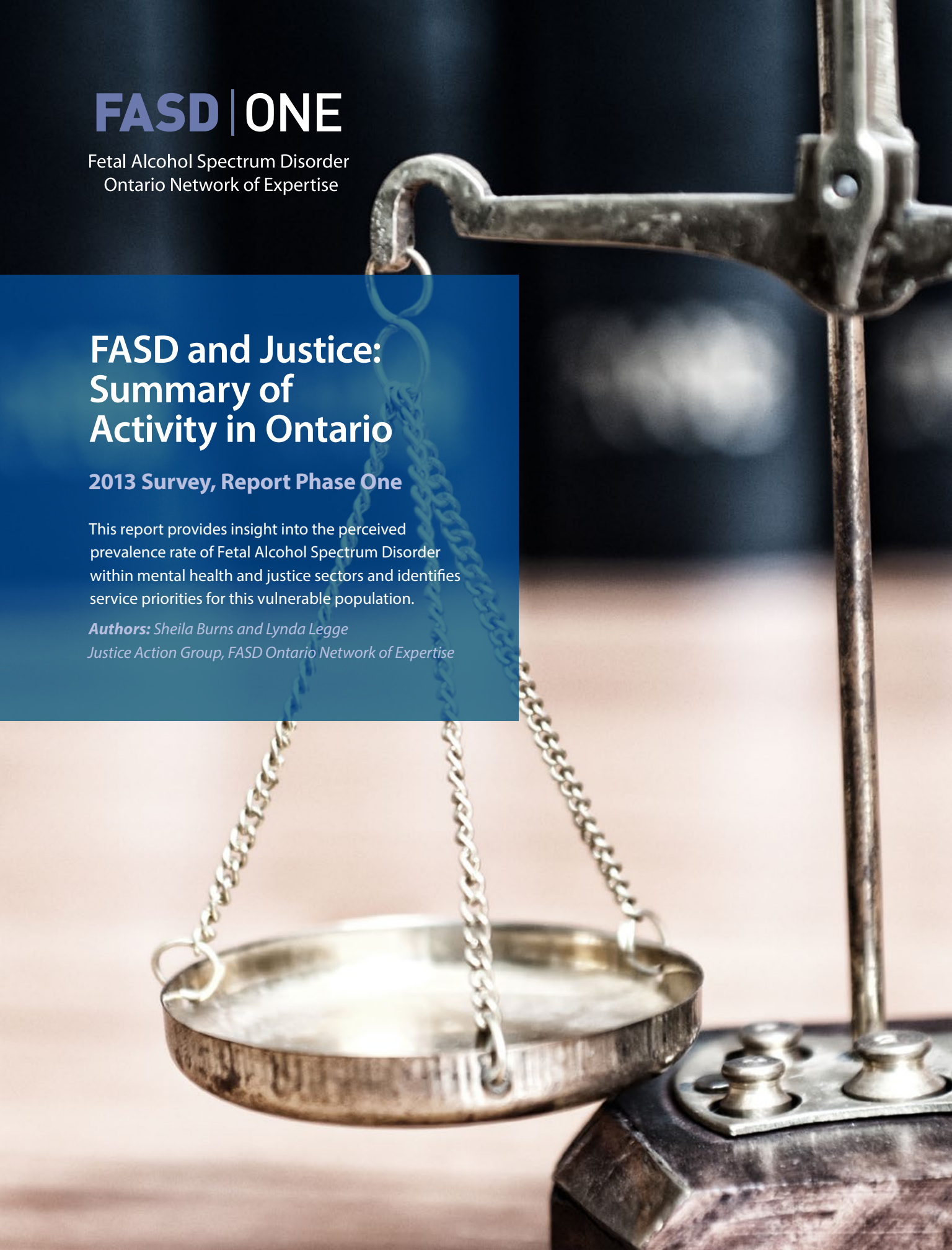
FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise



FASD and Justice: Summary of Activity in Ontario

2013 Survey, Report Phase One

This report provides insight into the perceived prevalence rate of Fetal Alcohol Spectrum Disorder within mental health and justice sectors and identifies service priorities for this vulnerable population.

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Survey working group

This report was prepared by Sheila Burns, Lead of the FASD ONE Justice Action Group and co-Lead Lynda Legge with support from justice group member Roxana Vernescu and Beth Anne Currie, research consultant with the Southern Network of Specialized Care.

FASD Ontario Network of Expertise

FASD ONE is a volunteer group that is advancing the discussion on Fetal Alcohol Spectrum Disorder prevention, diagnosis and effective interventions. For more information, visit www.fasdontario.ca.

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Survey Report Phase One

Introduction

What is hidden or lost in crime and victim statistics is the over-representation of individuals with the neurodevelopmental disability Fetal Alcohol Spectrum Disorder (FASD).

FASD is one of the most common, preventable disabilities in the western world and is believed to occur in one percent of the Canadian population (Health Canada), an estimated 130,000 in Ontario. However, research suggests that the rate of FASD among the inmate population may be 28 times higher than in the general population (MacPherson 2011) and that youth with FASD are 19 times more likely to be confined in a young offender's facility than their non-affected peers (Popova 2011).

The FASD Justice Survey developed by the Justice Action Group of the FASD Ontario Network of Expertise (FASD ONE) sought to understand the perceived impact of FASD on legal and justice services in Ontario and to identify existing or emerging tools that could guide effective practice.

Background

FASD is an umbrella term rather than a diagnosis. It refers to several medical diagnoses of permanent neurodevelopmental disabilities or malformations in other organ systems caused by prenatal exposure to alcohol. Diagnoses include Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), Alcohol Related Birth Defects (ARBD), and Alcohol Related Neurodevelopmental Disorder (ARND). Each diagnosis reflects specific constellations of damage including facial dysmorphology, organ or skeletal deformities, growth delays, and significant neurological deficits (1.5–2 standard deviations) in a minimum of three areas of brain function (Chudley 2005).

The brain damage can affect memory, sensory integration, language processing, social communication, adaptive functioning (daily living), emotional regulation and other executive functions (ability to anticipate, plan, organize appropriately and to adjust or accommodate to change). It is the cluster of brain-based deficits that, when unrecognized, leads to involvement in the justice system—as victims, accused and offenders. In addition, those with the disability are vulnerable to abuse as children, adolescence and adults as services fail to recognize and/or respond to their lifelong needs (Streissguth 1996, 2004, 2007, Fast, Clark E. et al 2004).

This gap in service response is the result of multiple factors:

- FASD is invisible in more than 90% of cases (Andrews 2011).
- Though a common form of developmental disability, the capacity to diagnose FASD is still limited (Clarren, Lutke 2011) and there often is no protocol to record prenatal exposure to alcohol and/or an FASD diagnosis.

Background (cont.)

- The diffuse brain damage caused by prenatal exposure to alcohol can result in areas of strength that camouflage profound social, behavioural, and learning deficits.
- Adverse life experiences of those with the disability complicate education, justice and mental health interventions. FASD mimics or co-occurs with mental illness so the origin of issues can be missed.
- Few programs have mandates to address the complex needs of those living with the disability; the required cross-sector coordination of services is often unavailable even with a diagnosis.

Missing a diagnosis of FASD compromises outcomes and has a domino effect of adverse consequences including unstable home life or family breakdown, abuse, being raised in the care of a child protection agency, school failure, addictions and mental illness, having children early, limited capacity to parent, chronic unemployment, homelessness and other vulnerabilities that result in a cycle of criminal involvement as victims and offenders (Streissguth 1997, 2004).

Systemic inaction on FASD is not benign; the disability can be devastating to families and has been estimated to cost the Canadian economy $6.2 billion annually (Thanh, Jonsson, Dennett, & Jacobs, 2011). These costs are felt across multiple sectors, and pertinent to this report, cripple the Canadian justice sector. Given the annual cost of approximately $3 billion for adult correctional services (Landry & Sinha, 2008) and a conservative FASD prevalence of 23.3% for youth offender populations (Fast, Conry, & Loock, 1999), a low-end estimate of costs of FASD for the Canadian justice system is roughly $700 million annually (23.3 % of CA $3 billion; Thanh et al., 2011).

Ontario has limited capacity to diagnose FASD (Clarren, Lutke 2011) which leaves the legal and justice system without the critical information required for fair and appropriate responses, supports, and/or interventions. Disability resources are not available to victims, accused or offenders who have not yet been diagnosed, resulting in a lack of appropriate interventions, and ultimately systemic discrimination against this vulnerable group.

FASD can be devastating to families and has been estimated to cost the Canadian economy ***$6.2 billion annually***

The justice system responds to a variety of victim, witness, and offender needs. Considerations of moral blameworthiness, proportionality, responsibility, fitness, and expectations are revised when dealing with mental illness or intellectual disabilities. Offender rehabilitation is considered in the context of history and individual challenges. Diversion, conditional sentencing, release programs, Gladue and mental health courts address distinct offender issues. Additional resources are provided to facilitate and sustain rehabilitation. FASD needs to be recognized within the justice system and accommodations extended to include individuals with FASD or suspected of having FASD. This will be advantageous for individual and community safety and reduce crime—the ultimate goal of the justice system.

The Justice Action Group of FASD Ontario Network of Expertise sought to identify activities within the mental health and justice system in Ontario to determine the perceived prevalence rate of clients with FASD or suspected of having FASD, to identify the systemic opportunities to track and respond to the disability, and to understand the challenges and priorities of the sector.

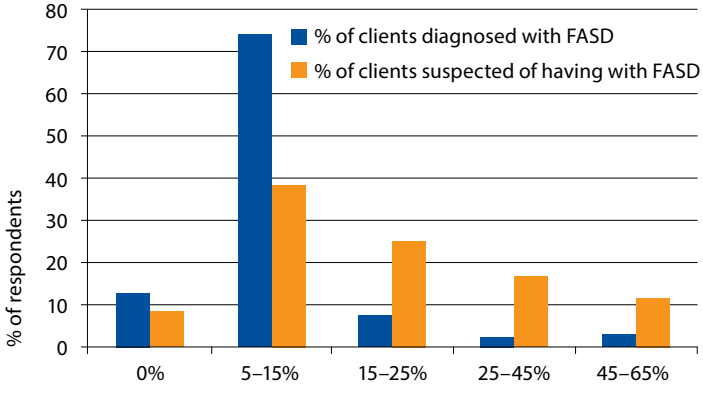
A survey was circulated through the Human Services and Justice Coordinating Committees (HSJCC), provincially mandated committees with members who would likely be aware of in FASD-related initiatives. Supported by the Southern Network of Specialized Care, 1,100 survey invitations were sent via email to HSJCC members during the summer of 2013. A 10% response rate to an 11-question on-line survey was achieved though there was limited feedback from closed custody institutions and victims' services.

Results of the survey indicate that many HSJCC justice, developmental and mental health services members identify FASD among their clients and many are concerned about the capacity to effectively address client needs. Training initiatives were identified that may change individual practice but these do not appear to elicit the systemic changes needed for effective intervention. Respondent concerns outstrip FASD activities in areas of research, evaluation, program development and innovation.

Prevalence of FASD

Most agencies (90%) recognize FASD among their client population. The number of clients with confirmed/suspected FASD suggests that a significant subpopulation of mental health and justice clients have the FASD profile—as high as 65% reported by 14% of respondents. The rate of suspected cases of FASD was always higher than that of confirmed diagnoses. A number of agencies ranked the rate of FASD or suspected FASD at zero (13% and 8.3%), a lower incidence rate than in the general population.

Prevalence rates of/suspected FASD



Respondents' survey comments identify the challenge of accessing assessment and FASD diagnostic services. Having to guess at the genesis of challenges is not optimal and is often ineffective. Diagnosis can direct and inform appropriate accommodations needed in the justice system and in his/her community, contributing to effective planning and efficient use of resources.

Recommendation

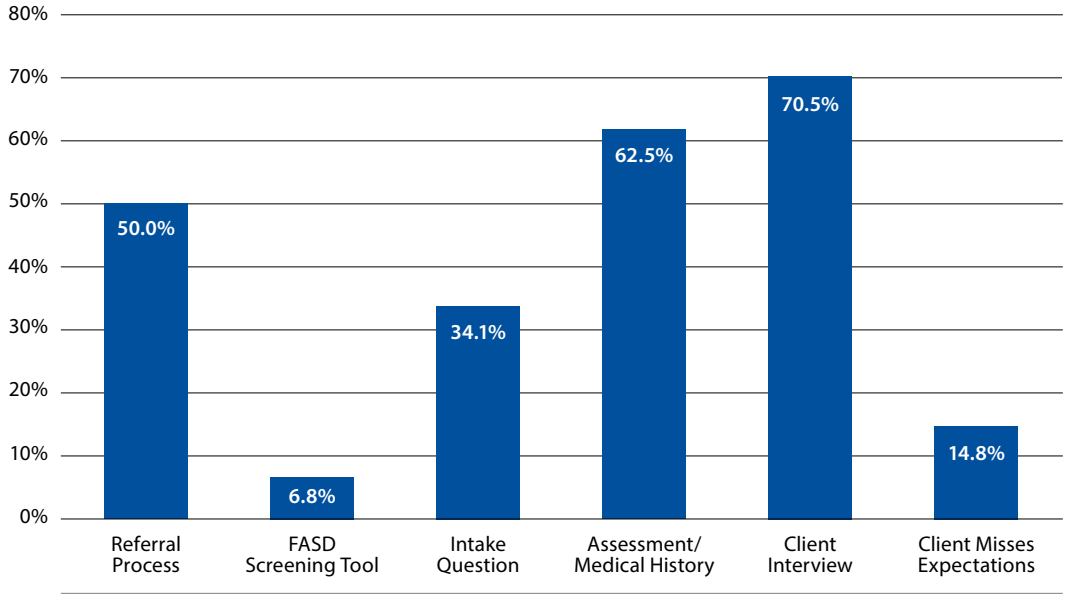
Using available screening tools and assessment results in facilitating a diagnosis when FASD is suspected. Develop a:

- protocol for referral and a diagnostic pathway,
- plan of care protocols for clients with/suspected FASD,
- plan of care protocols for clients suspected of having FASD but for whom a diagnosis is not possible due to lack of facial dysmorphology & growth delay or prenatal history.

Tracking a diagnosis under the FASD umbrella

Survey respondents identified many opportunities to track or record FASD diagnoses that could help inform intervention strategies. More than 30% of agencies either don't check for a diagnosis or rely solely on self-reports (clients indicate their diagnosis). Having FASD includes cognitive impairments, memory, sequencing and recall deficits. Individuals with FASD may not know they have the disability, may be embarrassed to talk about their diagnosis, or may not understand the importance of sharing the information. This limits or impairs an agency's ability to set appropriate expectation or program accommodations or to effectively advocate for clients.

Identifying and tracking FASD suspected/diagnoses



System's opportunities to identify FASD or suspected FASD

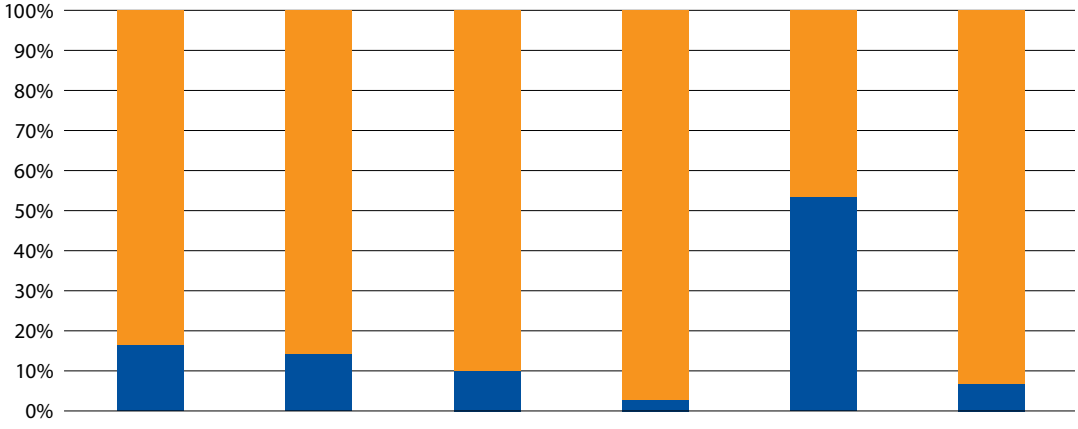
A diagnosis of FASD or suspicion of the disability shapes service delivery strategies. It informs assessments, treatment, and interventions to ensure clients are provided with appropriate and effective interventions.

Recommendation
Agencies formally and consistently track FASD diagnoses or suspected cases of FASD and provide programming and services to meet learning, social and developmental needs.

Systemic Change through Innovation, Research, Pilot Projects, Evaluation, Training

The FASD Justice Survey sought to identify agencies and groups that are exploring issues related to FASD in five categories: program innovation, research, pilot projects, evaluation and training . With the exception of training, most survey respondents did not identify FASD-related justice initiatives. Training initiatives were identified by 53.3% of respondents; these ranged from one-time events to FASD components in agency orientation and staff development. By comparison, fewer than 10% and 3% of respondents respectively identified programs and evaluation.

Respondent awareness of justice-related initiatives



	Research	Pilot Projects	Programs	Evaluation	Training	Other
No initiatives identified	83.64%	85.61%	90.20%	95.84%	46.40%	93.48%
Initiatives identified	16.36%	14.30%	9.80%	2.80%	53.40%	6.52%

Rate of response in each category varied from 42%–55% of overall responses

The value of training is limited if there is no strategy to build tools, programs, and policies that address the learning, behaviour or developmental needs of those with the disability (Burns, Bloom 2013). Coordination of community services was a common theme among the limited number of responses and is perceived to improve outcomes. There were examples of agencies collaborating to stretch or tailor services to meet needs of clients with/suspected FASD. This is a low-cost approach to achieving efficiencies and program effectiveness and is an element of effective FASD practice (Hall, Cunningham, Jones 2010).

Phase Two of the Survey Summary Report will explore details of initiatives identified in the survey and will seek to address the gaps in responses from closed custody institutions and victims' services.

Highlights of Responses to Justice-Related Initiatives:

RESEARCH

» Aboriginal Legal Services of Toronto and Anishnawbe Health Toronto
» "Exploring the impact of effective practices for adults with FASD living in the community and their contact with the Criminal Justice System" Grey Bruce and Surrey Place

PILOT PROJECT

» Interaction with clients who have mental health issues/limitations including clients with/suspected FASD diagnosis by Legal Aid Ontario
» Specialized mental health courts

PROGRAM INNOVATION

» Mental Health Services of Renfrew County's Court Support & Diversion Program in partnership with local Crown's Office
» Drug Treatment Court team & Mental Health Court—Waterloo Region incorporates treatment into this justice-related program which can mean harm reduction and self-help strategies when no 'cure' is available
» Equine Assisted Life Skills Training Program
» Collaborations and community partnerships that bridge, coordinate and/or lead services that address needs of clients with FASD
» Video conferencing for assessment and diagnosis

EVALUATION

» FASD prevalence rates in youth justice by Youth Justice Crown Attorneys
» Enhanced Extrajudicial Sanctions Program for First Nations youth 12–17 in conflict with the law has expanded to include youth with FASD

TRAINING

» A variety of in-services, workshops and conferences including embedded training in agency/ministry orientation and on-going professional development

INITIATIVES

» Collaboration with the Mental Health diversion program at Canadian Mental Health Association in Kenora providing psychological assessments for FASD (via video conference)
» A Complex Needs Committee bridges and coordinates a spectrum of services for those with FASD

OTHER

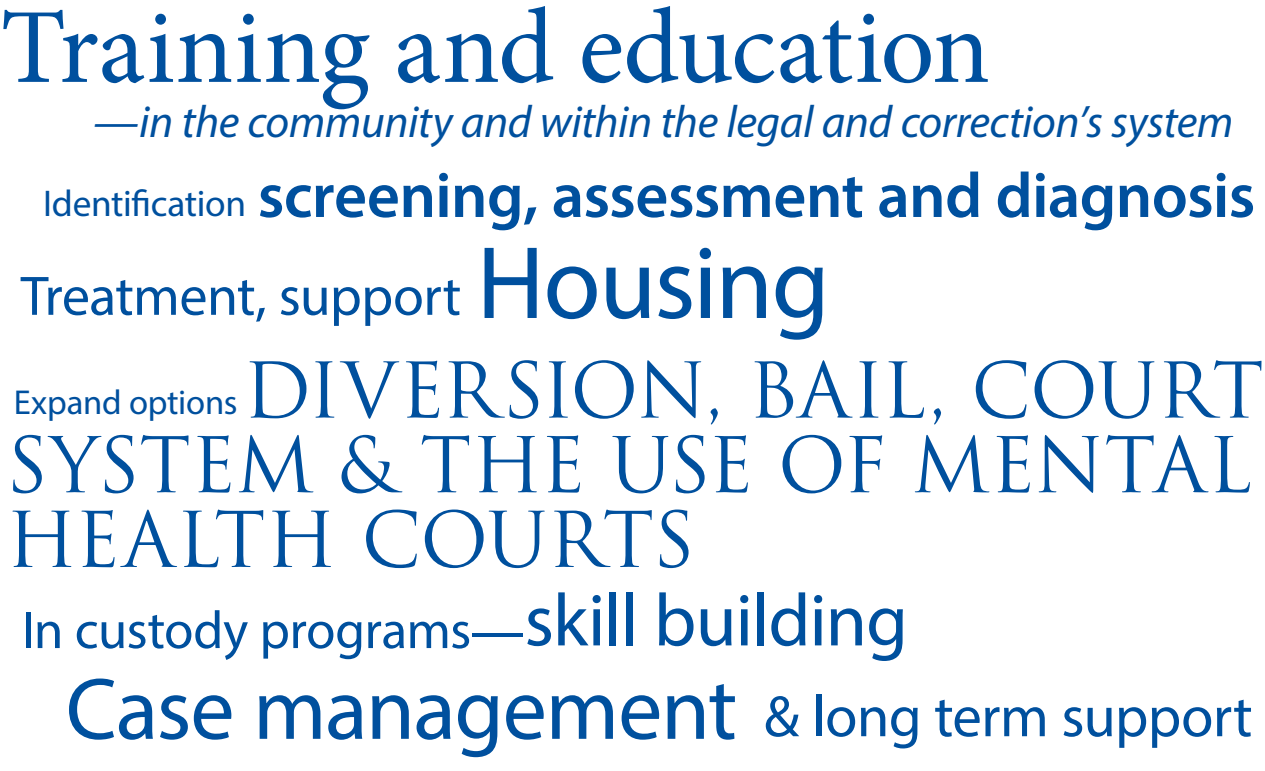
» Awareness and primary prevention initiatives
» Community partnerships that advance collaboration among mental health, addictions, health, education, protection, social services, justice and developmental services

Recommendation
Ministry leadership in justice, health, and developmental and social services add a mandate to coordinate FASD-informed interventions in training, policies, protocols and programs across the lifespan.

Priority Issues

Survey respondents expressed concern regarding appropriate programming and the long-term wellbeing of clients with/suspected FASD. Priority issues included the need for more professional education and more options and flexibility to respond to the legal and social needs of clients. Comments cited the need for identification, assessment and access to diagnosis to improve client plans of care and skill building programs both in and outside of institutions as appropriate use of time and resources. The coordination of services within the community is perceived as an important factor in reducing the cycle of victimization and offending behaviour.

The word theme chart below highlights frequently cited priority issues submitted by 86 respondents (font size reflects the commonness of priorities).



Additional comments were provided by 25 respondents reflecting both frustration and optimism that the system can become more responsive to the needs of individuals with FASD. Feedback suggests that FASD-responsive strategies can be integrated into the existing service system to ease the burden of living with this lifelong disability and enhance community and individual safety.

Conclusion

FASD was defined in 1973; forty years later there is still no coordinated response in Ontario. There is however awareness of FASD among developmental and health services and in the justice system.

This includes an emerging understanding of the implications of FASD on an individual's capacity to make reasoned, informed and considered decision as well as the need for accommodation and support. Access to a fair and impartial legal system requires that family, civil and criminal systems consider this neurodevelopmental disability when evaluating parental capacity and rights, access to financial supports and social services, and when considering the moral blameworthiness of individuals.

The survey found that individuals with FASD comprise a significant portion of clients in the mental health and justice service sectors and confirm FASD as a risk factor for involvement in the legal system. Agencies are concerned about services for this vulnerable population and see many action opportunities. The few examples of research, program innovation and evaluation are not proportional to the prevalence rate or the cost of FASD to the mental health and justice system. The survey did not adequately capture FASD initiatives in closed custody or victim services but that may reflect the dissemination strategy.

Many organizations understand the vulnerabilities innate to those living with FASD and the need for and value of a coordinated institutional and community response. Training may change individual practice but has not translated into system-wide FASD-informed interventions from the court docket or institutional or community settings. Respondents identify the need for cross-sector collaboration as the most effective approach to stopping the revolving door of victimization and criminalization of individuals with FASD.

Policy and protocols are needed to encourage and support FASD-informed programming.

- There are multiple opportunities to screen for the diagnosis. Identification of the disability early informs service delivery, uses resources more effectively and improves outcomes.
- Professional development/training in FASD needs to extend to programs, policies and practice.
- Cross-sector FASD-sensitive programming is needed to provide for the lifelong needs of clients. Local FASD networks are an effective approach to addressing local priorities.
- Ministry leadership, engagement and coordination can accelerate research, evaluation, and program innovation and address the systemic gaps that are barriers to better service delivery and outcomes.

FASD falls across the mandates of agencies and ministries. Many survey responses mirror those identified in the national dialogue and the 2013 Consensus Statement on Legal Issues of Fetal Alcohol Spectrum Disorder (FASD) Consensus Conference on FASD hosted by the Institute of Health Economics. Prevention and effective management can occur with cooperative coordination of services—drawing on multiple areas of expertise and resources.

The survey responses not only identify a systemic challenge but a readiness and willingness to address the complex issues faced by youth and adult services, health and mental health, and justice and corrections to innovate programs toward meaningful and effective supports for those living with FASD.

Next Steps

The FASD ONE Justice Action Group extends our deepest appreciation to those who completed our survey.

We are pleased to engage in discussion with groups wishing to improve their response to victims, witnesses, clients, accused and offenders who have/are suspected of having FASD.

Phase two of our summary will highlight survey findings on program innovation, research, pilot projects, evaluation and training and review any additional findings from victims services and offender facilities.

For an electronic copy of this report or for additional information on FASD go to www.fasdontario.ca.

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About FASD ONE (Fetal Alcohol Spectrum Disorder Ontario Network of Expertise)

FASD ONE is a volunteer collaborative comprised of Ontario practitioners, parents/caregivers, and specialists committed to the prevention of Fetal Alcohol Spectrum Disorder and the development and dissemination of evidence-based information that will support practitioners, as well as individuals affected by FASD, and their families. FASD ONE members represent communities across Ontario, as well as the health, child welfare, justice, early intervention, addiction and mental health, education, and corrections sectors.

FASD ONE has sought province-wide input to inform recommendations for action on FASD. The 2013 Blueprint for Action symposium, which was attended by 180 stakeholders representing community, regional and provincial organizations, identified priority issues. Priorities focused on prevention, education, early intervention, child welfare, assessment and diagnosis, and legal issues. These priorities reflect the sectors and ministries touched by FASD, the need for coordination of a response, and the value of that effort to communities, stakeholders, and families across the province.

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For more information, visit **www.fasdontario.ca** or email **info@fasdontario.ca**