members, and community partners. Formative evaluation findings regarding the program model, activities and participants are presented first, followed by summative evaluation findings.

Youth Outreach Program Participants

At any given time, there were 24 youths receiving one-to-one support (12 per youth outreach worker). As well, throughout the program, an average of 28 participants each week accessed a group (two groups occurred each week, with an average of 14 youths per group). Over the duration of the YOP, a total of 50 individual youths received intensive support services and/or took part in groups. In addition, there were 37 youths whose involvement was episodic, for a total of 87 individual youths who took part in the YOP program.

Program participants were comprised of:

- 46 males and 41 females
- 86 (self-identified) Aboriginals and 1 non-Aboriginal
- 93% aged 12 to 17; 7% age 18 and over.

Potential program participants were identified and referred by high school staff (counsellors, teachers, alternative program staff) based on the criterion of having behaviors and/or characteristics associated with FASD. At the same time, YOP staff engaged prospective participants via outreach since many youths were highly distrustful of programs and workers associated with "systems."

Youths receiving one-to-one support were those with whom staff had established a relationship, who had requested staff assistance, and who may have been attending group sessions. Staff met with these youths approximately one to two times per week: as a result of their success in connecting with the youths, YOP staff continuously had full caseloads. However, the YSWs were only able to provide intensive support to 24 youths at any given time. Youths who attended sporadically could not be given the same level of support, due to limited resources. Staff met with this group of youths about four or more times per month.

Many of the youths were enrolled in a modified school program and/or were not regular school attendees. The youths' lives were characterized by involvement with multiple systems, all with their own mandates, responses,

demands, and expectations. None of these systems were tailored to meet the needs of individuals living with FASD.

Youth Outreach Program Model and Activities

The Youth Outreach Program was guided by a relational approach, which emphasized that people grow and change as a result of their relationships with others, and in particular as a result of long-term, supportive, trust-based relationships (Leslie, 2007). As well, planning and delivery of program activities took place in the context of an FASD-informed framework: careful attention was paid to ensure that accommodations were provided in the physical environment, and in communication, activity programming, and one-to-one work with the youths (Malbin, 2002; Rutman, 2011).

Program activities consisted of:

- intensive individualized one-to-one support and advocacy
- after-school groups (providing opportunities for life skills activities, a nutritious meal, safe and healthy recreational activities, and peer support for youth)
- engaging families (this posed significant challenges, and in fact was often impossible, due to the issues of and dynamics within the youths' families)
- liaising with community service providers (e.g., heightening awareness of relevant stakeholders about the challenges and barriers faced by Aboriginal youth-at-risk).

More specifically, the one-to-one support and advocacy activities undertaken by the two Youth Support Workers included:

- providing emotional support
- facilitating and providing reminder calls and transportation to appointments with various professionals within the community and in other communities
- assisting youths to understand legal or medical issues or service systems
- advocating for youths to access legal, health, education, child welfare, recreational and/or support-related services
- connecting youths to school through support with homework, attendance and communication with educators
- assisting youths to develop resumes and/or access (pre-)employment support services
- promoting youths' involvement in safe recreational activities
- facilitating youths' connection with safe and trustworthy natural supports
- assisting youths to find safe housing
- assisting youths with conflict resolution, and peer and family relationships
- identifying risky behaviors and promoting harm reduction and healthy lifestyles.

Outcomes for Youth Outreach Program Participants

We begin our presentation on outcomes for YOP participants by sharing excerpts of our interview with one youth, "Lila," whose comments illustrate both the interconnectedness of outcomes and the complexity of the issues experienced by many of the youths in the program:

> *The program has made a huge positive difference for me. [The Youth Support Worker] has helped me a lot. I was really stressed about my homework. [The Youth Support Worker] sat down with me and helped me complete my homework. She makes appointments for me and helps me remember and get to them, like getting on birth control and getting my Depo shot, and like going to the doctor and to the dentist. She's helped me do a resume and with finding work. She's also helped me to stay positive, helped me stay away from booze and negativity, and to stay in school. [The Youth Support Worker] has attended their meetings with me, and helped me with what to say in public—she has helped give me confidence to do public speaking and to say what is important . . . The [YOP] group is a positive place to go. There are no put-downs there, and it's a place where you build your self-esteem. Before, I had almost dropped out of school, but I'm not like that anymore . . . I'm going to school and will graduate in June; I've got goals for myself—in September I'll be upgrading at the College; I'm not drinking anymore; I'm more home-oriented; I'm now a big-time ski-dooer; and I have a positive relationship with family members.*

Building on Lila's perspective, evaluation findings based on multiple sources of data (e.g., the Staff Ratings of Youth Outcomes scale; community partners' rating of youth outcomes; interviews with YOP participants, staff, families and partners) revealed that the YOP led to a number of positive outcomes for youths. Outcomes included:

- improved safety (e.g., safer housing) and reduced risk of harm and victimization
- improved sexual health, mental well-being, nutrition, dental health
- improved social relationships and support from peers
- improved self-confidence and self-esteem
- healthier relationships with partners (reduced abuse, increased understanding of healthy relationships)
- increased emotional support
- increased practical support, assistance in emergencies, and support related to transportation and accompaniment to meetings and appointments
- improved life skills (e.g., communication, budgeting, paying bills, shopping, food security)
- improved school-related success
- improved job-related skills
- reduced substance use
- improved knowledge and/or use of other community resources
- increased participation in healthy recreational activities.

Findings from the qualitative interviews were an important source of evidence of outcomes. A sample of participants', families', and community partners' responses to the open-ended question of what difference, if any, the YOP had made to youth participants have been thematically categorized by area of outcome and are presented below.

Improved self-confidence and self-esteem

I feel better about myself. —YOP participant

The Youth Outreach Program has given youth a much stronger sense of self and self-esteem. They are learning that they are important and that there is someone there for them. Some of the youths are also joining a youth leadership group. They are also learning new skills and trying things that take them out of their comfort zone (e.g., cross-country skiing)—this also boosts self-esteem and is a reflection of their higher self-esteem.
—Community partner

Improved school-related success

Yes, there has been lots [of difference due to YOP]. I've been going to school more, and I'm doing better in school—my marks are getting better. My YSW encourages me to stay in school . . . I'm applying for courses at the College. —YOP participant

Youth who go to the YOP program have better attendance at school and are successfully completing their courses. —Community partner

Improved social relationships and support from peers

Youths learn about bullying, and become accountable in not bullying other youths. YSWs explain that bullying [is something you're accountable for] even if you're just watching. —Community partner

Kids who didn't like [our children] before have become their friends. This happened through the group. It's a fantastic change for the better. —Family member

Reduced substance use

I used to be addicted to alcohol and marijuana. The support worker encourages me to really slow down and concentrate on school. I could not have done this alone. I've basically quit drinking and smoking pot now. —YOP participant

We have a sigh of relief, knowing that our kids are at a safe place, without drugs or alcohol. —Family member

Healthier relationships with partners

I had a bad relationship with my boyfriend. The YSW helped me deal with this and to leave him. —YOP participant

Improved life skills

I have a youth—she wouldn't have a chance without this program. The Youth Support Worker acts as an advocate; the YSW also gets in touch with the youths, helps them learn how to communicate—tell their story to people who need to hear it. The YSWs are the bridge—they help kids open up and speak for themselves. —Community partner

Improved knowledge and/or use of other community resources

Because of the program, we are able to get early warnings—the YSWs encourage the youth to share issues with us before a crisis happens. Early warnings may include having someone on the premises who shouldn't be there. Working with their YSWs, the youth now recognize their issues and areas that they need to work on. –Community partner

Outcomes for Community Service Providers and Partners

Community partners also benefited from the YOP. A thematic analysis of interviews provided evidence of:

- Improved collaborations amongst community-based service providers
- Improved understanding of FASD, and shifts in some community partners' practice in relation to working with youth with FASD
- More informed/realistic expectations for youth with FASD
- Proactive planning and action to avert crisis

In the words of one service provider:

Youth Support Workers have worked collaboratively [with me], as a bridge between youth and the justice system—this is unique in our community. The program benefits me, knowing that there is someone available to support these youth, that we're on the same page together, ensuring that their probation or bail conditions are met. I can trust that youth are receiving services and that they're not on their own.

Key program elements and approaches that made a difference

Prior to their involvement with the YOP, the majority of youth participants were distrustful of programs, systems, or workers. In response, the YSWs focused on outreach strategies to find and meet with youth in the community. Trusting relationships slowly developed, and as this occurred, the intensity of the support-related activities deepened.

In addition to this outreach-based approach, a number of other factors contributed to the program's success. Most important from the youths' perspective were the weekly activities, which gave them something positive and fun to do; the safe, positive and non-judgmental atmosphere of the groups; and the assistance and support they received from the Youth Support Workers. In the words of one youth:

> *The support workers are there when I need them. They help me cope with stuff and get my school work done.*

From the community partners' perspective, the key features that made a difference included:

- the program team's strong knowledge of FASD
- the Youth Support Workers' availability, accessibility and their proactive approach
- the Youth Support Workers' success in developing trusting relationships that paved the way for youth to develop positive relationships with adults, service providers and/or peers
- the non-judgmental, empathic approach
- the individualized support to the youths, based on each youth's issues and needs.

Discussion

The Youth Outreach Program made an important contribution to the development and implementation of a program model for promoting positive change for highly marginalized youth with limited community and family support. Key attributes of the program can be summarized as follows:

- The program model is rooted in a social determinants of health approach.
- The importance of trust and relationship building with marginalized and "suspicious" youth is recognized.
- The impact of trauma in the lives of this population is recognized.
- The program allows for different stages of readiness for change, and gives youth the ability to choose their level and intensity of involvement.
- FASD-informed practices are used.
- There is a focus on hope and positive outcomes.
- The importance of community engagement and buy-in is recognized.

The participants in the YOP program were hard to reach and high-risk; many experienced a combination of violence and/or victimization, trauma, alcohol and other substance use, poor school attendance, criminal justice involvement, poor or unstable housing, and complicated lives in which there were few, if any, positive role models.

Once engaged, however, many youth were very receptive to the individualized support the program offered. Indeed, staff worked within a "stages of change" framework (Prochaska, & DiClemente, 1984) and gave youth room to indicate their readiness and make their own decisions about the nature and intensity of their involvement in YOP activities.

While the YOP's intended focus was on providing intensive support to youth in order to reduce criminal involvement and/or substance use (and other secondary or tertiary effects of FASD), what emerged were improvements in a number of areas not directly related to typical indicators of either. Improvements were demonstrated in many areas of youths' lives, including emotional health, sexual health, participation in healthy recreational activities, safer housing and food security, access to and use of health-related services, and attitudes and achievements related to education.

The length of time required to develop trusting relationships between program staff and highly vulnerable youth with FASD—especially given the experiences of trauma-affected youth with FASD—has important implications for evaluation and the development of evaluation logic models. If relationships are the basis for behavior change, logic models and timeframes for achieving outcomes cannot short-change the time required for program workers to develop trust-based relationships that are experienced as safe and non-judgmental. Moreover, the logic model needs to reflect the non-linear processes related to wellness and healing.

When working with youth who face numerous hardships and challenges including FASD, a social determinants of health perspective may provide a better framework for identifying potential outcomes (Network Action Team on FASD Prevention from a Women's Health Determinants Perspective, 2010) and for framing issues for youth with FASD. Therefore, when designing programs for youth with FASD, planners and policy makers are encouraged to consider using a framework that recognizes and addresses:

- poverty, lack of resources, food insecurity
- lack of social support
- transience, homelessness, unsafe housing
- violence in relationships, vulnerability, victimization and trauma
- disconnection from culture and traditions
- stigmatization and social exclusion
- unemployment
- not completing school.

Finally, addressing the social determinants of health may *also* lead to a reduction in substance use and criminal involvement; however, achieving these results requires long-term vision, commitment, and ongoing program funding. In the meantime, a social determinants of health framework focuses attention on wellness goals that are critical at an individual, family, community and systems level. Along these lines, we suggest that one of the most significant accomplishments of the Youth Outreach Program was that it provided youths with behaviors or characteristics of FASD with a sense of hope. These youths began to see other possibilities for themselves in terms of their relationships, substance use, school attendance, and future goals.

References

BC Stats (2013). LHA 55 (Burns Lake). Retrieved April 13, 2013 from: http://www.bcstats.gov.bc.ca/StatisticsBySubject/SocialStatistics/SocioEconomicProfilesIndices/Profiles.aspx

Leslie, M. (2007). Engaging pregnant women and mothers in services: A relational approach. In N. Poole and L. Greaves (Eds.), *Highs and lows: Canadian perspectives on women and substance use* (pp. 239–246). Toronto, ON: CAMH Press.

Malbin, D. (Ed.). (2002). *Trying differently rather than harder* (2nd ed.). Portland, OR, United States: FASCETS Inc.

Network Action Team on FASD Prevention from a Women's Health Determinants Perspective. (2010). *10 Fundamental components of FASD prevention from a women's health determinants perspective.* Vancouver, BC: Canada Northwest FASD Research Network and BC Centre of Excellence for Women's Health. Retrieved April 13, 2013 from http://www.canfasd.ca/files/PDF/ConsensusStatement.pdf.

Prochaska, J. & DiClemente, C. (1984). *The transtheoretical approach: Crossing traditional boundaries of therapy*. Homewood, IL, United States: Dow Jones-Irwin.

Rutman, D. (2011). *Substance-using women with FASD and FASD prevention. Service providers' perspectives on promising approaches in substance use treatment and care for women with FASD.* Victoria, BC: University of Victoria.

Streissguth, A. P., Barr, H. M., Kogan, J., Bookstein, F. L. (1996). *Understanding the occurrence of secondary disabilities in clients with fetal alcohol syndrome (FAS) and fetal alcohol effects (FAE).* Final Report for Centers for Disease Control and Prevention. Seattle: University of Washington School of Medicine, Department of Psychiatry and Behavioral Sciences Report No.: R04/CCR008515.

Weinberg, J. (2009). Direct and indirect mechanisms for alcohol damage to the brain. A presentation to the Institute of Health Economics Consensus Development Conference on Fetal Alcohol Spectrum Disorder—Across the Lifespan. Retrieved April 13, 2013 from http://www.ihe.ca/documents/007-Weinberg.pdf

Appendix A

Staff ratings of youth outcomes

Anticipated Outcomes	Strong positive change	Some positive change	No change/ impact that I see	Some negative change	Strong negative change	Don't know/ can't tell
Youth had someone to talk to about things that matter to them						
Youth accessed transportation and/or accompaniment to appointments						
Youth improved life skills, such as budgeting, paying bills, shopping, tenant rights, etc.						
Youth obtained safer housing and/or assistance related to housing						
Youth improved their nutrition (made healthier food choices, accessed healthier food)						
Youth accessed health or mental health services						
Youth improved their sexual health (birth control, morning-after pill, STD/HIV assessment, etc.)						
Youth had healthier relationship with their partner (reduced abuse, increased understanding of healthy relationships)						
Youth had healthier relationships with peers						
Youth had healthier relationships/connection with (extended) family or their culture						
Youth reduced their problematic use of alcohol and/or drugs						

Anticipated Outcomes	Strong positive change	Some positive change	No change/ impact that I see	Some negative change	Strong negative change	Don't know/ can't tell
Youth reduced their involvement in criminal behavior, including involvement in gangs						
Reduced victimization of the youth by others						
Youth had greater self-confidence, self-esteem (e.g., makes more eye contact, is more communicative)						
Youth felt more positive and hopeful						
Youth increased their participation in healthy recreational activities, sports, etc.						
Youth improved their attendance at school						
Youth were able to get support/ accommodations related to school attendance/performance						
Youth enrolled in post-secondary program or vocation training						
Youth improved job search and/or (pre-) employment skills, including communication skills						
Youth have more knowledge about and/or use other community resources						
Other _____						