

**Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario**

Laughter, friendship, love

Living with FASD....



Moving Forward and Supporting Families Affected by FASD March 2008

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INTRODUCTION

At the October, 2007 face to face annual meeting of the FASD (Fetal Alcohol Spectrum Disorder) Stakeholders for Ontario, the Intervention and Support Working Group committed to a strategic planning process. This report sets out the results and action plans of that planning session, held February 13th and 14th, 2008.

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother consumed alcohol during pregnancy. These effects may include physical, mental, behavioural and learning disabilities. The disability is **lifelong** and is a spectrum of disorders that can include Fetal Alcohol Syndrome (FAS), Partial FAS (pFAS), and Alcohol Related Neurodevelopmental Disorder (ARND).

*"We are running out of time!!! This must happen soon. Our children are dying, a slow painful or quick suicidal death. It is no longer an if situation but when!!!! And, I say within the next year we need to make positive inroads. Now now now now now!!" **Caregiver/ Professional who supports all ages*

To aid with this planning session, a short needs survey was circulated to all known service providers, support groups and other groups/individuals affected by or dealing with FASD-affected families and individuals. The needs survey was key to confirming anecdotal and known gaps in supports and services available to families supporting an individual with FASD. In addition, it has given a voice to many who are struggling daily, those who are frustrated and are suffering due to huge gaps in services and understanding both in our general communities but particularly in government ministries. These ministries include Education, Health, Child & Youth Services, Community & Social Services and Youth Correctional Services. Families have reported that they are isolated, financially strapped and breaking down due to the lack of available services and resources for families across the province.

The action plans noted at the end of this report were arrived at from the survey needs and also from the experiences within the working group. They are goals for the next 2-3 year years and focuses on respite needs, knowledge transfer and general services needed by families supporting an individual with FASD (See Action Plans). A complete list of opportunities to better support families and individuals affected by FASD is outlined in *Appendix 'E'*.

This report will provide a road map for the Working Group as well as serve as a guidepost for the Stakeholders Group about the issues that are crucial to all families and to service providers throughout the province. It is hoped that this information will be used to raise awareness of FASD at the provincial government level, including its challenges and its impact, and help lead to solutions and a sense of political urgency that results in significant action being taken to effectively support this population.

WHO WE ARE

FASD Stakeholders for Ontario is a group of service providers and care providers/parents that works together to address issues related to FASD in the province (www.fasdontario.ca). See *Appendix 'A'* for more detail on the structure and purpose of the Stakeholders Group.

There are five sub-committee working groups, of which Intervention and Support is one. The mandate of the Intervention and Support Working Group (I&S group) is to:

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario

Focus on building capacity within service sectors and systems and the general community to be able to respond appropriately to the unique and diverse needs of those living with FASD.

In March of 2005 and 2006, the Intervention and Support Working Group planned and hosted a weekend camp during March for families affected by FASD. These camps provided an important opportunity for respite for families and their children. The camps were well-attended, and the participants felt empowered and connected after the camp. Respite was identified as a significant need in the survey recently completed and it was evident the camps met this need.

A camp manual was created, fulfilling our mandate to help build capacity. The manual is based on these two experiences and the recommendations that came out of the evaluations by participants, staff and volunteers, and can be made available to others. Groups in the South-West Ontario region and the Greater Toronto Area are now looking to duplicate the camp experience for families in their area by working collaboratively in the community.

The planning and execution of the camps took a large amount of time, effort and coordination in part due to the scale of the camp. It was recognized that the funding provided to plan and run the camp was not commensurate with the true cost when the "in-kind" contribution of volunteer commitments made is accounted for.

Going forward, the Working Group wished to develop a strategic plan with a broader focus, as was reflected the final message from the camp report:

"The camp has led the committee to the conclusion that there is a lot more work needed to support families than we can do on our own. We need to become the voice of families. We need to educate politicians/funders/decision makers on the life-long supports that are needed for these families. FASD needs to be on their radar with dedicated funding and training provided. Families are struggling to understand FASD themselves; we need to educate the professionals at schools/daycares/camps about FASD and the solutions that can help them succeed at providing an environment essential to the child's learning needs."

Intervention and Support Working Group Camp Report, 2007

NEEDS SURVEY

The survey was conducted using an internet online survey tool in January and February, 2008. The survey was emailed to known FASD e-lists, support groups and agencies that deal with clientele with the disability. It was also distributed to a small group of workshop participants in the fall of 2007. The survey was designed to gain a preliminary understanding of the needs of people who are caregivers of individuals affected by FASD, whether they felt they were being serviced adequately, and what services and supports were lacking. Service Providers such as front-line workers in the mental health professions, special education resource teachers, and personal support workers, also completed the survey from the perspective of looking at their clients' needs. The numbers in this report reflect 311 respondents who took the survey.

**Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario**

The summary of the completed Needs Survey is included in a separate pdf, [surveysummaryAPPB](#). Responses were categorized (i.e., education, respite etc.) and the needs categories and definitions are included in *Appendix 'C'*.

*"I don't "get" help. I have to seek, speak, challenge, ask, push, pull, develop and advocate to get the help and information I need."
**Caregiver of preschool and school-aged*

Respondents

In the first two questions respondents provided information about their roles in FASD support and the age distribution of the individuals with FASD whom they supported. Respondents were characterized as follows:

- Caregiver: 60% - 182 responses
- Professional service provider: 37.5% - 113 responses
- Other (volunteer, have FASD, relative): 25.2% - 76 responses
(28 respondents were both caregivers and service providers; there were overlaps in other categories as well)

- Ages of children supported, noting many supported more than one age group:
 - Preschool - 60%
 - School-aged - 97%;
 - 19 and over - 61%;

- Geographic location:
 - Northern Ontario - 12.8%
 - Central Ontario - 9.5%
 - Eastern Ontario - 13.5%
 - South Western Ontario - 22.6%
 - Greater Toronto Area - 44.5%

*"I feel that the Ontario government and its Ministries are ignoring FASD and I am so disappointed. People affected by FASD are not getting their needs met within current services; in fact, using regular education and mental health standards for services may cause more damage or secondary disabilities for individuals with FASD."
Caregiver/Professional/Person with FASD supporting all age groups*

Results

Question 3 asked them to rank the statement "I get the help, interventions and support I need."

Fully **66%** disagreed or strongly disagreed with this statement, ranking the level of support and intervention received either in their caregiver or service provider role as unsatisfactory. Only **13%** were satisfied with the level of services and support they receive.

Question 4 asked the respondent to list three interventions and supports "I need the most, I wish I had or that should be put in place as soon as possible."

Results of the survey are listed below, with a chart contrasting the differing (and similar) needs chosen by caregivers and service providers in *Appendix 'D'*.

**Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario**

Category	Caregivers	Service Providers
Education System, Supports, Understanding and Services	55.8%	46.5%
Respite	46.6%	22.1%
Transition to Adulthood	30.7%	23.3%
Knowledgeable Service Providers	22.7%	33.7%
Strategies for Caregivers	19.0%	16.3%
Understanding and Awareness in Community	17.2%	17.4%
Financial Needs	16.6%	15.1%
Case Management	16.0%	25.6%
Medical Services	12.3%	11.6%
Diagnostic Services	9.8%	33.7%
Support Groups – Caregivers	9.8%	4.7%
Support Groups – FASD-affected	8.6%	12.8%
Support for Daily Living	7.4%	16.3%
Legal and Justice Services	3.1%	4.7%
Other	1.8%	1.2%

*"Where and how does one find a support person(s) who can help your adult child to: find a job, deal with alcohol problems, resolve social/emotional issues, help with financial issues?"**
Caregiver of young adult*

The highest ranked needs for both caregivers and service providers were in the **education system**. For caregivers, **respite** was second, with needs around **transitioning to adulthood** as third. For service providers, **diagnostic services** and **knowledgeable service providers** were tied for second with **case management** needs third.

Limitations

Notification of the on-line survey was e-mailed to Ontario groups and individuals providing FASD interventions and supports with the request to "please forward" the notification as much as possible. Using this methodology we feel we achieved good coverage of the province's caregivers and service providers who are aware that they are supporting people who have or may have Fetal Alcohol Spectrum Disorder.

However, because the survey was done on the internet, there may be limitations around who the survey reached, since not everyone has easy access to the internet. Paper surveys were also distributed at three fall 2007 workshops on FASD issues, in the start-up phase of the survey and were captured in the database. In addition, the survey reached very few individuals who themselves were affected by alcohol, and the respondents most likely have diagnosed individuals in their care. Of the 311 respondents, 89% fully completed the survey, or 277.

Implications

For us, the implications are clear:

- Educators may not be aware of or knowledgeable of FASD and its implications for affected individuals;

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario

- The education system is not providing the academic, behavioural or environmental supports necessary to provide the education needed by an individual affected by FASD;
- Many families are burnt out – respite care is needed, difficult to find and often unaffordable;
- There is a dearth of supports around housing and employment and daily living needs as youth with FASD move to the adult world;
- Diagnostic services are few and often not accessible to those outside of greater metropolitan areas;
- Professionals who understand FASD and who are able to link agencies to provide knowledgeable case management are few.

".. that we need to work together more as service providers to help support children, youth and families with FASD."
Service Provider for young children

Because the group saw the education as an issue that needs to be addressed at the provincial and provincial ministry level, it was felt that a new separate work group is needed to deal with the significant challenges presented by FASD and the education system. As such, it was recommended back to the FASD Stakeholders for Ontario chair that such a group be established.

In addition, there is a Diagnosis and Disability Working Group under the FASD Stakeholders for Ontario umbrella. As such, diagnosing services was not seen as a priority for this group to address, but the survey results will be forwarded for their group to utilize.

Transitions to adulthood and case management are two large areas of needs and somewhat intertwined. The action plans below focus initially on assisting with transferring more knowledge to caregivers and service providers, as well as respite. Once the information is gathered about effective practices and available services, the issue of case management (someone who coordinates services for an individual affected by FASD) will be easier to address. Effective case management should include all the transition pieces needed for youth when leaving school for work and home for their own housing.

With these needs in mind, the Intervention and Support Working Group developed a list of opportunities for the coming years to address the needs of survey respondents.

To order our process and make our list realistic, the following criteria were chosen to aid in prioritizing the many opportunities and needs presented. To be chosen as a current action item the opportunity had to

- Reflect the Needs Survey
- Be Doable and Manageable (by a group of volunteers with other jobs)
- Meet the mandate to build capacity
- Be provincial in scope/focus
- Be sustainable
- Have a large impact

Based on these criteria, the various opportunities were grouped into strategic priority areas.

Strategic Priorities

- 1) Services provided to children, youth and families (includes respite, support groups)

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario

- 2) Knowledge Transfer (increase knowledge available for both caregivers and professionals)
- 3) Communication & Awareness (of FASD to all affected and broader community)
- 4) Research and Evaluation (of what works and what doesn't; sharing that information)
- 5) Advocacy (Needed at government levels as well as in our community settings)

A complete record of the potential opportunities that arose from the session is listed in *Appendix 'E'*.

Some opportunities were deemed outside the scope of the group or of this planning session such as

- National NGO on FASD
- Push ownership of FASD knowledge, wisdom and advocacy up to medical and social services professions, including tying into post-secondary curriculum
- Defining the role of I/S working group vs. stakeholders group
- New Working Group for Education System – recommendation to FASD Stakeholders for Ontario
- Links- provincial/federal/local – these are important, but are beyond the scope of this committee.

ACTION PLANS

Below is an outline of three areas of priority which the group will be working on over the next two years.

I Services and Knowledge Transfer: Effective Practices

One of the common needs identified by both caregivers and service providers was the need for knowledgeable service providers. It was decided that it was important to look at the services and literature now available in Ontario to get an inventory of both known and unknown services (this would include anecdotal evidence of practices working well).

"a self help book for the teaching professionals and parents alike" Caregiver of school-aged child

1. The goal is to develop a guideline for effective practices in the support of people affected by FASD in Ontario. To achieve the goal, the group aims to determine the essential elements necessary for each category of services provided. An assessment of these services will be conducted, and the data would be analyzed as it pertains to the current literature of effective practices for knowledgeable service providers. Parent support groups across the province will be consulted regarding services that have worked well for them.

By August 2008

- Bring together all the known documents, services etc. that outline effective intervention strategies.
- Develop a list of unidentified services, across the province, which have a history of acclaimed effective intervention for those affected by FASD.
- Define what the essential elements should be, based on effective practices.

To begin this research, contact will be made with several ministries to identify the pivotal people or agencies who are currently providing these services (using effective practices), in specific service sectors. The result of these discussions will provide an idea of where

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario

there may be supportive agencies, and perhaps identify to the government where they are lacking in their supports. The five agencies suggested were Housing, Employment, Child Welfare, Justice and Mental Health.

2. In September 2008, the objective is to hire someone to conduct the analysis and assessment of these services, comparing the practices to known effective practices and to develop an updated document outlining effective practices for intervention on behalf of the Stakeholders Group.

The measure of success will be the production of the document outlining effective practices and dissemination of the document to all those agencies, support networks, groups etc. involved in providing services and support from birth through adulthood to children and their families affected by FASD. *December 2008*

II Services: Respite

Respite services were identified as a significant gap on the survey. Families needed a break; whether it was a two-hour dinner without their child, or a weekend to recover some emotional strength. Three main activities, which will have a direct impact on helping families to obtain services, were the focus.

*"Respite; time to recoup and gain emotional strength in dealing with the child."
Caregiver of school-aged child*

1. Identify the range of Respite service possibilities
 - Define respite
 - Research who is providing it and where
 - Research what's been evaluated

An available social work placement student with Toronto CAS will do the research and provide a directory by *December 2008*. The measure of success will be the production of the directory.

2. Gather success stories from across Ontario on respite
 - Contact Support groups
 - Survey on website
 - Use existing local and regional networks

The group will seek out funding so that the success stories can be communicated in a variety of ways – multimedia. Consider looking into schools (like Ryerson) that offer media and communication programs. The final product of the stories will be the measure of success by *December 2008*.

3. Develop an Advocacy Strategy to address the need for respite for families affected by FASD
 - Identify current limitations and challenges, including identification of barriers to access respite such as transportation, sustainability, financial cost
 - Do a cost/benefit analysis
 - Recommendations for action
 - Hire someone to assist in developing a public education and advocacy campaign and to put a formal plan in place.

The group will look to bring in some new committee members with experience in advocacy.

**Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario**

The measure of success will include these items:

- o a measureable increase in the respite services available and the use of these services;
- o an increase in permanency for children in care; and
- o a reduction in family breakdowns. *June 2009*

III Knowledge Transfer – Website & Communication

Enhancing the existing website will aid in the transfer of knowledge and communication so much needed by families coping with FASD issues. This action will dovetail with the one above on Effective Practices, as the results from it can feed the website.

1. Add two tabs or directories to the front of the webpage directory – one for caregivers and one for service providers.

The information for each tab would include:

Caregivers

- Success stories
- Links to other useful sites
- Support Group information
- Respite information
- Strategies
- Question & Answer section

Service Providers

- Resource information
- Links to resources
- Links to other websites

There would also be space for regional area updates, events going on etc. This project would require a subcontractor to perform the web work with completion slated for *March 2009*.

The measures of success would include an increase in

- # of unique hits on the site;
- # of geographic areas represented;
- # of agencies providing information to post;
- # of links supported;
- # of downloads made from the site;
- # of success stories posted.

"More widespread knowledge needs to be shared so that the general public can understand that often the invisible disabilities are often just as severe, perhaps even more so as the visible ones. Our kids aren't bad or spoiled due to poor parenting." Caregiver of school-age children

IV Working Group Structure

During the planning process it became obvious that processes and structure of how the group would implement these action plans needs to be addressed. As such, a conference call to deal with these issues will be held in April, 2008. Items such as new membership and orientation process, need for sub-committees, roles of all members, including lead positions and email protocol will be discussed.

SUMMARY

From the information presented in the Needs Survey, and by the comments from respondents noted in this report, we can see there is a large opportunity for this working group to have a broader impact on those caring and providing services for children, youth and adults affected by FASD. These children, youth and adults have wonderful gifts and

**Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario**

talents – creativity in music and art, ability to work well with younger children, a knack for working with animals, are among them. For these individuals to realize and sustain those talents, they will require lifelong support and interdependent relationships and partnerships in our communities.

The goal is not only to work on the plans detailed here, but to embark on a journey of raising awareness of FASD, its implications, and the gaps in services, through this work and the continued work of the FASD Stakeholders for Ontario group. It is only when there is broader community awareness and understanding, broader and steadfast government support in all areas, that an adequate job of serving those in Ontario with FASD and those who support them will be accomplished. There is excellent work being done across Ontario to support individuals affected by FASD. When we have identified, accessed and harnessed these resources, making them available to all who need them, we will create that interdependent place where every child, youth and adult affected is known as an individual with skills, talents and abilities, rather than someone with FASD.

*"We need to provide supports to people with FASD to enable them to be productive members of society and keep them off the streets and out of the legal system. In the long run, it's cheaper for society to provide support up front than to deal with crises and incarceration."
Caregiver/Volunteer of adult*

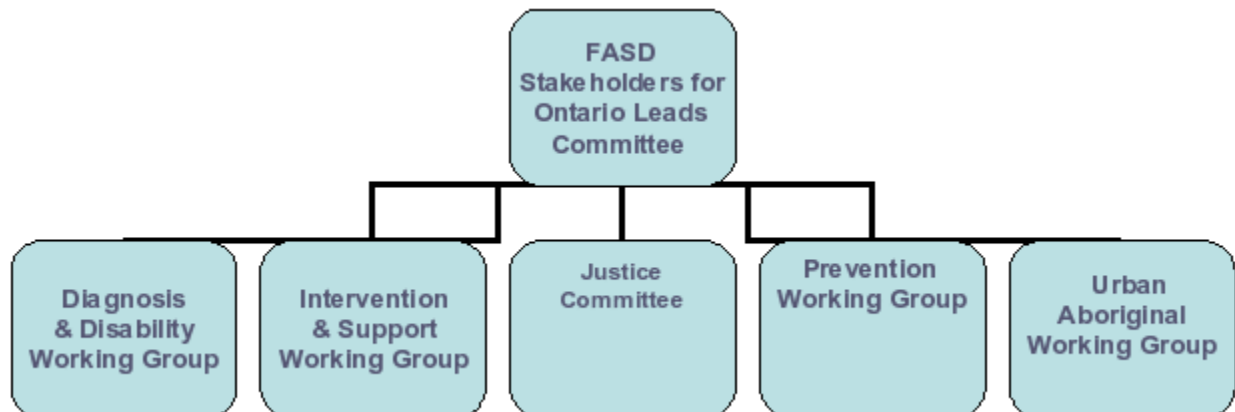
*This report was prepared by Sandy Halloran, Facilitation & Planning Services
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Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario
APPENDIX A

FASD Stakeholders for Ontario is a group that works together to address issues related to FASD in the province. Our membership includes experts and specialists in research, health promotion, diagnosis, justice services, community and policy development, and service delivery, as well as family members who have intimate knowledge of the practical needs of individuals with this disability.

FASD Stakeholders for Ontario consists of 5 Working Groups/Committees and a Leads Committee. The Leads Committee is comprised of 2 members from each Working Group. The Leads Committee meets through periodic teleconferences and one annual face-to-face meeting. Working Groups develop and implement annual work plans based on the priorities stated in their Terms of Reference. The number of Working Groups can be amended by vote of the Leads Committee as necessary to meet the priorities and objectives stated in the Terms of Reference.

Organizational Structure of FASD Stakeholders for Ontario



Members of the Intervention & Support Working Group

- Mary Cunningham, FASD Advocate/Educator, Kitchener (parent of individual affected by FASD)
- Nancy Hall, FASD Community Development Facilitator, Hamilton Taskforce on FASD
- Stephanie Jones, Home Management Consultant, Community Living Toronto
- Chris Margetson, FASD Specialist (birthmother of individual with FASD, foster mom to several youths affected by FASD)
- Yvette Nechvatal-Drew, Executive Director, Girls Incorporated of Durham
- Sharron Richards, Manager of Community Development & Prevention Program, Children's Aid Society of Toronto
- Elspeth Ross, Co-Facilitator, FASD Group of Ottawa; Educator on FASD and Adoption (parent of individuals affected by FASD)
- Jennifer Sells, Program Manager for Community and Prevention Programs, Keystone Child, Youth and Family Services in Owen Sound
- Pat Spadetto, Manager of Early Childhood and Parental Supports, Timiskaming Brighter Futures (funder of this session)
- Laura Spero, Fetal Alcohol Prevention and Awareness Educator, Southwest Ontario Aboriginal Health Access Centre, London

Please visit our website at www.fasdontario.ca or contact us at info@fasdontario.ca.

Moving Forward and Supporting Families Affected by FASD
March 2008

**Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario
APPENDIX C**

**NEEDS SURVEY
CATEGORIES and DEFINITIONS**

Category	Caregivers	Service Providers
Case Management	16.0%	25.6%
Diagnostic Services	9.8%	33.7%
Education System, Supports, Understanding and Services	55.8%	46.5%
Financial Needs	16.6%	15.1%
Knowledgeable Service Providers	22.7%	33.7%
Legal and Justice Services	3.1%	4.7%
Medical Services	12.3%	11.6%
Other	1.8%	1.2%
Strategies for Caregivers	19.0%	16.3%
Respite	46.6%	22.1%
Support for Daily Living	7.4%	16.3%
Support Groups – FASD affected	8.6%	12.8%
Support Groups – Caregivers	9.8%	4.7%
Transition to Adulthood	30.7%	23.3%
Understanding and Awareness in Community	17.2%	17.4%

Case Management

A case manager co-ordinates the identification of and access to appropriate resources for the family. A case manager may also play a role in advocating for appropriate services for the family. Many caregivers and service providers were frustrated that one agency knew what help they needed while another had no idea what FASD even was. The hand off between agencies or between an agency and a school was rarely done well, if at all.

*"Children and youth need services which are FASD-specific, not just standard services they have now."
Service Provider*

Diagnostic Services

Diagnostic services for FASD are only available in a few centres. In more remote parts or rural areas of Ontario, it was deemed almost impossible to access any of the services available. Obtaining a diagnosis was seen as crucial to getting the proper supports needed.

*"School support - there is little known about FASD and how to help our children."
Service Provider*

Education

Respondents told us that there is little support in the schools and there is no general understanding of FASD. Responses from caregivers such as this quote were common in the survey.

Financial Needs

Having access to funding for assessments, diagnostic services, respite or pharmaceuticals were all important to caregivers. Because the majority of individuals affected by FASD have a difficult time staying employed, financial help via ODSP or other supports was generally needed.

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario
APPENDIX C

Knowledgeable Service Providers

The frustration of trying to get support and no one understanding how to help underlies this category. It ranked fourth in importance for caregivers, but service providers ranked it higher at 33.7%, tied for second, because they realize how inconsistent the knowledge is within their own agencies and specialties. They were asking for more professional development themselves so they could help their clients.

Legal and Justice

While a small number noted legal and justice issues, such as dealing with courts, police and law makers as a need, it is a legitimate issue that these systems need more education and information around FASD.

Medical

Medical includes in the need for assessments, doctors who understand FASD and can refer families to the right supports, and the need for medical professionals (psychologists and psychiatrists) to do more around prevention awareness.

Strategies for Caregivers

Many caregivers were asking for strategies to help them manage their children, manage their transitions and manage their schooling.

Respite

Families need a break from looking after their affected children and adults. Camps, personal support workers, a few hours respite a week so the adult caregivers can gain their own emotional balance represent an urgent need for families.

Support for Daily Living

These were generally needed for older youth and adults. They include structure, help to get and keep employment, general looking after themselves as their caregivers can only do so much.

Support Groups

Support groups are needed in more communities for caregivers. Groups and activities that are appropriate for affected children and adults were also requested.

Transition to Adulthood

Housing needs, employment needs, transitioning and giving some structure and support. Adults with FASD need employers who are supportive and aware of the specialized needs of these employees.

Understanding and Awareness in the Community

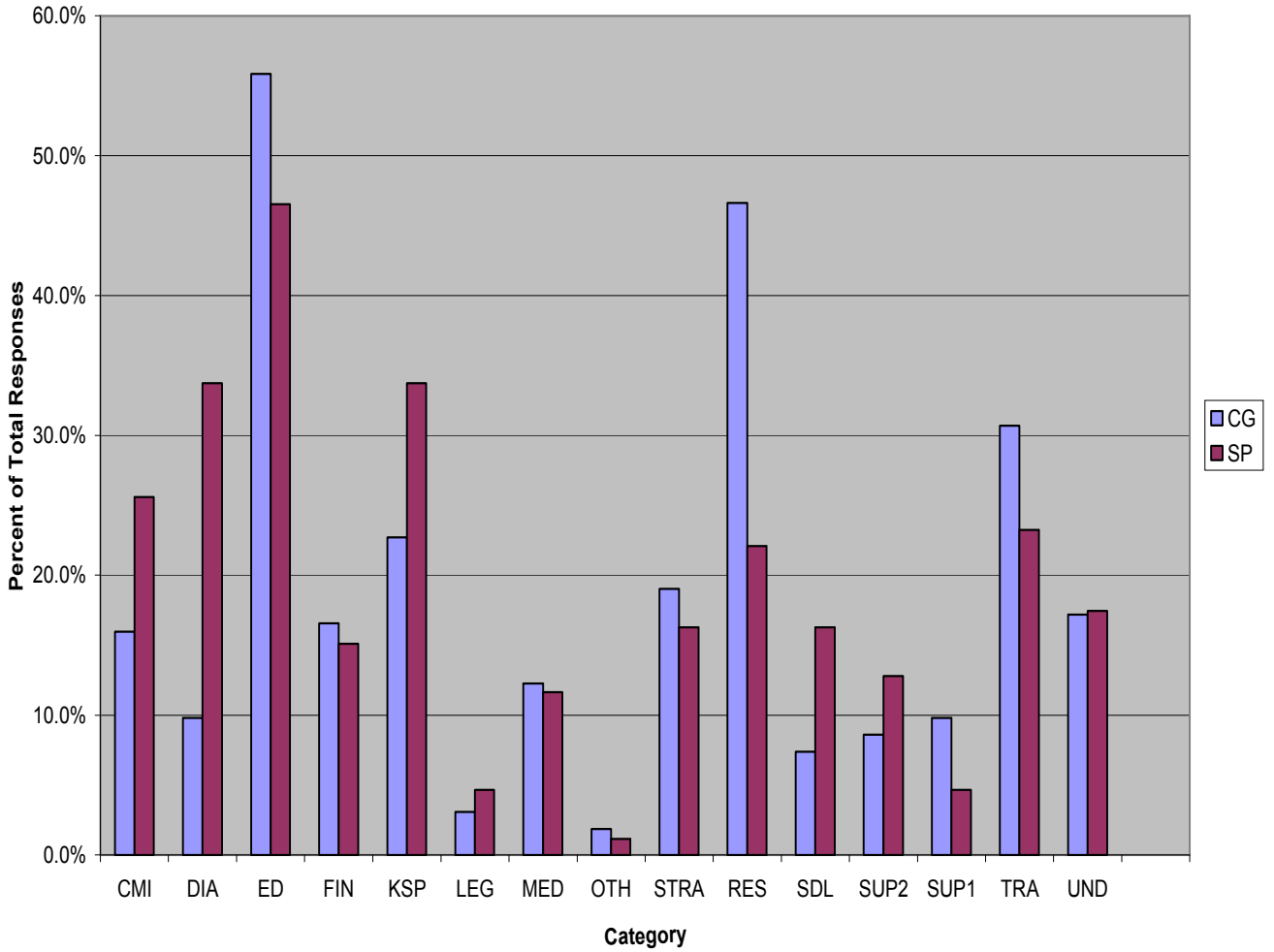
Those who work and live with FASD affected individuals felt that there is a general lack of understanding and awareness most places they go. Reducing the stigma attached to FASD and gaining some compassion were also on their wish list.

"Where are there programs that provide what an adult with FASD needs to be successful? Especially for adults with FASD with all the secondary disabilities?"
Caregiver of young adult.

"Medical and educational professionals THINK they know about FASD, but they are remarkably ill-informed. As an educator myself, I know that the training I received did not come close to helping me teach kids with FASD. In fact, it is often the opposite. Example: You are told to fill your classroom with eye-catching and stimulating materials. For a child with FASD, this makes learning considerably more challenging because of all the visual distractions and sensory overload." Caregiver of school-aged children

**Moving Forward and Supporting Families Affected by FASD
 March 2008
 Intervention and Support Working Group,
 FASD Stakeholders for Ontario
 APPENDIX D**

Comparison of Responses from Caregiver & Service Providers



**Moving Forward and Supporting Families Affected by FASD
 March 2008
 Intervention and Support Working Group,
 FASD Stakeholders for Ontario
 APPENDIX D**

LEGEND

Category	Graph Name
Case Management	CMI
Diagnostic Services	DIA
Education System, Supports, Understanding and Services	ED
Financial Needs	FIN
Knowledgeable Service Providers	KSP
Legal and Justice Services	LEG
Medical Services	MED
Other	OTH
Strategies for Caregivers	RES
Respite	SDL
Support for Daily Living	STRA
Support Groups – FASD affected	SUP1
Support Groups – Caregivers	SUP2
Transition to Adulthood	TRA
Understanding and Awareness in Community	UND

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario
APPENDIX E

Strategic Priority	Complete List of Projects/Tasks
Advocacy	Amend legislature thinking that Alcohol is not a disability issue therefore is an issue with inability/ability to qualify for ODSP
	Identify who has the power to Do and who has the Power to influence
	Very powerful Group of parents and affected youth = voice of FASD in Ontario. How do we create this group; Advocacy for their needs; Providing the support to this community so they can become powerful. Look at how others have been successful – Developmental Handicap and Autism
Communication & Awareness	Better ways of communication; Power to Act; Effectively; Better defined to whom and what; Dissemination of the right info to the right people; consider how we turn that information into action.
	Website Development - One pager on web for families to give to respite provider (pamphlet as well); All About Me” – document for parents to use to describe child to service providers Problem solving Q & A on web for parents Tab on website on education, with details IPRC etc., strategies around how tos Updates from Ministry and special services at home Develop success stories on the website;
	“Being your best with FASD”
	Normalize the disability- okay to have FASD
	Support Groups have access to all info, resources and support they need.
Education	Education Working Group – share info.
	RTO- retired teachers of Ontario- train some of them to be FASD advocates in schools
Knowledge Transfer	General awareness understanding of FASD;
	Get FASD on curriculum for health Care providers teachers, CYC,EAs ECEs etc.
	Knowledge of FASD is integrated into all service providers training
	Develop a booklet to explain FASD for parents to be given out by Service providers (can we leverage the GTA one?) What is there that we can already use.
	Society’s attitude surrounding women and alcohol abuse; Every service provider has reflected on their own feelings around alcohol and how it impacts on their practice
	More education for parents, service providers by bringing in speakers (workshops / conferences)
Links	Linkage between provincial and local initiatives
	Collaborative ways of working, how do we harness the energy to move forward. Find other sub-committee (in FSO and elsewhere) that are already doing things that support our mandate

Moving Forward and Supporting Families Affected by FASD
March 2008
Intervention and Support Working Group,
FASD Stakeholders for Ontario
APPENDIX E

	Provincial FASD Stakeholders – provincial advocate that our group feeds into; May need a new group to work on this advocacy
	Stakeholders-local level conversations – how can we help and support?
Research & Evaluation	Evaluate and research – need to show positive impact, need research; Dr. Deb Goodman, CAS, has done extensive research; need evidence-based/cost-benefit analysis
	Best/Effective Practices – on how to support individuals with the disability and their families, use the knowledge and experience in this group
	Collect all that info out there – how do we harness that and do it in a supportive way
	Report “Whats Up”, completed- scan of what is going on in Ontario (Elspeth is working on a report on this) Could be placed on the website as a baseline for going forward.
	Wisdom of Practice
Services for Youth, Children and Adults	
	Parents support groups have FASD child specialists to program/match kids
	Pilot parents model, mentoring - Community Living has something like this; Capacity building for parents
	Range of respite services, providers need to be well trained, supervised and supported
	Would like everyone (child/adults) with a child affected with FASD have someplace to go for support, schools/camps that provides respite, education, network/connection; To remove isolation
	Respite project- sharing success stories (different in areas of Ontario)