



**Parenting Guidelines for Families of  
Children with FAS/FAE  
Evaluation Report  
June 30, 2006**

Parenting Guidelines For Families of Children with FAS/FAE

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# Evaluation Report

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VON Canada  
110 Argyle Avenue  
Ottawa, Ontario  
K2P 1B4  
Phone: (613) 233-5694  
Fax: (613) 230-4376  
[www.von.ca](http://www.von.ca)

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## National and Regional Project Advisory Committees

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**Karen Palmer**, Canadian Centre on Substance Abuse (CCSA), Ottawa, ON

**Jill Dockrill\***, Fetal Alcohol Syndrome Treatment and Education Centre Inc. (FASTEC), Belleville, ON

**Corrie Melville**, Alvin Buckwold Early Childhood Intervention Program, Saskatoon, SK

**Dr. Rod Densmore\***, Parent/Workshop Facilitator, Salmon Arm, BC

**Dwaine Souveny**, FASD Outreach Services and Friends of Children with Special Needs, Red Deer, AB

**Beryl Trimble**, Maple Ridge FAS/ADD Resource Centre, Maple Ridge, BC

**Brad Watson**, Society of Special Needs Adoptive Parents (SNAP BC), Vancouver, BC

**Danna Ormstrup**, Region 3 FASD Partnership, High River, AB

**Nola Harper**, YWCA Crabtree Corner, Vancouver, BC

**Marion Tudor\***, Saskatchewan Fetal Alcohol Support Network, Regina, SK

**Dr. Wayne Podmoroff**, Department of Justice, Government of Nunavut, Iqaluit, NU

**Jean Voysey**, Kitikmeot School Operations, Kugluktuk, NU

**Winnie Banfield**, Department of Health and Social Services, Government of Nunavut, Iqaluit, NU

**Rebecca Foreman**, Trenton, ON

**Suzanne Boivin\***, Parent, Gatineau, QC

**Elspeth Ross\***, Fetal Alcohol Syndrome Association of Ottawa (FASAO), Ottawa, ON

**Lois Roberts**, Aboriginal Family Centre, Happy Valley-Goose Bay, LB

**Rick Dillon**, Department of Health and Community Services, Government of Newfoundland and Labrador, Gander, NL

**Debbie Thibault**, Federation of Foster Families of Nova Scotia, Halifax, NS

**Darlene Oakes\***, Addictions Services, PEI Provincial Health Services Authority, Charlottetown, PE

*Retired members as of March 2005:*

**Shirley McGuire**, Saskatchewan Association for Community Living (SACL), Saskatoon, SK

**Carol Gregson**, Department of Health and Social Services, Government of Nunavut, Iqaluit, NU

**Frederick Montpetit**, RN, Rankin Inlet Public Health, Rankin Inlet, NU

**Linda Blackmore\***, Parent, New Brunswick Foster Family Association, South Esk, NB

**Mary Berube\***, Catholic Social Services, Edmonton, AB

\*parents/caregivers of children/adults with FASD

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## VON Canada Staff and Consultants

**Anne Yuill**, Vice President, VON Canada Eastern Region

**Heidi Greek-Hilchie**, Director of Planning and Development, VON Canada Eastern Region

**Melissa Lee-Ross**, Project Coordinator, VON Canada

**Christine LeBlanc**, Healthy Baby and Me, VON New Brunswick

**Steven Dukeshire**, Research and Evaluation consultant

**Alison Bursey**, Research assistant

**ThreeTon Marketing & Communications**, Designer

**Eleanor Beaton**, Editor

**José Ouimet**, Translator

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## WHAT? Did we do what we said we would do?

### *A Participatory approach*

The VON FASD Project was designed at its outset to create best practice parenting guidelines for families of children with FASD. This was the overall goal of the project. There were a number of objectives and activities outlined to fulfill this goal that can be found in the *Activities* section of the Final Report.

Although the project officially began on April 1, 2002, project work began in earnest on July 1 of that year with the hiring of a full-time Project Coordinator. Throughout the course of the project the goal and objectives remained the same but project activities were adjusted to allow for an enhancement of the participatory approach that has been so relevant throughout the project. The Project Coordinator made it her business to ensure that the project took a participatory approach from beginning to end and made this a priority in developing and enhancing research methods and protocol, defining Project Advisory Committee membership and meetings and initiating project “add-ons” such as the project-specific website and FASD listserv.

The activities that were undertaken allowed for the participatory approach to remain paramount. Starting with the establishment of the National and Regional Project Advisory Committees (PACs), the project sought to bring the perspective of the FASD community on board. This was done by making contact with key FASD stakeholders across Canada with a national and regional perspective, informing them about the project and requesting their participation. At their outset, the National and Regional Project Advisory Committees met separately, then as “regional pairs” in 2003 (Central and Atlantic; Western and Northern), and finally as one group in late 2004. The Advisory Committees provided the guidance the project needed and helped to identify key stakeholders and research participants to carry the work forward. All meetings were held by teleconference and communication was mainly email-based. This permitted the flexibility required by committee members, who resided in all five time zones and in many different areas of Canada. Participation was enhanced through the virtual meeting process.

Although membership was comprehensive, there were many key FASD stakeholders that were not part of the committees. The project sought to gain their perspective through establishing collaborative relationships with the groups, organizations and agencies that had a vested interest in FASD. The Project Coordinator relied on PAC feedback and Internet research to guide the contact process. Most contact was made by phone and email. In order to enhance the participatory process further and allow FASD stakeholders to stay connected to the project and to each other, a project-specific website and listserv was developed and launched in March 2003. This was a new activity within the work plan that facilitated communication and participation. Stakeholders and other interested persons now had a way to receive project updates and information on other FASD organizations, initiatives and research, especially via the listserv where members are free to post information that is of interest to the FASD community. The website, which became part of the VON national website in 2006, houses the final report and other project materials. The website has enjoyed moderate popularity while the listserv has been

identified as one of the most worthwhile unintended outcomes of the project. As of March 2006, over 200 members from across Canada, the United States, Australia and Europe were subscribed to the list.

Once the key stakeholders had been engaged, the project sought feedback based on a bottom-up, parent-centred qualitative research approach. As discussed earlier, a needs assessment was conducted via key informant telephone interviews with 17 parents of children and adults with FASD across Canada (see **Research Report** for needs assessment questions). This piece was essential to discover what parents needed in terms of best practice parenting guidelines. The one-on-one telephone interviews between the Project Coordinator and research volunteers allowed for a level of intimacy and validation, permitting parents to express their needs as well as what has worked for them in raising a child with FASD. By giving voice to those that the project was designed to assist, the target audience became fully engaged. The knowledge collected from this process was then used as a basis for further research and development of materials. This led to the realization that something more than just guidelines was needed. In fact, a tool written specifically for parents was required in order for the project to be fully successful. This led to a new piece of work for the project.

After learning what parents need in terms of best practice parenting guidelines and format, a series of six focus groups (45 participants in total) was held in communities across Canada (see **Research Report** for focus group questions). As mentioned previously, expert opinion was sought within these groups in order to collect information relating to best practice parenting guidelines in the field of FASD based on the topics that parents identified as areas of need as well as possible format for a parenting tool. This process involved not only service providers and professionals, but also long-time parents of children with FASD and adults with FASD themselves. It allowed people with the same concerns to sit around the table and share wisdom for the good of others who may be facing the reality of FASD for the first time. While the information collected was not as relevant as had been anticipated, it was used as the basis for further investigation into parenting guidelines and provided for the format of the parenting tool itself. The focus group process was evaluated and results were favourable.

An addition to the original work plan, the development of a Web-based parenting survey grew out of the need for more specific information relating to parenting guidelines—specifically tips, techniques and strategies to use in raising children with FASD and guiding them as adults. The survey was launched via listservs and through the distribution lists of PAC members in July 2004 and closed in September 2004 (see **Research Report** for survey questions). In total, 183 responses were received from all areas of Canada, the United States, and other countries such as Australia, France, the Netherlands, South Africa, Switzerland, and the United Kingdom. This was yet another opportunity for participation from the FASD community (internationally, in this case) which led to a richness of information that was not fully achieved during the focus groups. Here, respondents also had the opportunity to identify key resources, which were fused into the work being done in tandem as part of an extensive literature review.

At this point, it had been discovered that none of the manuals or websites in existence containing practical tips, techniques and strategies for caring for children and adults with FASD (i.e., guidelines) had been evaluated. This posed a challenge for defining the guidelines under development as “best practices”, as there was no “best practice” comparison point as per conventional definition. Therefore, in line with the project’s participatory philosophy, guidelines became defined as “parent-driven best practices” due to the fact that they were identified by parents themselves and fell within a framework of “need themes” that had also been parent-identified.

The bottom-up research process that had involved over 200 families, caregivers and front line workers culminated in an intense development of the parenting guidelines. In order to expedite the process, a Working Group was formed in November 2004 based on PAC membership. This group provided the necessary expertise to validate the guidelines and provide additional resources to complete the picture, once again drawing on community knowledge. PAC input was also sought in addition to review by other FASD stakeholders close to the project.

Once the guidelines were complete, they were sent to the contracted editor to be prepared for inclusion in the educational materials (i.e., parenting tool). The Working Group guided the review of edited materials but feedback was also sought from other members of the FASD community to ensure clarity and readability. PAC members also had the opportunity to provide feedback on the edited version, including naming of the parenting tool “Let’s Talk FASD”, cover illustrations and suggestion and approval of endorsements from the FASD community.

The dissemination process was directed by PAC input in addition to ideas for promotion and marketing. The key dissemination activity was the delivery of seven orientation sessions across Canada in early 2006. Orientation sites where results have been shared include Millbrook First Nation, Nova Scotia; We’koqma’q First Nation, Nova Scotia; Happy-Valley Goose Bay, Labrador; Gatineau, Quebec; Ottawa, Ontario; Thompson, Manitoba; Regina, Saskatchewan. Participation in both the conferences/workshops and orientation sessions included residents of the community in which the event was held as well as participants from other areas of that province and in some cases, other parts of the country. In total, 308 participants attended these sessions (see *Figure 1* in *Activities* section of **Final Report** for more details).

In an attempt to reach communities that did not receive orientations, a DVD was created and distributed that contains a videotaped presentation by the Project Coordinator in English and a similar presentation in French by a Francophone member of the PAC. These sessions were videotaped at the Ottawa and Gatineau orientations, respectively. The DVD has been distributed to members of the PAC and other key stakeholders in the FASD community. It is anticipated that this DVD will be used as an education tool to inform organizations, agencies and groups about the guidelines and the existence of *Let’s Talk FASD*.

Additional means of dissemination have included promotion of the project through listservs, newsletters and word of mouth in the FASD community. In addition, presentations at various conferences and workshops were delivered across Canada in the final two years of the project.

Venues included Niagara, Ontario; Saint John, New Brunswick; Moncton, New Brunswick; Happy Valley-Goose Bay, Labrador; via videoconference to sites across Nova Scotia; Ottawa, Ontario; Muskoka, Ontario and Sydney, Nova Scotia.

It is without question that the project accomplished what it set out to do and much more. By staying true to the participatory process, the project gave the FASD community a product of its own knowledge for those who are struggling with the reality of FASD for the first time as a parent or who wish to learn more from those who experience its reality on a day to day basis.

## WHY? What did we learn about what worked and what didn't work?

### *The Community is our Reason for Success*

In order for our project to be successful, securing the involvement of the FASD community was essential. The term “FASD community” refers to those who have involvement or a vested interest in FASD prevention, education or intervention or who work with those who are affected by FASD, including families of children and adults with FASD (parents and caregivers as well as extended family members).

Because the entire process was designed to be participatory and based on a bottom-up perspective, the Project Coordinator's first task was to build a strong base of support among FASD stakeholders in each province and territory. Due to the fact that the project was national in scope, regional representation was crucial to ensure that the realities of those living in different areas of the country were captured. As mentioned, this was done through the establishment of one National and four Regional Project Advisory Committees, communication with other stakeholders across Canada and procurement of research volunteers with diverse backgrounds, held together by a common thread of parenting or working with children and adults with FASD.

An excellent example of the importance of community involvement can be seen in the project's definition of “child”. Although the project was originally geared toward Health Canada's definition of “child” (0-18 years), it became apparent that much was needed to support parents of adult children with FASD. This information may not have come to light if the participation of the FASD community was absent from the project in its initial stages. PAC members and other stakeholders were quick to point out the absence of information available for families of adult children with FASD. With the permission of Health Canada, the project responded and revised its definition of “child” to connote a relationship between a caregiver and the individual in their care. Therefore, the term “child” came to be known in a relational sense and included the child of a parent or caregiver at any age. By doing so, the project responded to community needs.

Recruitment of PAC members was relatively successful, although many key stakeholders that were approached were unable to participate because of other commitments. However, the recruitment process itself, which involved email and phone contact and an initial orientation session with new members, was generally well-received. In retrospect, it may have been easier to establish one, larger Project Advisory Committee composed of one or even two members from

each province and territory for ease of meeting planning and time effectiveness. This will be a consideration for future projects.

In the third year of the project, the experience of the PAC members was once again evaluated. This allowed for suggestions for improvement and the identification of next steps for the project as it moved into its fourth year of funding based on an amendment to the original three years of the project.

As mentioned previously, the development and launch of a project-specific website and listserv was a key means of keeping the public informed about the progress of the project and sharing other, relevant FASD information. A departure from the original work plan, it broadened the base of community support for the project which was exemplified through the volume of inquiries received by the Project Coordinator via phone and email.

Recruitment of research volunteers also depended on connections to the target population via PAC members and other prominent stakeholders. In many cases, these people were the target population; for instance, many PAC members were also parents of children with FASD. However, the powerful network that exists within the FASD community allowed for requests for participation to be passed along and expressions of interest received quickly.

The first stage of the research process involved the telephone needs assessment. Although long and fairly intense, the 17 in-depth interviews allowed the Project Coordinator to understand the specific needs of the target population in terms of parenting guidelines. While this process actively involved the target population in a very meaningful way, some challenges included keeping the volunteers on track, keeping within a designated time frame for each call and extracting detailed information on needs. The process itself was also very time-consuming. Perhaps a written needs assessment questionnaire would have been better suited to our needs.

The second stage of the research process involved the facilitation of six focus groups held across Canada to determine a format for the parenting tool and best practices. These groups involved between three and ten research volunteers each and ran for approximately two hours with a break at midpoint. This format provided a unique opportunity for members of the FASD community to share ideas around the same table and to contribute meaningfully to the research objectives. While the group synergy produced some wonderful outcomes, there was also a focus on issues of concern that moved away from the original intent. The moderator (Project Coordinator) played a very active role in keeping the group on task. The focus groups were also evaluated via a written questionnaire distributed at the end of each group, as discussed previously.

After reviewing the results of the focus groups, it was determined that more detailed information regarding parent-driven best practices was required. This was accomplished through a web-based survey, as discussed previously. The survey proved to engage the largest segment of the target population, producing 183 responses in total. The richness and detail of responses received allowed the project to move forward with the development of the guidelines and enrichment of the resource list included as part of the parenting tool. This was the most successful piece of

research completed as well as the most cost-effective and efficient. The web-based survey format will be considered for future projects, including evaluation of the parenting tool.

As had been discussed previously, the development of a parenting tool itself is a departure from the original work plan. However, in being true to a commitment to a participatory, community-based approach, we heard that parents need more than a research report containing guidelines and more than simple “educational materials”. Therefore, the concept of a parenting tool with the guidelines embedded within became a reality. The development of this tool involved an editing and layout process done by a professional design team. The progress and direction of the content and format of the tool was guided by feedback from the project’s Working Group and PACs, who were also consulted on the development of the guidelines themselves. However, the basis of the work was guided by feedback from the target population in regards to what they wanted to see in regards to guidelines within the parenting tool (i.e., themes, topics, layout, etc.). The production of the tool itself has also broadened the base of support for the project and allowed the target population to access information that has in many ways been written “by parents, for parents” in a format that they can relate to and understand easily.

While all activities and strategies existent in the original work plan were retained, many were embellished or enhanced and new activities added in response to community input, as discussed previously (website and listserv, web-based survey, development of parenting tool, etc.) These were all successful and worthwhile ventures. The work plan and its objectives provided a strong framework for these enhancements.

A real success in terms of project planning was the focus on constant involvement of the FASD community, who helped to guide its direction and revise activities as necessary, albeit in the later stages of the project in an informal manner. The activities contained within the original work plan, although retained and followed through for the most part, could have been revised earlier on through a project planning *process* that would have allowed room for more extension revisions as the community saw fit. This process was absent within the initial stages of the project and could have been expedited through a facilitated meeting (i.e., teleconference) with PAC members, stakeholders and VON staff members, specifically those who were responsible for the development of the original proposal and work plan.

Overall, the success of the project is owed to the involvement of the community. Without the direct involvement of key stakeholders and the target population, the parent-driven aspect of the project would have been absent and we would have simply created a duplication of parenting guidelines already in existence. In addition to giving the community voice, the project has allowed it to successfully share its knowledge to the benefit of parents and individuals with FASD across Canada.

## SO WHAT? What difference did it make that we did this work?

### *Giving Voice and Taking it to the Street*

The fact that the project allowed parents of children with FASD to have their say made a significant impact. The project collected the lived experience from over 200 parents and caregivers across Canada, the United States and other parts of the world. The fact that the Web survey was opened to participants outside of Canada allowed the project to reach those with similar experiences and showed that these experiences are very much like the experiences of parents living in Canada.

The fact that people who participated in the research (i.e., the target population) realized that they were not alone contributed to a significant change in knowledge regarding isolation. Lessening the feeling of isolation on the part of our research participants was an unexpected outcome of our project, allowing for a sense of connectedness with others in the national and international FASD community. For example, focus group participants expressed value in meeting together and how it built community; needs assessment participants expressed that it was valuable to them to have people ask them about their needs. In some cases, these participants imparted valuable information based on their own experiences.

Change in knowledge, attitude, skills and behaviour is a potential forthcoming result of the parenting guidelines that have been developed. Unfortunately, due to the fact that the guidelines were not launched until the end of the project, a measure of change in knowledge, attitude, skills and behaviour based on the awareness and utilization of the guidelines on the part of the target population, community groups, service providers and caregivers is unknown at this point. However, we can refer to other research-based and non-research based education materials and the effects such materials have produced. For example, many of our research participants noted the usefulness of a variety of FASD parenting manuals and websites in existence and how knowledge and utilization of this information has led to a change in knowledge, attitude, skills and behaviour. From this, we can extrapolate that the parenting guidelines will also influence such a change, particularly with its unique emphasis on the delivery of practical tips, techniques and strategies based on the direct experiences of parents and caregivers themselves. However, the development of an evaluation plan has allowed concrete steps to be outlined in conducting a formal evaluation of the guidelines and parenting tool (see Attachment 1).

The involvement of PAC members and various other stakeholders throughout the process has also had an impact. The project has allowed individuals from across Canada to connect in meaningful ways. Many new connections and partnerships were formed between members of the National and Regional PACs and other stakeholders throughout the course of the project. The sharing of information on the FASD listserv was another effective communication tool that allowed members to share knowledge, inform about upcoming events and recruit involvement in various projects and studies.

VON's involvement in the FASD community throughout the project has increased awareness of the VON brand across Canada and brought knowledge to the organization about FASD. As VON's first foray into the field of FASD, the project helped to establish VON as a player among those working in the field. Although some PAC members expressed concern about partnering with an organization that typically has had relatively little involvement with the FASD community, VON's strong orientation to a participatory approach and the national credibility that VON's brand gave to the project quickly allayed and offset these concerns. In particular, working with a well established national organization greatly facilitated the establishment of national links. In addition, the VON family (staff) benefited from an increased body of knowledge about FASD. The hiring of a full-time Project Coordinator allowed for this body of expertise to be developed through the Eastern Region office and shared with the organization as a whole. The involvement of a number of subcontract staff (research consultants and assistants, evaluator, website development/design group and administrative support persons) also enriched the experience and increased awareness of FASD among these individuals, who in many cases have passed this information along to others.

The parent-driven best practice parenting guidelines and connective resources (i.e., resources, listserv) developed as a result of the project address key determinants of health for families of children with FASD. For example, there are ideas provided to improve the home environment, enhance learning strategies, and strengthen social supports both for the child and the parents themselves. Thus, they have the potential to enhance social support networks, education and literacy, social and physical environments, personal health practices and coping skills and healthy child development.

There is a need to evaluate the parenting tool after it is distributed to the parents and caregivers of children with FASD. Such an evaluation will assess the process, frequency and consistency by which parents use the guidelines as well as the outcome of these interventions on the affected children and adults in their care. This evaluation component was not included in the project plan due to the timeframe but has been proposed in an evaluation plan attached to this report (Attachment 1). This evaluation component will allow for a direct assessment of the guidelines and the change that they have affected among the target population, community groups, service providers and the project sponsor. This process has been initiated by the development of an evaluation tool that may be incorporated into stakeholders' programs to address client (i.e., parent) satisfaction with the guidelines (Attachment 1).

The key partnership that was developed as a result of the project was between VON and the FASD community itself. As mentioned previously, the project represented VON's first piece of work in the field of FASD. A significant contribution to the knowledge about VON among FASD stakeholders and subsequently knowledge about FASD within VON as a national organization was gained as a result. Because of this, awareness of the final product is high and thus its distribution is expected to continue beyond the initial funding. The process by which the guidelines were developed may be used for future VON projects and may also be utilized by others who wish to develop parent-driven best practices in a variety of areas.

While the guidelines themselves are easily transferable to other communities that work with families and children affected by FASD (i.e., those outside of Canada or minority groups within Canada), the process by which the guidelines were developed is transferable to a variety of disciplines and communities, as discussed above. While the guidelines were specific to the needs of parents of children and adults with FASD and worked with the FASD community in their development, the process itself could be extrapolated and made relevant for any community or discipline that sees a need for parent-driven best practices or best practices overall. In addition to the development of guidelines themselves, the process that made these relevant for the target audience (i.e., development of the parenting tool) may also be used in other communities to translate complex information and make it relevant for a target audience.

The overall impact of the project was to give voice to those who are living and working with FASD on an everyday basis and to develop information in response to their needs and experiences. This information was then shared with others in the same situation (i.e., other parents and front-line workers) via the parenting tool. We believe that the product and process made a significant difference in decreasing isolation, increasing knowledge and enhancing the connectedness of those working in the field as both parents and professionals.

## NOW WHAT? What could we do differently?

### *Reflecting Back to Learn*

As the project unfolded, it became necessary to make changes to the data collection methods and some project activities. In terms of research, this meant an enhancement of data collection methods to enhance community involvement and depth of information. Changes included the inclusion of PAC members as key informants in the needs assessment and focus groups as well as the addition of a web-based survey (see Research Report for more information). These enhancements and additions enhanced the sample quality, especially in terms of the needs assessment and focus group through the involvement of community members with significant experience in parenting a child with FASD or working with families affected by FASD.

The formation of a working group and integration of National and Regional PACs into one committee were also implemented as more effective ways to achieve project objectives, especially during the third year of the project. The working group brought the necessary focus to the development of the guidelines and the formation of one PAC brought national, regional, provincial and local perspectives together in a more useful forum.

The project's true strength was its empirical, research-based component. The emphasis on results based primarily on parent input allowed the project to remain community-based. While research participants included a unique mix of parents and "traditional" experts in the field, the focus remained on parental input. Thus, the focus was switched to *parent-driven* best practice guidelines to respond to the voiced need from parents for results that are "empirically proven by parents themselves".

The involvement of a research consultant in the project to guide the research process was invaluable to ensure this process ran smoothly. This specialized knowledge allowed for effective data collection and thorough analysis of the results. This is just one example of an area of knowledge deficit within the project that was subcontracted in order to ensure that objectives were met. Other examples include the involvement of a research assistant to complete the literature review and design team to guide the development of the parenting tool.

Although the involvement of subcontracted personnel in addition to the Project coordinator helped to fill in the majority of knowledge gaps, additional areas of knowledge development were identified that would allow the work to proceed more effectively. For example, it would have been extremely helpful to have a professional writer to guide the development the final report. A publicist would also have been helpful to deliver effective and cost-friendly promotional mechanisms for the project and parenting tool. Finally, the involvement of community members who have first-hand experience in the development of parenting manuals (FASD-focused and otherwise) would have been an asset to the process.

Overall, the project was well supported by both the funding agency (Public Health Agency of Canada) and the sponsoring organizations (VON Canada/Eastern Region). PHAC provided an appropriate level of both knowledge-based and fiscal support through the strong involvement of project consultants in both areas. The consultants were accessible and worked to address concerns and inquires in a prompt and satisfactory manner. They also brought together “sister projects” of the FAS/FAE Strategic Project Fund through organized teleconference meetings with project leads and held an FASD Showcase in June of 2005 to highlight the results of each project.

As a sponsoring organization, VON Canada/Eastern Region was highly supportive of the project. The organization shared their expertise on both a regional and national level through the involvement of Eastern Region staff in a supervisory, administrative and consultative capacity and VON Canada staff in a fiscal (accounting), communications-based (website and listserv) and research capacity (national project staff and VON E-Ethics Committee).

In terms of cost-effectiveness, the project was managed on a minimum budget and all objectives were able to be met within the funding structure. However, some measures that were undertaken to fit within this funding structure were reflected upon as being less effective than other alternatives by community members involved in the project. For example, although all meetings with PAC members were held by teleconference and this contributed significantly to cost savings, members voiced an opinion that at least one face to face meeting within the second or third year of the project would have been more effective. One member who responded to the PAC evaluation wrote:

*“I think it would have been good to have at least one face to face meeting with all the committee members [early in the project]; I think it would have been helpful for sharing ideas and getting to know the other participants and establishing rapport (there were some meet and greets organized at conferences but that was not a formal business meeting)”*

Due to the fact that the project concentrated almost exclusively on the involvement of those within the FASD community, soliciting involvement from individuals in other areas such as special needs communities, justice and general practitioners was not actively explored. Since the project was parent-driven, it was felt that these individuals might not have the expertise to contribute effectively. However, individuals in these areas need to be informed about FASD and the results of the project (this is discussed in more detail in the next section of the evaluation report). Other significant experts in the FASD community might have been included in the project; however, some of these key informants did not have the time to volunteer with the project when approached. Still others were unable to commit to PAC membership and acted in a consulting role throughout the project. The enhanced involvement of the “big names” in FASD would be a welcome addition to future projects of the kind.

In order to expand the network of people involved in working on this issue it is necessary to expand information to all those that work with families of children and adults with FASD. This was a constant theme throughout the research and evaluation process. Developing a connection to systems (such as social services, Children’s Aid, justice) was especially emphasized by members of the FASD community. To date, the project has attempted to ensure that systems are involved and informed, yet many areas have yet to be reached. It is envisioned that the promotion of the parenting guidelines and tool through the distribution of the DVD will allow for enhanced visibility and interest in the project results.

The majority of the project’s needs were met as successfully as possible given the amount of funding provided. The highly committed, passionate and dynamic involvement of PAC members as project volunteers was the backbone of the project. The engagement of research participants was another key component in ensuring the success of the project. Support from the Public Health Agency of Canada, VON Canada/Eastern Region, subcontracted personnel and the community as a whole further contributed to meeting needs. As one PAC member wrote:

*“The importance and utility of this project for the larger picture of FASD in Canada went beyond just the scope of the creation of the best practices tool. Through this project a regional and national “connectedness” developed with individuals from all across Canada sharing information together. The website and email distribution network became an excellent source of information.”*

In terms of envisioning a better way of developing realistic project goals and objectives in the initial planning stage, consulting with those in the FASD community in its development may have been very helpful during this process. At the project’s outset, the work plan provided the participatory framework and allowed for changes based on participant input. Consultation with the PACs throughout the process contributed to the continuing shift in objectives and activities, although the initial goal remained the same. In every way, the participatory approach drove the process. Additionally, the flexibility of the funder, sponsor, project staff and volunteers allowed the necessary changes to take place.

Management and administrative systems changed through the project to become more effective. For example, the PAC structure was streamlined twice. A working group was developed to focus attention on the development of the guidelines. The need for various subcontracts that developed was fulfilled in order to meet the needs of the project. While the project coordinator remained a constant throughout, she worked within the existing VON structure to ensure deliverables were completed. Overall, improvements and additions to the way the project was run were implemented with the goal of improving the process and the results.

## THEN WHAT? How do we plan to use the evaluation findings for continuous learning?

### *Moving it Forward*

Evaluation findings were used on an ongoing basis to contribute to the planning and implementation of the project strategies and activities. Starting with the orientation questionnaires that were distributed to members of the Project Advisory Committees at the outset of the project, feedback was sought from project stakeholders and research participants at each stage of the process. Continual evaluation of the PAC structure allowed for necessary changes, such as consolidation of committees in two stages. Stakeholder feedback allowed the project to adapt to new realities and become more proficient in both planning and implementation.

Not only were the experiences of project participants measured and analyzed through the use of feedback questionnaires, research findings were also used to drive subsequent research protocol and focus. For example, the need themes identified as part of the key informant interviews were used to structure focus group questions and identify a relevant sample. Gaps in information from the focus groups initiated the development of the Web survey, which focused on providing opportunities for members of the community to share key resources and parenting tips, techniques and strategies based on their experiences. Development of the resource collection was driven by the results of the Web survey. These three key research pieces drove the development of the guidelines, which in turn were parent-driven by members of the community, bringing the process full circle. The fact that each research component drove the next was a planned, deliberate process. The project work plan was flexible enough to allow for this sequential process whereby each component built on the next. In the fourth year of the project, participants in the orientation sessions directly benefited from the evaluation results as each session was evaluated via a written questionnaire. The results of these evaluations can be found in Appendix B of the **Final Report**. This feedback was then used to modify subsequent sessions, improving the process overall.

Project findings will be used for future knowledge development in a number of ways. The fact that the process itself can be replicated will allow other groups to adapt the research methods to their own needs. The guidelines can be used to direct trainings to both parents and service providers and have the potential to influence policy in terms of the informational needs of families living with FASD. Systems-based resource and support needs (i.e., those other than informational needs) that were discovered through the project research as an unintended outcome

provide empirical data to support a community response to FASD prevention, awareness, education and supports. In addition, the gaps in knowledge that have been identified can be used to guide the development of new knowledge specialties for systems such as health, justice and social service. Although these systems-based resource and support needs have not been investigated as this activity was outside the scope of the project, the hard data remains available for analysis at a later date.

Final evaluation learnings will be documented and distributed through the VON website and in hard copy to interested parties as part of the final report. PAC members will also participate in the distribution process, acting as a vital link between the project and members of their respective communities. These learnings also exist implicitly within the guidelines themselves and thus within the parenting manual, which are also available online and in hard copy.

Additional means of dissemination of evaluation results have included presentations at conferences and workshops and delivery of orientation sessions to members of the community. This information has been discussed in the first section of this report.

Alternative ways to present the evaluation results so that more people can make use of the learnings include local, regional and national media coverage as well as submissions to academic journals and community newsletters.

The evaluation results can be used for new project planning in a number of ways. Most importantly, results can be used to identify what works and what doesn't work in regards to specific project activities, which can be used in setting direction for a project. More specifically, some key future activities have been identified throughout the evaluation process. These are discussed in the *Recommendations* section of **Final Report**, but are outlined here as they relate to evaluation.

One prospective project direction that emerged from our research is an evaluation of the guidelines and parenting tool. The evaluation plan presented in Attachment 1 outlines a tentative course of action for this process, which would allow the guidelines to be the first of their kind to be formally evaluated. The creation of a second edition of the parenting tool based on the results of the evaluation would be an additional prospective activity with its basis in evaluation. As suggested above, unintended outcomes of the project may also be used to guide future projects focusing on knowledge development and resource allocation. Finally, the evaluation process itself may be used as a template to be replicated or revised as part of potential project planning.

As suggested above, evaluation results may be used to influence policy and research priorities by providing empirical evidence of the needs of the FASD community to inform the development of new projects and solicit a response from governmental agencies, community groups, health professionals, the legal system and any other organizations that have a vested interest in FASD. It is hoped that the evaluation results will allow the project to live on through enhancing the lives of individuals, families and communities affected by FASD.

## Attachment One: Evaluation Plan for the Let's Talk FASD Toolkit

### *Background for Evaluation*

One of the original objectives of this project was to review the existing “best practices” literature on caring for children with FASD. However, as mentioned in previous sections, although we were able to find material with suggestions on how to care for children with FASD, we were unable to find any literature that actually formally evaluated the effectiveness of these practices. In reviewing the literature for development of the Best Practices document and Toolkit, it became clear that very few, if any, tools for helping children with FASD had been formally evaluated. This lack of evaluation means there is little research that either confirms or refutes the anecdotal evidence we heard over the three years of the project of the value and impact these tools have had on the lives of parents and caregivers of children with FASD. Further, the lack of evaluation means there is little information as to how these tools can be used to maximize their effectiveness.

One of the main strengths of the toolkit, *Let's Talk FASD*, was the generation of material through a participatory approach that allowed parents and caregivers of children of FASD to both contribute and validate the techniques and strategies contained within the Toolkit. However, that situation meant any suggestions provided in the *Let's Talk FASD* Toolkit were based solely on parent/caregiver experience, rather than formal evaluation procedures. Although parent/caregiver experience may provide a good indicator of the success of different strategies, it does not substitute for formal evaluation.

Development of a toolkit as extensive as *Let's Talk FASD* was well beyond the original mandate of the original three year project. To avoid the criticism of other tools, that is, the lack of evaluation, it is strongly recommended that a thorough evaluation of “*Let's Talk FASD*” be conducted. Unfortunately, the current project has reached its conclusion, both in terms of time and monetary resources. Therefore, any extensive evaluation will require additional funding. A proposal for carrying out an evaluation is provided below.

In brief, a two step evaluation is proposed. The first step, which involves a brief mail survey to all individuals who receive a copy of *Let's Talk FASD* in a one time mass mail out, would examine overall impressions of the Tool as well as provide a brief description of how the Toolkit was used and suggestions for improvement. The second step involves in-depth interviews to gain a better idea of how parents/caregivers used the Toolkit and the impact it had on the lives of their children and families. This two step process would provide information that can be used both to inform parents/caregivers of the best uses of the Toolkit as well as to provide guidance for the improvement of future Toolkits or the development of new resources by other practitioners. At the end of the evaluation proposal is a time line for carrying out the evaluation.

The combined evaluation of the mail survey and interviews would, for the first time that we know of, provide a toolkit for helping children with FASD that has been formally evaluated. From the point of view of the project, this evaluation would serve two important purposes. First,

it would allow organizations or individuals who want to use the Toolkit to make evidence-based decisions, that is, they would have information about what works in the Toolkit and how it could best be used to benefit children with FASD and their families. Second, Toolkit updates could be informed by considerable input from the Toolkit's actual users. This type of evaluation would be consistent with the participatory approach used throughout the entire project. It is this participatory approach combined with a formalized needs assessment and evaluation that will set this Toolkit apart from all others currently in the field of FASD.

## *Step 1: Mail Survey*

### *Background*

Approximately 800 *Let's Talk FASD* Toolkits have been mailed to people who indicated an interest in receiving the Toolkit. The database of individuals was accumulated over the course of the four year project. The mail out of Toolkits provides an ideal opportunity for follow up of a large number of users of the Toolkit soon after they first utilize the Toolkit. Timing the mail survey to follow the mailing of the Toolkits within a reasonable time frame will permit people to experience using the Toolkit and the changes that may have occurred as a result, while at the same time ensuring that not so much time passes between the survey and the Toolkit reception that there would be significant memory biases.

### *Sample*

All individuals who were sent a copy (or copies) of the *Let's Talk FASD* Toolkit will be mailed a brief followup survey.

### *Methods*

A survey with a self-addressed, stamped envelope will be sent to all individuals who were mailed a copy of the *Let's Talk FASD* Toolkit (see Figure 1). The two page survey will ask ten closed-ended questions pertaining to the format and content of the Toolkit. The remainder of survey will consist of two open-ended questions that ask respondents to indicate how the Toolkit helped them to better care for children with FASD and ways the Toolkit could be improved. Finally, respondents will be asked whether they would agree to be contacted for a follow-up interview and those who agree will be asked to provide their first name, telephone number, and age of child(ren) with FASD or suspected of being affected by FASD. Survey recipients will be asked to complete the survey as soon as possible and to return it in the self-addressed, stamped envelope.

### *Analysis*

Quantitative data will be analyzed through descriptive statistics (such as means, standard deviations). Qualitative data will be coded to determine how respondents indicated that the Toolkit helped them and ways the Toolkit could be improved.

**Figure 1 : Toolkit Questionnaire**

*LET'S Talk FASD*

**Please check the statement that best describes your primary role or responsibility in caring for children with FASD. Please check only one statement.**

\_\_\_\_\_ I am a parent or caregiver of a child or adult with FASD

\_\_\_\_\_ I am a professional or volunteer who works with children or adults with FASD

\_\_\_\_\_ I am both a parent/caregiver of a child with FASD and a professional/volunteer who works with children/adults with FASD.

**Which language version of the toolkit did you use?**

\_\_\_\_\_ English

\_\_\_\_\_ French

**For each statement below, please circle the response that best matches your evaluation of the toolkit.**

	CONTENT AND DESIGN	1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree
1	Overall, I am very satisfied with the information contained within the Toolkit	1	2	3	4	5
2	The toolkit is visually appealing	1	2	3	4	5
3	The toolkit is easy to use	1	2	3	4	5
4	The toolkit content is useful	1	2	3	4	5
5	The content addresses my areas of concern	1	2	3	4	5
6	The guidelines are clearly presented	1	2	3	4	5
7	This is one of the best resources I have ever seen in terms of ideas for caring for children with FASD	1	2	3	4	5
8	I would recommend this toolkit to parents/caregivers of children affected by FASD	1	2	3	4	5
9	I would recommend this toolkit to professionals that work with children affected by FASD	1	2	3	4	5
10	I am very satisfied with the quality of this toolkit	1	2	3	4	5

**OVER PLEASE →**

1. Please tell us about your experience with LET'S Talk FASD, particularly how it has helped you to better care for or provide services to children/adults with FASD. Please feel free to add additional pages as necessary.

2. Is there any way LET'S Talk FASD can be improved? Please feel free to add additional pages as necessary.

**May we contact you in the future for more information on your experience with the toolkit? If so, please provide your first name, phone number and/or email address.**

**Thank you for taking the time to provide us with your feedback.  
Your individual responses will be kept confidential.**

## *Step 2: Parent/Caregiver Telephone Interviews*

### *Background*

Although the mail survey would provide parents'/caregivers' overall impressions of the Toolkit as well as some insight into their experience using the Toolkit, the survey results would not provide in-depth information pertaining to how parents/caregivers used the toolkit, what worked well, how strategies were implemented, and the effects on the children being cared for. Thus, the second component of the evaluation would be in-depth, qualitative interviews to gain a deeper understanding of how the Toolkit was used and the manner in which it impacted on the lives of parents/caregivers and their families. It is only through a more in-depth assessment that we would be able to gain the understanding necessary to help health care providers and parents/caregivers better use the Toolkit as well as make changes necessary to improve the Toolkit.

### *Sample*

On the mail survey, respondents will be asked if they would be willing to agree to a telephone interview about their experience using the Toolkit. From those who indicated that they would be willing to participate in an interview, a sample will be drawn. There are a number of ways the sample could be drawn. We propose that a sample of 32 respondents be selected, representing four different age groups of children, one group aged 0-6 years, a second group aged 6-12 years, the third group aged 13-18 years, and the fourth group aged 19 years and older. These four age groups were selected based on differences in physical, cognitive, emotional, and social development.

### *Methods*

As noted, participants will be selected from those who indicated on the mail survey that they would be willing to participate in an interview. Because participants will come from across the country, telephone interviews will be conducted. Each potential participant will be contacted by telephone and for those who agree to participate an interview time will be set up. The telephone interview will take approximately one hour and the questions will focus on the Toolkit's content and format, how parents/caregivers used the Toolkit, how they implemented the suggested strategies, how well the strategies worked, and the reasons why respondents perceived strategies as working or not working. A proposed interview protocol is presented in Table 1.

### *Analysis*

All interviews will be audio-taped and the tapes transcribed. Transcribed interviews will be coded based on identified, *a priori* themes (e.g., content and format, strategies used, implementation, and impact) as well as emergent themes. The coded data and themes will be summarized and presented in a final report.

**Table 1: Possible Questions for One-to-One Evaluation Interviews**

<p>The following represents potential topics that may be covered in the evaluation interview. Questions may be changed, deleted, or supplemented by additional topics depending on the specific needs of the evaluation.</p> <p>Please tell me what you thought about the layout of the toolkit.</p> <p><i>Prompts</i></p> <ul style="list-style-type: none"><li>Easy to read</li><li>Easy to find information</li><li>Organized in a useful manner</li></ul> <p>In general, how do you use the toolkit?</p> <p><i>Prompts</i></p> <ul style="list-style-type: none"><li>Read through completely to gain general knowledge and ideas</li><li>Use it to find new ways of parenting/caring</li><li>Use it to solve immediate behavioural needs as they occur</li></ul> <p>In what ways has the toolkit been useful to you?</p> <p><i>Prompts</i></p> <ul style="list-style-type: none"><li>Gotten good ideas</li><li>Implemented ideas</li><li>Resource materials</li></ul> <p>Has the Toolkit helped your child in any way [have respondent try to identify specific ways the toolkit helped]</p> <p><i>Prompts</i></p> <ul style="list-style-type: none"><li>Better able to self-control behaviour</li><li>Better performance (home, school, extra-curricular activities)</li><li>Emotional (happier, greater self-esteem, etc.)</li></ul> <p>What was the single best thing about the toolkit? Why?</p> <p>What could have made the toolkit better for you?</p>
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## Proposed Evaluation Timeline and Costs

Because carrying out an evaluation would extend the project beyond its time and monetary resources, a proposed timeline for the evaluation and projected costs are outlined below.

**Table 2: Timeline and Costs of Proposed Evaluation**

<b>Activity</b>	<b>Time</b>
Mail-out survey (n=500)	Week 1
Surveys returned	Week 2-3
Data Entry	Week 4-5
Quantitative Data Analysis	Week 6
Qualitative Data Analysis	Week 7
Final Report	Week 8
Finalize Final Interview Protocol	Week 9
Select Interview Respondents	Week 10
Set up and Conduct Interviews (n=32)	Week 11-13
Interview Transcription	Week 14-19
Interview Data Analysis*	Week 20-22
Final Report	Week 23-28

## Notes



CANADA