

Evaluation of *Let's Talk FASD*

**A report presented to the
Victorian Order of Nurses**

**Prepared by
Steven Dukeshire, PhD
Melissa Lee-Ross, BSW
Renée Garbes, BSc
May, 2007**

ACKNOWLEDGEMENTS

The success of the *Parenting Guidelines for Families of Children with FAS/FAE* project would not have been possible without the outstanding efforts and commitment of many people. With deepest gratitude, they are acknowledged here.

NATIONAL AND REGIONAL PROJECT ADVISORY COMMITTEES

Special recognition for the success of the project goes out to members of our National and Regional Project Advisory Committees as our information project partners.

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

A very special thank you is extended to our many research volunteers and the parents and family members of children and adults with FASD as well as those affected by FASD. Your knowledge and wisdom has brought the project to life.

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

FUNDERS

Funding for this project was provided by the Public Health Agency of Canada's Fetal Alcohol Syndrome/Fetal Alcohol Effects Strategic Project Fund.

The views expressed in this report do not necessarily represent views of the Public Health Agency of Canada.

EXECUTIVE SUMMARY

Let's Talk FASD is a resource tool designed to provide techniques and strategies to parents and caregivers of children with FASD. *Let's Talk FASD* was developed over a four year period using a participatory approach whereby parents and caregivers were able to provide input into the development of this Toolkit. *Let's Talk FASD* was completed and distributed in hard copy format beginning in May, 2006. Further, a PDF online version was also posted on the VON website.

In February, 2007 an evaluation of *Let's Talk FASD* was undertaken. The evaluation included an online survey designed to assess people's evaluation of the Toolkit in terms of its content, format, and usefulness. An evaluation survey was also developed for the web-based version of *Let's Talk FASD* that was launched in May, 2007.

Individuals who had used *Let's Talk FASD* were invited to complete the survey through messages to FASD related list serves and personal invitations sent to individuals who had indicated an interest during the course of the development project. Ninety-six people completed the survey between March-April, 2007. Respondents came from across Canada and the United States. About half of the respondents were parents/caregivers (primarily adoptive and foster parents) and half were professionals/volunteers of children with FASD. Almost everyone had used the English version of the Toolkit. Just under half of the respondents had read a download copy of *Let's Talk FASD* and another quarter had read both. However, it was observed that most parents/caregivers had only used a download copy while most professionals/volunteers had used a paper copy. This indicates that parents/caregivers may be more likely to access their information from web-based sources, pointing to the importance of launching the more user-friendly website.

Overall, participants gave very positive ratings to the format, content, and usefulness of *Let's Talk FASD*. Responses to two open-ended questions further indicated respondents' positive views toward *Let's Talk FASD*. They noted that the Toolkit was clearly and concisely written in a user friendly manner and included practical techniques and strategies for caring for children with FASD. Some respondents expressed concern about the accessibility of *Let's Talk FASD*. They indicated the PDF version was difficult to download and assemble once it was printed. Others mentioned they would appreciate greater access to more print copies. There were also suggestions for changes or additions in the Toolkit's content, but no common theme emerged from among these comments. The suggested changes and additions are listed in the full report.

Based on the results of this evaluation, there are two main recommendations. First is to try to increase the availability and accessibility of *Let's Talk FASD*. The launch of the web-based version is likely to address many of the concerns pertaining to accessibility. There is also likely the need, if possible, to produce more print copies that can be freely or at least inexpensively distributed. Second, this evaluation failed to adequately assess how parents/caregivers actually use *Let's Talk FASD* and the impact it has on helping

them care for their children. With that in mind, a further evaluation is required that would identify parents who are newly caring for a child with FASD and who used the Toolkit. Ideally, semi-structured, one-to-one interviews would be undertaken with them to determine specifically how they used the resource and the impact it had on helping them care for children with FASD.

TABLE OF CONTENTS

BACKGROUND	1
METHODS	1
<i>Online Survey Evaluation of Print/PDF Format of Let's Talk FASD</i>	1
<i>Evaluation of Web-Based Version of Let's Talk FASD</i>	2
RESULTS	2
<i>Respondent Characteristics</i>	2
<i>Version of Let's Talk FASD Used by Respondents</i>	4
<i>Assessment of Let's Talk FASD</i>	4
<i>Respondents' Thoughts and Comments About Let's Talk FASD</i>	8
<i>Experience with Let's Talk FASD</i>	8
Format/Content	9
Parent/Caregiver Use of <i>Let's Talk FASD</i>	9
Dissemination/Distribution	10
<i>Ways to Improve Let's Talk FASD</i>	11
Better Accessibility.....	11
Additional Content/Other Comments	12
<i>Evaluation of Web Version of Let's Talk FASD</i>	13
CONCLUSIONS/RECOMMENDATIONS	13
APPENDIX A: EVALUATION SURVEY	15
APPENDIX B: LIST SERVE MESSAGES	20
APPENDIX C: WEB-BASED FEEDBACK EVALUATION SURVEY	23

BACKGROUND

Let's Talk FASD was the result of a four year project by VON Canada to develop a Best Practices Toolkit to help parents and other caregivers of children and adults with FASD. A participatory approach was used in generating the material for the Toolkit that allowed parents and caregivers of children with FASD to both contribute and validate the techniques and strategies contained within this resource. However, using a participatory approach meant the material contained in *Let's Talk FASD* was based primarily 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. More information on the development of *Let's Talk FASD* can be found in the full report at www.von.ca/fasd.

Let's Talk FASD was completed and distributed in both English and French beginning in May, 2006. It was made available for free both in hard copy and downloadable PDF format. A web-based version based on the print copy was launched in May, 2007.

In March-April, 2007, an evaluation of *Let's Talk FASD* was undertaken with the goal of determining what parents/caregivers thought about the Toolkit, how they used it, and ways in which they thought it could be improved. Further, an evaluation was developed for the web version that was recently launched.

This report describes the administration and results of the evaluation of the print/PDF version of *Let's Talk FASD* and as well as describes the development of the feedback survey for the web-based version.

METHODS

Online Survey Evaluation of Print/PDF Format of Let's Talk FASD

An online survey was developed to assess parents'/caregivers' evaluation of *Let's Talk FASD*. The online survey was hosted on surveymonkey.com, a website that allows for the development, hosting, and analysis of web-based surveys. Both English and French surveys were developed. The surveys asked for respondent characteristics including the respondents primary role (parent/caregiver or professional/volunteer) in caring for a child/adult with FASD, how many children with FASD parents/caregivers had cared for, relationship to the child they cared for, how long they suspected or knew their child had FASD, and whether their child had received a medical diagnosis of FASD. All respondents were also asked to identify what region of Canada they lived in, the size of the community they lived in, and the language that was easiest for them to speak and read.

Respondents were asked which version (paper copy or download) and which language of *Let's Talk FASD* they had used. They were also asked to answer ten different items on 5 point Likert scales ranging from 1 (strongly disagree) to 5 (strongly agree). These items were designed to evaluate respondents' assessment of the format, content, and usefulness of the Toolkit. Respondents were also asked two open-ended questions. The

first asked them to describe their experience with *Let's Talk FASD* and the second asked for suggestions on how the Toolkit could be improved (see Appendix A for a copy of the survey).

The online survey was available from late March to late April, 2007. Announcements (see Appendix B) inviting anyone who had used *Let's Talk FASD* to complete the survey were sent out on the following list serves: FASD_National_Link, Fasdnews, FASDAY, Olderfas, FASD Group of Ottawa elist (includes the FASD Coalition of Ottawa), WebBoard of the Ontario Early Years Connection under topics: "FASD: General Information" & "Resources, Links & Information", three small Ontario FASD community lists, CANGRANDS, AdoptionCanada, small Adoption Council of Canada elist, and Elspeth Ross' personal Canadian FASD elist in both English and French. A reminder (see Appendix B) was also sent through the same list serves approximately one week prior to the end of the survey. Individuals who had requested and were sent a copy of *Let's Talk FASD* were contacted by e-mail and personally invited to complete the survey. In addition, an invitation was sent to former members of the Project Advisory Committee and Working Group.

Descriptive statistics were used to analyze quantitative data. The two questions requiring written responses were topically/thematically coded to categorize respondents' experiences with *Let's Talk FASD* and suggestions for improvement.

Evaluation of Web-Based Version of Let's Talk FASD

Questions for the evaluation of the web-based version were developed and the feedback survey was included with the launch of the web site in May, 2007.

RESULTS

Respondent Characteristics

Ninety-six respondents completed the online survey. Three respondents completed the French version of the survey with the remainder completing the English version. As shown in Table 1, the majority of respondents (28.6%) were from Ontario with the Prairie provinces contributing the second largest (20.6%) number of respondents. Just over half (54%) came from communities of 50,000 or more people. Over 95% indicated that English was the language easiest for them to speak and read. It should be noted that one third of respondents did not answer these demographic questions.

Of the respondents, 40.2% identified themselves as a parent or caregiver of children with FASD, 40.2% as a professional or volunteer who works with children with FASD, and just under one fifth as both a parent/caregiver and professional/volunteer. Of those who indicated they were a parent/caregiver of children with FASD, 35.2% had cared for one child, 35.2% for two children, and 29.6% for three or more children. Most respondents identified themselves as either adoptive or foster parents. Most (83.3%) knew or suspected their child had FASD for four or more years and most (79.2%) had received a diagnosis of FASD for at least one of their children.

Table 1. Characteristics of Survey Respondents (n=63)

Characteristic		%
<i>Primary role or responsibility in caring for children or adults with FASD</i>	Parent or Caregiver	40.2
	Professional or Volunteer	40.2
	Both	19.5
<i>Number of children with FASD you have you cared for*</i>	1	35.2
	2	35.2
	3 or more	29.6
<i>Relationship to the child or children affected**</i>	Birth parent	7.3
	Foster Parent	21.8
	Adoptive Parent	67.3
	Grandparent/extended family member	12.7
	Other	18.2
<i>Length of time known or suspected your child has FASD*</i>	Less than 1 year	1.9
	1-3 years	14.8
	4 or more years	83.3
<i>Received a medical diagnosis of FASD from a doctor for at least one of your children*</i>	Yes	79.2
	No	20.8
<i>Size of community you live in</i>	Less than 1000 people	11.1
	1,000-4,999	11.1
	5,000-9,999	7.9
	10,000-49,999	15.9
	50,000 and over	54.0
<i>Language easiest for you to speak and read</i>	English	98.4
	French	1.6
	Other	0.0
<i>Where do you live</i>	Atlantic Canada (NB, NF, NS, PE)	17.5
	Quebec	4.8
	Ontario	28.6
	Prairies (AB, MN, SK)	20.6
	British Columbia	6.3
	Northern Territories (NT, NU, YK)	4.8
	United States	15.9
	Other country	1.6

*Answered only by respondents who indicated they were a parent/caregiver of a child with FASD

**More than one response could be provided

Version of Let's Talk FASD Used by Respondents

Just under half (45.9%) of respondents read a download copy of *Let's Talk FASD*, 29.6% read a paper copy, and 24.3% read both. Most had used just the English version of the Toolkit (94.6%) (see Table 2).

Table 2. Versions of *Let's Talk FASD* Used by Respondents

Characteristic		%
<i>Version of Let's Talk FASD</i>	Paper Copy	29.6
	Download Copy	45.9
	Both	24.3
<i>Language of Let's Talk FASD</i>	English	94.6
	French	2.7
	Both	2.7

Assessment of Let's Talk FASD

Overall, respondents gave a very positive evaluation of *Let's Talk FASD*. As can be seen in Table 3, respondents indicated that they found the Toolkit visually appealing (mean 4.3 out of 5), easy to use (4.3), content useful (4.4), addressed their areas of concern (4.1), and had clearly presented guidelines (4.3). Respondents also indicated that it was one of the best resources they had ever seen on taking care of children/adults with FASD (4.0) and would recommend giving the Toolkit to parents/caregivers (4.4) and professionals (4.4) of children/adults with FASD. They also indicated that they were satisfied with the information presented (4.3) as well as the quality of the Toolkit (4.4).

Based on responses to the open-ended questions, it appeared that there was some concern about the ability to download the online version of *Let's Talk FASD* and that the download copy did not have the same visual appeal or ease of use as the paper copy. To determine whether respondents actually rated the two versions differently, the ten evaluation items were broken down by version of Toolkit. As can be seen in Table 4, participants who only used a paper copy rated *Let's Talk FASD* slightly higher on most items than those who only had used a download copy. It is noteworthy that the largest difference between those with paper copy versus download copy was seen for the item "The Toolkit is visually appealing" (mean 4.3 versus 4.0). Also noteworthy is the much higher ratings given by respondents who had both paper and download copies of *Let's Talk FASD*. Although there is no direct data to support this interpretation, it is likely that individuals who really liked *Let's Talk FASD* would also be more motivated or have greater reason to use *Let's Talk FASD* and therefore were more likely to use both versions.

Table 3. Assessment of Format, Content, and Usefulness of *Let's Talk FASD*

Item	Mean	Percent				
		1	2	3	4	5
The Toolkit is visually appealing	4.3	0	0	3	69	26
The Toolkit is easy to use	4.3	0	1	3	61	33
The Toolkit content is useful	4.4	0	0	1	60	37
The content addresses my areas of concern	4.1	0	1	10	64	23
The guidelines are clearly presented	4.3	0	0	1	69	28
This is one of the best sources I have ever seen in terms of ideas for caring for children or adults with FASD	4.0	0	3	20	33	19
I would recommend this Toolkit to parents/caregivers of children or adults affected by FASD	4.4	0	0	3	51	45
I would recommend this Toolkit to professionals that work with children or adults affected by FASD	4.4	0	0	3	54	41
Overall, I am satisfied with the information contained within the Toolkit	4.3	0	1	3	63	31
I am satisfied with the quality of this Toolkit	4.4	0	0	3	59	37

Responses were on a five point scale with 1=Strongly disagree to 5=Strongly agree
Percentages may not add up to exactly 100% due to rounding

Let's Talk FASD was primarily intended to be a resource for parents and caregivers of children with FASD. Therefore, respondent ratings were separated by their primary role as either parent/caregiver or professional/volunteer. As can be seen in Table 5, professionals/volunteers tended to rate *Let's Talk FASD* higher on most items than parents/caregivers. One possible explanation for the differences may be that each group would use the Toolkit for different purposes, and therefore, experience it differently. Based on the responses to the open-ended questions, professionals/volunteers often gave the resource to parents or used it to help facilitate workshops or other types of information sessions. On the other hand, parents/caregivers actually had to apply the

suggested strategies and techniques to their everyday life of caring for children with FASD. Thus, each group was using *Let's Talk FASD* in different ways, something which may have impacted their rating of the Toolkit.

Table 4. Assessment of "Let's Talk FASD by Version Used

Item	Version of Toolkit			Overall Mean
	Paper Copy	Download Copy	Both	
The Toolkit is visually appealing	4.3	4.0	4.6	4.3
The Toolkit is easy to use	4.3	4.1	4.6	4.3
The Toolkit content is useful	4.3	4.2	4.8	4.4
The content addresses my areas of concern	4.0	4.0	4.6	4.1
The guidelines are clearly presented	4.2	4.1	4.7	4.3
This is one of the best sources I have ever seen in terms of ideas for caring for children or adults with FASD	3.8	3.8	4.7	4.0
I would recommend this Toolkit to parents/caregivers of children or adults affected by FASD	4.3	4.3	4.8	4.4
I would recommend this Toolkit to professionals that work with children or adults affected by FASD	4.2	4.3	4.8	4.4
Overall, I am satisfied with the information contained within the Toolkit	4.3	4.1	4.7	4.3
I am satisfied with the quality of this Toolkit	4.4	4.2	4.7	4.4

Table 5. Assessment of "Let's Talk FASD by Primary Role

Item	Version of Toolkit			Overall Mean
	Parent or Caregiver	Professional or Volunteer	Both	
The Toolkit is visually appealing	4.1	4.4	4.3	4.3
The Toolkit is easy to use	4.2	4.4	4.2	4.3
The Toolkit content is useful	4.2	4.5	4.5	4.4
The content addresses my areas of concern	4.0	4.2	4.0	4.1
The guidelines are clearly presented	4.1	4.4	4.4	4.3
This is one of the best sources I have ever seen in terms of ideas for caring for children or adults with FASD	3.8	4.1	4.0	4.0
I would recommend this Toolkit to parents/caregivers of children or adults affected by FASD	4.2	4.6	4.5	4.4
I would recommend this Toolkit to professionals that work with children or adults affected by FASD	4.3	4.4	4.5	4.4
Overall, I am satisfied with the information contained within the Toolkit	4.1	4.4	4.3	4.3
I am satisfied with the quality of this Toolkit	4.1	4.5	4.4	4.4

Another potential reason that professionals/volunteers may have rated *Let's Talk FASD* differently than parents/caregivers is that they may have had different versions of the Toolkit. As can be seen in Table 6, there is evidence to support this idea. Less than 20% of respondents who identified themselves primarily as parents/caregivers of children with FASD had a paper copy of *Let's Talk FASD*, while over 80% had only a download copy. Conversely, over 80% of respondents who identified themselves primarily as professionals/volunteers had a paper copy of *Let's Talk FASD*. Perhaps more importantly, these results speak to distribution and accessibility issues. Based on these data, it is clear that many parents/caregivers access their information on-line and therefore accessed the PDF version of *Let's Talk FASD*. One could speculate that people

who rely primarily on the internet for information and resources will greatly benefit from the recently launched web-based version that seems to have a more user-friendly, clearer lay out than the PDF version. However, it should be noted that professionals/volunteers indicated that they distributed copies of *Let's Talk FASD* and used them in workshops. Thus, there is the possibility that many parents/caregivers actually do have access to a print copy through caregivers/professionals but did not necessarily respond to this survey.

Table 6. Version of Toolkit Used by Primary Role

Primary Role Caring for Children with FASD	Version of Toolkit		
	Paper Copy	Download Copy	Both
Parent/caregiver	11.5	80.8	7.7
Professional/volunteer	43.3	16.7	40.0
Both	29.4	47.1	23.5

Respondents' Thoughts and Comments About Let's Talk FASD

Respondents were asked to provide their thoughts and comments on how they used *Let's Talk FASD* as well as means by which the Toolkit could be improved. A summary of what they said is provided below. In keeping with the participatory approach used in the development of *Let's Talk FASD*, direct quotes are used where possible to allow respondents to express their thoughts in their own words. However, the overall experience of using *Let's Talk FASD* may be best summed up in the words of one respondent:

I have found this toolkit to be the very best available at this time, for professionals, caregivers and individuals affected by FASD. Since distributing my first copies, I am constantly receiving requests for copies from across Canada. This toolkit makes an excellent 'first time' resource as well as providing much needed and highly useable information for everyone connected with children/adults with FASD.

Experience with Let's Talk FASD

Respondents were asked to provide information about their experience using *Let's Talk FASD* and in particular how it helped them to care for or better provide services to children/adults with FASD. Thirty-nine respondents provided comments. All comments could be captured under three main themes: Format/Content, Parent/Caregiver Use of *Let's Talk FASD*, Dissemination/Distribution. Each of these themes is discussed below.

Format/Content

Many respondents (primarily those who identified as professionals/volunteers) provided comments pertaining to the format or content of *Let's Talk FASD* itself. Respondents indicated that they felt *Let's Talk FASD* was well laid out and written in a clear, concise, easy to understand format and user-friendly manner. Respondents also noted that the Toolkit was practical in its suggestions and provided much needed information. They also liked that it was primarily parent driven. There were a couple of respondents who remarked on the developmental nature of the Toolkit, one who felt it was not age appropriate for older students but another who loved that it was developmental and included adulthood. Two respondents appreciated that the Toolkit was available in French and noted a scarcity of French resources on this topic. A couple of respondents also indicated that they liked the availability of the Toolkit as a free download and one person mentioned liking the helpful resources/links.

Gives very practical suggestions in easy to understand language. Is organized in sections to allow quick access to the most relevant info.

The book is well laid out and finding resources is easy to do.

I like that it is current and content was derived from frontlines.

I really like the way it is set up. It is easy to understand and uses user friendly language.

It's great that it's in French as there are so few resources available that are in French.

Reading real anecdotes experienced by parents or educators of children living with the syndrome is comforting. As I am responsible for three children with this syndrome, I can relate to many of the situations.

Parent/Caregiver Use of *Let's Talk FASD*

There were relatively few comments as to how parents/caregivers used *Let's Talk FASD* in caring for their children with FASD. The most common comment was that some parents/caregivers already knew everything in the Toolkit based on years of experience with their child. However, the same respondents also indicated that they wished they had had *Let's Talk FASD* when they first cared for a child with FASD.

I would have liked to have seen it 7 years ago! Instead I found out most of this information the hard way.

I have been working with my child for many years and this information would have helped me in his earlier years.

One other person indicated that the resource allowed him/her to better understand that FASD children are limited in their adjustment and the need to adjust to them. Another respondent indicated that it was a good resource when going to talk to teachers. Finally, a respondent indicated that it helped her to better understand FASD and explain it to an adult with FASD as well as to explain some of his problems and potential problems to his employer.

It has helped us understand the way things ARE better and that we need to adjust to them -- that they are limited in their adjustment.

It reminded me that some things are beyond these children's control. At the same time, it encouraged me that the occurrence of FASD is controllable through getting accurate but easily understood literature out there . . . and this is a great example!"

It helped me to better understand [an adult with FASD] and explain it all to him. It also helped when I needed to explain some of his problems and potential problems with his employer. The concrete things I could actually do were a big help.

Dissemination/Distribution

It is clear, based on the comments provided, that most of the professionals/volunteers as well as some of the parents/caregivers either recommended or gave *Let's Talk FASD* to others or used it when providing information to groups or individuals. Listed below is a sampling of the ways respondents indicated that they distributed the Toolkit or used it to convey information to others.

I used it as a teaching tool and found that it really helped people understand the issues.

I provide hard copies of the resource at my training sessions, as well, I provide the VON website to participants.

I recommend Let's Talk FASD as THE basic manual for parents and professionals.

It has been a valuable resource that I can share with parents – it gives wonderful tips and examples.

Since distributing my first copies, I am constantly receiving requests for copies from across Canada.

I passed it out to numerous people who work in the schools. They in turn share it with families.

Let's Talk FASD has been a wonderful resource to include in a FASD Tool Kit that has been widely distributed amongst high schools and post secondary schools in [regions in Ontario]. In addition, copies of this book have been lent out to families who are struggling with the challenges of FASD.

I have passed it on to another mom whose child may also have FASD and she has also found it very helpful.

I specifically have used this tool to provide information to aid parents and professionals to better support children, youth, and adults.

I am a consultant for FASD. I provide hard copies of the resource at my training sessions as well, I provide the VON website to participants.

Parents are thrilled to receive this booklet which is so easy to use and answers so many of their questions.

I e-mail it to the FASD families I see.

It is also well accepted when provided to Moms who are living with children with challenging behaviours which have not yet been diagnosed.

I have ordered many and everyone has used it! I have equipped my Centre and they are using it with every family affected by FASD.

Ways to Improve Let's Talk FASD

Thirty-five individuals provided responses to the question "Is there any way 'Let's Talk FASD' can be improved?" Six of the respondents took this opportunity to express their opinion that *Let's Talk FASD* did not require any improvement.

I haven't found anything that needs improvement, as yet.

I don't think it needs improvement.

The remaining responses have been categorized under the following two themes: Better Accessibility and Additional Content/Other Comments.

Better Accessibility

A number of respondents expressed frustration with the accessibility of *Let's Talk FASD*. A few respondents indicated that the online PDF copy was difficult to download and properly assemble and others indicated that they would like to have access to more (free) paper copies.

I have not been able to download it successfully. A more user-friendly e-version would be great.

The page numbering makes it challenging to print and assemble.

The online version is great, but does not print out as expected. In addition, many families cannot readily access an online version . . .

Be available in printed form, at no cost

More availability of paper copies

Print copies should be easily available. This resource needs promotion.

I would like to have more access to hard copies.

Additional Content/Other Comments

There were suggestions for additional content or changes to content, although no topic was mentioned by more than two respondents. The following topics were suggested as possible additions to *Let's Talk FASD*. They are provided in the respondents' own words, with minor editing for clarity.

- Tool specific to older students and adults
- More background information on FASD
- Section on respite care
- Information re sexuality differences, e.g., homosexuality, how to support young adults who self-identify as being gay
- More examples
- Personal stories from First Nations
- Produce separate English and French versions
- A bit more depth of information – more “meat”
- Proofread it again. Add more examples (experiences of real people who have FASD) and review some of the existing examples for relevance and comprehension
- Training should be provided for judges and lawyers
- Just add more information is all I can think of to improve this. Keep it current as this is an on-going learning process for all involved
- Perhaps something in more depth for physicians, nurses, mental health professionals would be helpful. Also, a guide for educators would be useful. Finally, perhaps a similar manual written from the point of view of the FASD individuals themselves, with their input. They might be able to touch on subjects related to inclusion at school and in the community, as well as avoiding or coping with addictions, trouble with the law, relationships, etc.
- One area that can always use tweaking is relating to the parent/caregiver who is at their wits end and doesn't know where to go or what to do next and especially who they can 'talk' to . . . an actual human resource.

- How about a second book which addresses the challenges of the school day or Train the Physician.
- Perhaps if there were more services for local areas listed in it somehow
- Perhaps to broaden the scope to include service providers
- Translated into Inuktitut
- Info sheets hard to find, move to end – each needs clear source and date. Younger one needs more on Schools; Older one should really be strengthened. More on need for advocate, money management. FASD what you need to know – remove last item: no “Exceptional memory” in those with FASD

Evaluation of Web Version of Let's Talk FASD

A short evaluation was developed for the web-based version of *Let's Talk FASD*. Because the web version is identical in content and very similar in format to the print version, there are advantages in terms of comparability to using identical questions for the two evaluation surveys. With that in mind, the evaluation for the web version consists of two parts. Upon accessing the website, participants will be asked to complete a short pre-survey to identify their primary role caring for children/adults with FASD, where they are from, and whether it is the first time they have accessed the web version of *Let's Talk FASD* (see Appendix C).

Included at a prominent place on the website will be an icon that when clicked, will allow participants the opportunity to complete a short, feedback survey. Respondents will again be asked their role pertaining to caring for children/adults with FASD and then asked to answer ten questions using 5 point Likert scales about the format, content, and usefulness of the Toolkit. These questions will be identical (with very minor wording changes) to the ten items used for the evaluation of the Print/PDF version of *Let's Talk FASD*. (see Appendix C)

The surveys for evaluation of the web-based *Let's Talk FASD* were launched simultaneously with the launch of the actual website. At the time of writing this report, there were no available results.

CONCLUSIONS/RECOMMENDATIONS

Ninety-six people responded to an online survey designed to determine their assessment of *Let's Talk FASD*. Overall, respondents indicated a high degree of satisfaction with the format, content, and usefulness of the Toolkit. When asked how to improve *Let's Talk FASD*, the two most common themes were that no improvement was needed and that there needed to be improved accessibility/availability – an indication of high acceptance of *Let's Talk FASD*. Likely, the launch of the web-based version of *Let's Talk FASD* will serve to address many of the concerns and difficulties related to accessibility and make the Toolkit much more widely accessed and utilized. This is particularly important in light of evidence that parents/caregivers seem to access this type of information primarily from on-line sources, therefore, it is critical that they have access to a user-friendly source.

Let's Talk FASD was most frequently used by professionals/volunteers to disseminate as a resource to parents/caregivers and as a teaching tool to facilitate workshops or other information sessions. Unfortunately, most respondents who identified themselves as parents/caregivers did not complete the open-ended questions, therefore, there is less certainty as to how they incorporated the Toolkit into their lives or how it helped them care for their children with FASD. Based on the few responses that were received, it seemed as if the Toolkit served to increase parents'/caregivers' understanding of their children and how they could use that understanding to better care for them and accept/adjust to them. Thus, based on these observations, it would appear that there is evidence of success in that professionals/volunteers are distributing the resource to those who need it and are using it to facilitate dissemination of information. What is less certain, though, is how parents/caregivers are actually using the Toolkit and how much it is helping them care for their children. Ideally, further evaluation would be done, identifying parents/caregivers who have just recently begun to care for a child with FASD and determining how they used the Toolkit and what impact that had on their lives. This type of evaluation could most effectively be done through in-depth, one-to-one interviews.

There were also many suggestions provided for additional content or changes in content. However, each of these suggestions was mentioned by one or at most two respondents. All suggestions were presented with the intention that they generate thoughts and ideas for improvement of any future versions of *Let's Talk FASD*.

Based on the results of this evaluation, there are two main recommendations. First is to try to increase the availability and accessibility of *Let's Talk FASD*. The launch of the web-based version is likely to address many of the concerns pertaining to accessibility. There is also likely the need, if possible, to produce more print copies that can be freely or at least inexpensively distributed. Second, this evaluation failed to adequately assess how parents/caregivers actually use *Let's Talk FASD* and the impact it has on helping them care for their children. With that in mind, a further evaluation is required that would identify parents who are newly caring for a child with FASD and who used the resource. Ideally, semi-structured, one-to-one interviews would be undertaken with them to determine specifically how they used *Let's Talk FASD* and the impact it had on helping them to care for their children.

APPENDIX A EVALUATION SURVEY

Victorian Order of Nurses (VON) Canada Eastern Region Let's Talk FASD Feedback Survey

Information and Consent Form

This survey is for parents, caregivers, or health professionals who have read or used the parent resource, *Let's Talk FASD*. Everyone who has read or used *Let's Talk FASD* is invited to complete the survey. If you do not have a copy of *Let's Talk FASD*, but would like one, it is available free of charge at www.von.ca/fasd.

Let's Talk FASD is the result of a four year VON FASD Best Practices Project, funded by the Public Health Agency of Canada. For more information on the project, please visit our website at any time at www.von.ca/fasd.

We now want to know what you think about *Let's Talk FASD* by completing this online survey. The survey will ask you your thoughts about *Let's Talk FASD*, and in particular, how you used it and how we can make it better. The survey should take no more than ten minutes to complete.

Completing this survey is voluntary and you may skip any question you do not wish to answer. Because we will not be collecting any identifying information, your responses will remain anonymous.

Results of the survey will be posted on our website (www.von.ca/fasd) in late summer. Please feel free to visit the website at any time to find out more information about the project or to get your copy of "Let's Talk FASD."

If you wish to contact us for information about the project, you can contact Melissa Lee-Ross by phone toll free (in Canada) at 866-777-7412 or outside Canada (toll call) at 902-674-0913 or by e-mail at melissa.lee-ross@von.ca.

Completing the survey implies that you have read this consent form and understand the following:

- Completing this survey is voluntary.
- You may skip any question that you do not wish to answer.
- Your answers are anonymous (that is, we do not collect any information that would allow us to identify you).
- The information you provide may also be used in reports and publications.
- All statistical information will be presented in summary form (e.g., group averages). No information will be presented that could identify individual respondents or their children.

Yes, I wish to complete the survey

No, I do not wish to participate at this time

Survey Instructions

Please complete this survey only if you have read or used *Let's Talk FASD*.

Answer the questions in this survey by making a checkmark next to the appropriate response for each question. The survey should take about 10 minutes to complete.

Please remember that completing this survey is voluntary and you may skip any question that you do not wish to answer.

Please tell us about yourself

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

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

Parents or Caregivers of Children With FASD

The questions in this section apply to parents or caregivers of children or adults with FASD.

3. How many children with FASD have you cared for (include adult children, even if they do not live at home)?

1

2

3 or more

4. What is your relationship to the child or children affected? Please check all that apply.

Birth parent

Foster parent

Adoptive parent

Grandparent/extended family member

Other (please specify) _____

5. How long have you known or suspected your child has FASD? (if you have more than one child, please consider the first child you knew or suspected had FASD)
- Less than 1 year
- 1-3 years
- 4 or more years
6. Have you received medical diagnoses of FASD from a doctor for at least one of your children?
- No
- Yes

Evaluation of the Toolkit

7. Which version of *Let's Talk FASD* did you read?

- Paper Copy
- Download Copy
- Both

8. Which language of the toolkit did you use?

- English
- French
- Both

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

Item	1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree
The toolkit is visually appealing	1	2	3	4	5
The toolkit is easy to use	1	2	3	4	5
The toolkit content is useful	1	2	3	4	5
The content addresses my areas of concern	1	2	3	4	5
The guidelines are clearly presented	1	2	3	4	5
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
I would recommend this toolkit to parents/caregivers of children affected by FASD	1	2	3	4	5

I would recommend this toolkit to professionals that work with children affected by FASD	1	2	3	4	5
Overall, I am satisfied with the information contained within the Toolkit	1	2	3	4	5
I am satisfied with the quality of this toolkit	1	2	3	4	5

10. 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.

11. Is there any way *Let's Talk FASD* can be improved?

Demographics

12. Where do you live?

- Atlantic Canada (NB, NF, NS, PE)
- Quebec
- Ontario
- Prairies (AB, MN, SK)
- British Columbia
- Northern Territories (NT, NU, YK)
- United States
- Other (please specify) _____

13. What size is the community that you live in?

- Less than 1,000 people
- 1,000 - 4,999
- 5,000 - 9,999
- 10,000 - 49,999
- 50,000 and over

14. What language is easiest for you to speak and read?

English

French

Other

Thank You

Thank you for completing the *Let's Talk FASD* Feedback Survey.

Results of the survey will be posted on our website (www.von.ca/fasd) in late summer. Please feel free to visit the website at any time to find out more information about the project or to get your copy of the Parenting Tool.

APPENDIX B LIST SERVE MESSAGES

First Message

Dear List Serve Members:

Have you read or used *Let's Talk FASD*, the resource guide for parents and caregivers of children and adults with FASD? If so, VON Canada would like to hear your thoughts about *Let's Talk FASD*, how you used it, and how we can make it better. To do this, we are asking you to complete a short online survey. Your responses to the survey will be anonymous as we will not ask for your name or any type of contact information. To complete the survey, please click on the link below.

Haven't yet seen *Let's Talk FASD* but would like to? You can download a free copy from www.von.ca/fasd or get a hard copy by contacting Melissa Lee-Ross by email at melissa.lee-ross@von.ca or by phone toll free (in Canada) at 866-777-7412 or outside Canada (toll call) at 902-674-0913.

To complete the survey in English, please click
<http://www.surveymonkey.com/s.asp?u=285533373070>

Pour compléter le sondage en français, veuillez cliquer
<http://www.surveymonkey.com/s.asp?u=288263529400>

Let's Talk FASD is the result of a four year VON Canada FASD Best Practices Project, funded by the Public Health Agency of Canada. For more information on the project, please visit our website at any time at www.von.ca/fasd

Thank you.

Steven Dukeshire
Program Evaluator

Chers membres de la liste de diffusion

Avez-vous lu ou vous êtes-vous référé à « Parlons de l'ETCAF », le guide-ressource pour parents et personnes soignantes d'enfants souffrant de l'ETCAF? Si oui, nous aimerions avoir votre opinion concernant « Parlons de l'ETCAF », et, plus particulièrement, comment vous l'avez utilisé et comment nous pouvons l'améliorer. Pour ce faire, nous vous demandons de compléter un court sondage en ligne. Vos réponses seront anonymes puisque nous ne demanderons pas votre nom ni aucune information dans le but de vous contacter. Pour compléter ce sondage, veuillez cliquer sur le lien ci-dessous.

Si vous n'avez pas pris connaissance de "Parlons de l'ETCAF" mais vous aimeriez le faire, vous pouvez télécharger une copie gratuite du site web ou vous pouvez obtenir une copie papier en communiquant avec Melissa Lee-Ross par téléphone sans frais (au Canada) au 1 866 777 7412, ou par appel interurbain (de l'extérieur du Canada) au (902) 674-0913, ou par courriel à l'adresse melissa.lee-ross@von.ca.

Pour compléter le sondage en français, veuillez cliquer
<http://www.surveymonkey.com/s.asp?u=288263529400>

To complete the survey in English, please click
<http://www.surveymonkey.com/s.asp?u=285533373070>

« Parlons de l'ETCAF » est le résultat d'un projet d'une durée de quatre ans intitulé « Le Projet des pratiques exemplaires en matière de ETCAF de VON » qui a été financé par l'Agence de santé publique du Canada. Pour de plus amples informations, veuillez consultez notre site web au <http://www.von.ca/fasd/French/index.html>

Merci

Steven Dukeshire
Responsable de l'évaluation du programme

Reminder Message

Thank you to everyone who took the time to complete our *Let's Talk FASD* Feedback Survey. If you have not completed the survey but would like to, we would love to hear from you. **The online survey will be available until 12 noon (Eastern Time) on April 24th** and only takes about three minutes to complete.

To complete the survey in English, please click
www.surveymonkey.com/s.asp?u=285533373070

Pour compléter le sondage en français, veuillez cliquer
www.surveymonkey.com/s.asp?u=288263529400

More information about the survey can be found in the original message that was sent out about the survey and is copied below.

Thank you.

Steven Dukeshire
Program Evaluator

Merci à tous ceux qui ont pris le temps de compléter notre questionnaire intitulé « Parlons de l'ETCAF ». Si vous n'avez pas complété le questionnaire et que vous aimeriez le faire, votre participation serait grandement appréciée. **Le questionnaire en ligne sera disponible jusqu'au 24 avril à midi (Heure de l'Est)**. Il vous prendra seulement environ trois minutes à le compléter.

Pour compléter le sondage en français, veuillez cliquer
www.surveymonkey.com/s.asp?u=288263529400

To complete the survey in English, please click
www.surveymonkey.com/s.asp?u=285533373070

De plus amples informations concernant le questionnaire peuvent être trouvées dans le courriel original qui a été envoyé antérieurement. Ce courriel est copié ci-dessous.

Merci

Steven Dukeshire
Responsable de l'évaluation du programme

ORIGINAL MESSAGE HERE

MESSAGE ORIGINALE ICI

APPENDIX C
WEB-BASED FEEDBACK EVALUATION SURVEY

Pre-Survey for Web-Based Version of 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.
- Other

Where do you live?

- Atlantic Canada (NB, NF, NS, PE)
- Quebec
- Ontario
- Prairies (AB, MN, SK)
- British Columbia
- Northern Territories (NT, NU, YK)
- United States
- Other country, please specify: _____

Is this the first time you have visited the *Let's Talk FASD* website?

- Yes No

Feedback Survey for Web-Based Version of 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.

_____ Other

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

	Item	1 Strongly disagree	2 Disagree	3 Neither agree nor disagree	4 Agree	5 Strongly agree
1	The website is visually appealing	1	2	3	4	5
2	The website is easy to use	1	2	3	4	5
3	The website content is useful	1	2	3	4	5
4	The content addresses my areas of concern	1	2	3	4	5
5	The guidelines are clearly presented	1	2	3	4	5
6	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
7	I would recommend this website to parents/caregivers of children affected by FASD	1	2	3	4	5
8	I would recommend this website to professionals that work with children affected by FASD	1	2	3	4	5
9	Overall, I am satisfied with the information contained within the website	1	2	3	4	5
10	I am satisfied with the quality of this website	1	2	3	4	5