

FASD & Justice: Ontario Survey Key Findings and the Future

Friday June 20th, 2014 Video Conference

Presenters: FASD ONE Justice Action Group

Sheila Burns, FASD Specialist, M.S. & Associates

Lynda Legge, Facilitator Southern Network of Specialized Care

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Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

Presentation Outline

- ▶ FASD Ontario Network of Expertise
- ▶ Putting FASD into context
- ▶ The connection between FASD and justice
- ▶ Findings of the Ontario FASD Justice Survey
- ▶ Highlights of the FASD Consensus Conference on FASD and Legal Issues
- ▶ Recommendations and future activity
- ▶ Questions and Comments

FASD Ontario Network of Expertise

- ▶ FASD ONE was founded in 2005 (formerly FASD Stakeholders for Ontario) with funding from Public Health Agency of Canada
- ▶ Volunteer collaborative of
 - ▶ caregivers
 - ▶ practitioners
 - ▶ specialists
- ▶ Advance an FASD strategy in Ontario towards the
 - ▶ Prevention of FASD
 - ▶ Better outcomes for individuals living with the disability by advancing development and dissemination of best practices

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FASD ONE Strategy:

Advance a provincial response to FASD with a focus on **protective factors*** in areas where FASD and services intersect

- Diagnosis
- Stable nurturing home life
- Absence from abuse/witnessing abuse
- Appropriate education and interventions
- Access to developmental service

(*Streissguth et al 1997)

FASD ONE Approach

- ▶ Action Groups with members with expertise in areas that can advance improved outcomes
 - ▶ Diagnosis - capacity building
 - ▶ Intervention and Support - effective practices
 - ▶ Education - advancing the profile of FASD so the school system can meet the learning, developmental and social needs of children and youth with the disability
 - ▶ Communication - conduit for dissemination of information on FASD, prevention, and emerging effective practices
 - ▶ Prevention - awareness initiatives including the improved systemic response to women with complex issues of substance misuse, mental illness, trauma, FASD etc.
 - ▶ Justice - increasing understanding of FASD and promoting the advancement of FASD-informed strategies in the legal and justice sectors
 - ▶ Lead - Sheila Burns - Co-Lead Lynda Legge and members Linda Clarke, Melody Hawdon, Debbie Moore, Dr. Roxana Vernescu, Aaron Gouin
 - ▶ Justice Survey support: Beth Anne Currie

Defining FASD

- ▶ FASD is an umbrella term describing a range of disabilities that may affect people whose mothers consumed alcohol while pregnant.
 - ▶ FAS
 - ▶ pFAS
 - ▶ ARND
- ▶ Different diagnoses reflect a spectrum of injury; the common element is that all individuals have brain damage.
- ▶ This brain damage is diffuse and the range board that results in deficits in social communication, executive, and adaptive function that impact an individual's ability to manage aspects of their lives

Diagnosis	Growth	Face	Brain	Alcohol
Fetal Alcohol Syndrome 1-3+:1000	x	x	x	x/o
Partial-FAS (pFAS)	some but not all of these		x	x
Alcohol Related Neurodevelopmental Disorder (ARND) 6-9+:1000	0	0	x	x

Canadian Guidelines (2005) define criteria for the spectrum of diagnoses. Four areas are evaluated using a 4 point Likert scale (4 represents the most severe damage)

Chudley A et al MAJ March 1, 2005 vol. 172 no. 5 suppl doi: 10.1503/cmaj.1040302

Diagnostic process is a multidisciplinary approach that:

- ▶ Evaluates growth and facial dysmorphology
- ▶ Confirms prenatal exposure
- ▶ Assesses brain function
 - ▶ Psychological testing
 - ▶ Occupational assessment
 - ▶ Speech and Language evaluation

FASD reflects organic/physical damage and is a medical diagnosis

for which Ontario has no health care billing number

- ▶ The diagnosis was supposed to help
 - ▶ Direct care and services for the affected individual
 - ▶ Support the mom
 - ▶ To assist with any substance misuse issue including in subsequent pregnancies
 - ▶ Most have untreated trauma and mental illness
 - ▶ Many have FASD themselves
 - ▶ Provide parenting support required to raise a child with a neurodevelopmental disability

However, the poor outcomes associated with the disability appear to have contributed to stigma and blame rather than the advancement of effective intervention

- ▶ Maternal death of women who have had a child with FASD (from accident, suicide, violence and disease) is 45x greater by age 50 Fetal Alcohol Spectrum Disorders: A Population Based Study of Premature Mortality Rates in the Mothers. Li Q, Fisher WW, Peng CZ, Williams AD, Burd L. 2011
- ▶ Incarceration rates for women with mental illness and/or addiction appears to be on the rise
- ▶ High rates of FASD in children in child protection, school drop-outs, unemployed, homeless
 - ▶ Cycle of failure now spans generations of individuals who are unable to meet our expectations

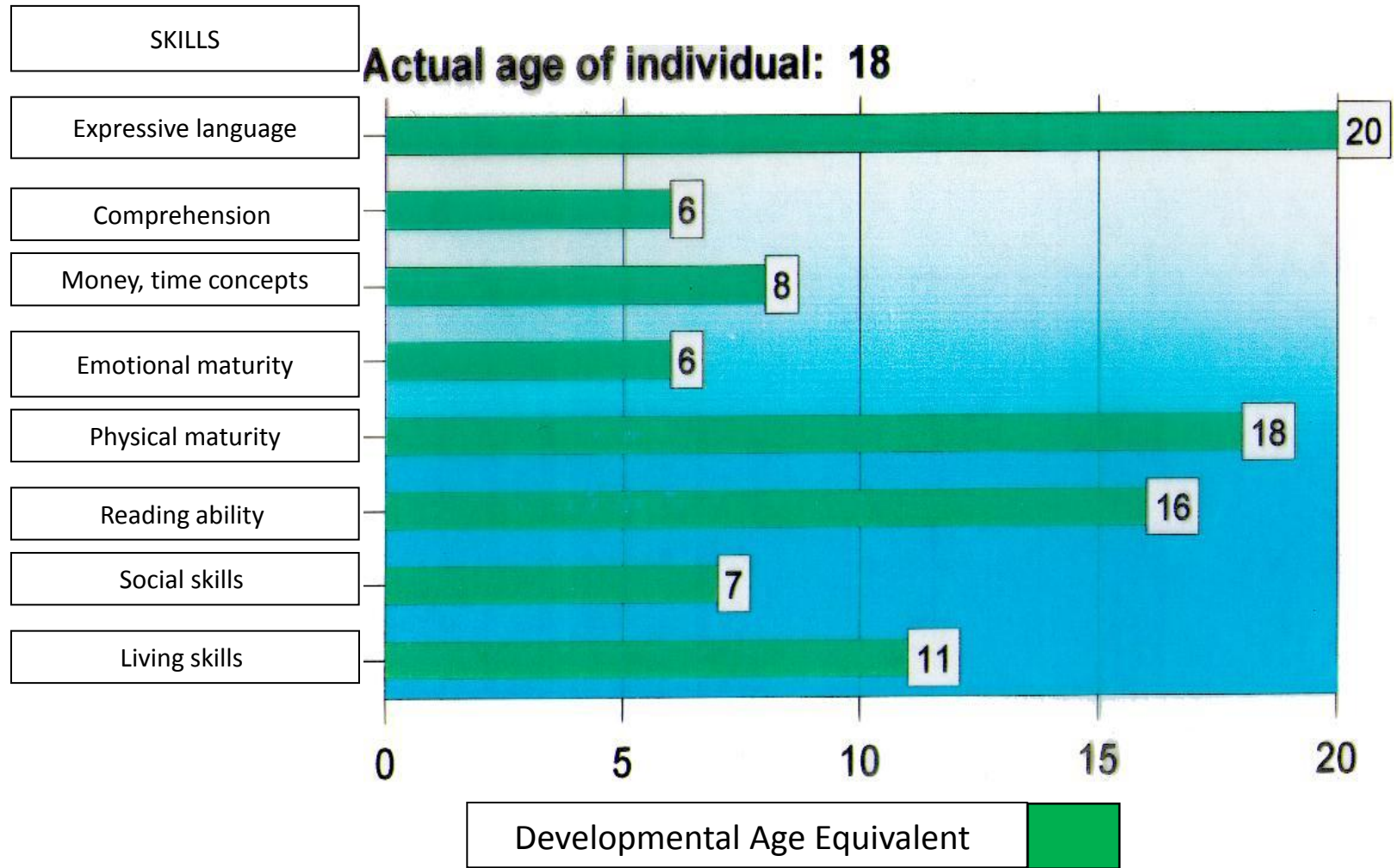
FASD

- ▶ Is a disability of thinking
- ▶ Areas of strength can camouflage significant impairment
- ▶ Adverse life experiences contribute and confuse intervention strategies
- ▶ Interventions that miss the organic brain injury contribute to poor outcomes

Areas of brain injury can include;

- ▶ memory
- ▶ sensory integration
- ▶ language processing
- ▶ social communication
- ▶ adaptive functioning (daily living)
- ▶ emotional regulation and other executive functions (ability to anticipate, plan, organize, and accommodate to change)

Chronological Development for Young Adults with FASD



Adapted from research findings of Streissguth, Clarren et al by D. Malbin 94

FASD and the justice system

- ▶ Youth with FASD are 19x more likely than non-affected peers to be incarcerated (Popova 2011)
- ▶ Adults with FASD are 28x more likely to be incarcerated (MacPherson, Chudley 2011)
- ▶ Recidivism rates among individuals is high though the research shows that the severity of offenses doesn't escalate
 - ▶ A repeat of the same offence
 - ▶ Breaching probation or parole
- ▶ There is also increased awareness that offences occur while in custody

FASD and the justice system

- ▶ The data suggests that the current system of interventions legal/justice punishment and deterrents are ineffective and may result in an inappropriate burden that can be devastating to individual and family
- ▶ Current interventions may contribute to criminalization and victimization
- ▶ Without a coordinated response, individuals with FASD will not receive the services needed to become contributing members of their community
 - ▶ Estimated to cost of FASD to the Canadian economy \$6.2 billion (Thanh, Jonsson, Dennett, & Jacobs, 2011)
 - ▶ Costs are felt throughout multiple sectors and are crippling the Canadian justice sector
- ▶ A strategy is required as indifference and inaction is not benign

FASD is a disability: that must to be considered in the legal and justice system

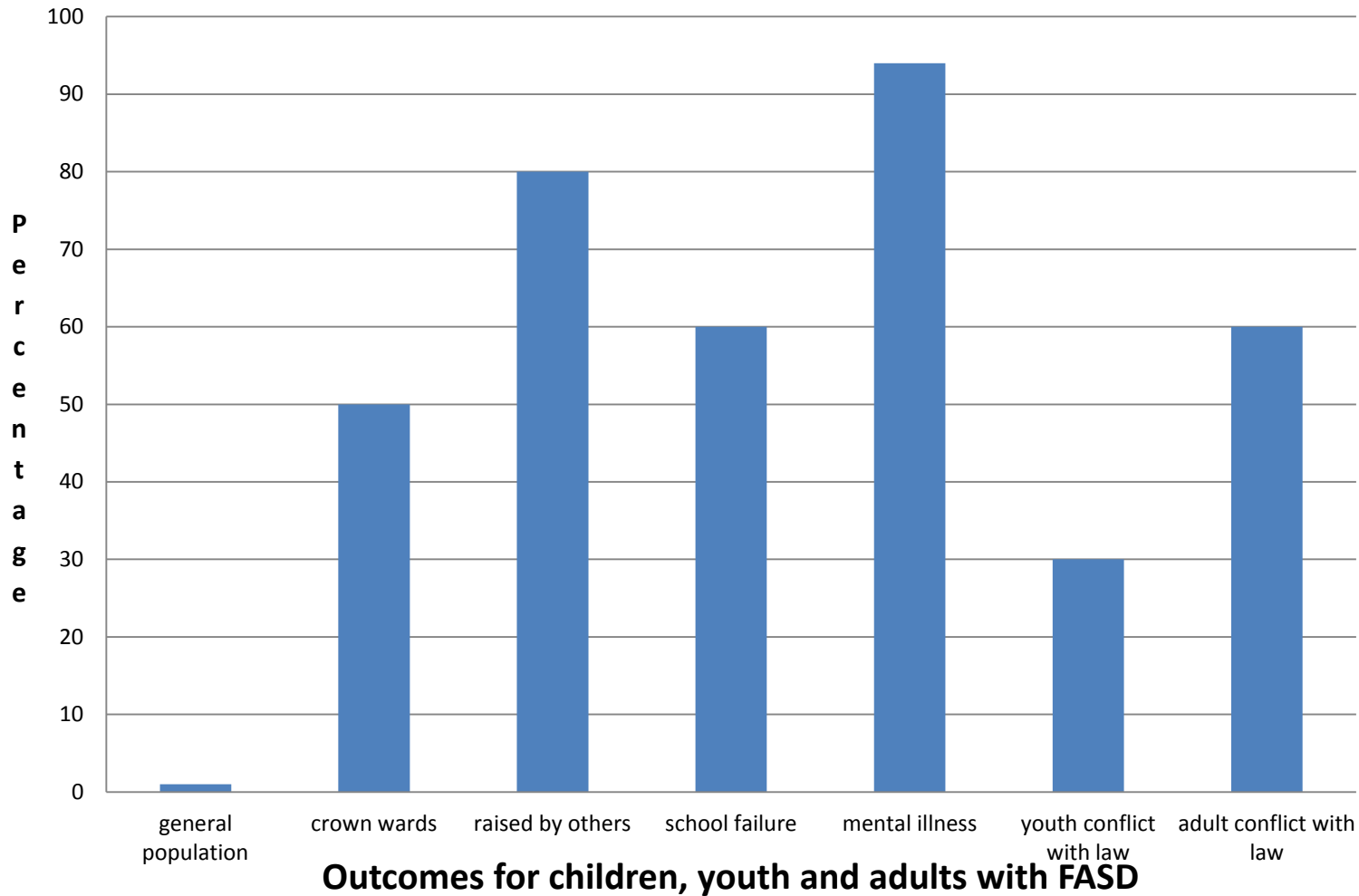
Consider Issues of:

- ▶ Moral blameworthiness
- ▶ Proportionality
- ▶ Breaches
- ▶ The rights of victims, accused and offenders
- ▶ The needs of victims, accused and offenders



Restrictive, punitive, expensive, ineffective and unhelpful responses for a chronic neurodevelopmental disability

FASD by the Numbers: Incidence & Prevalence Rate



Individuals with FASD are heavy users of the system.

Streissguth 96, Sampson 97, Conroy 2011, CAS-Toronto 2009

FASD ONE Justice Survey

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Findings

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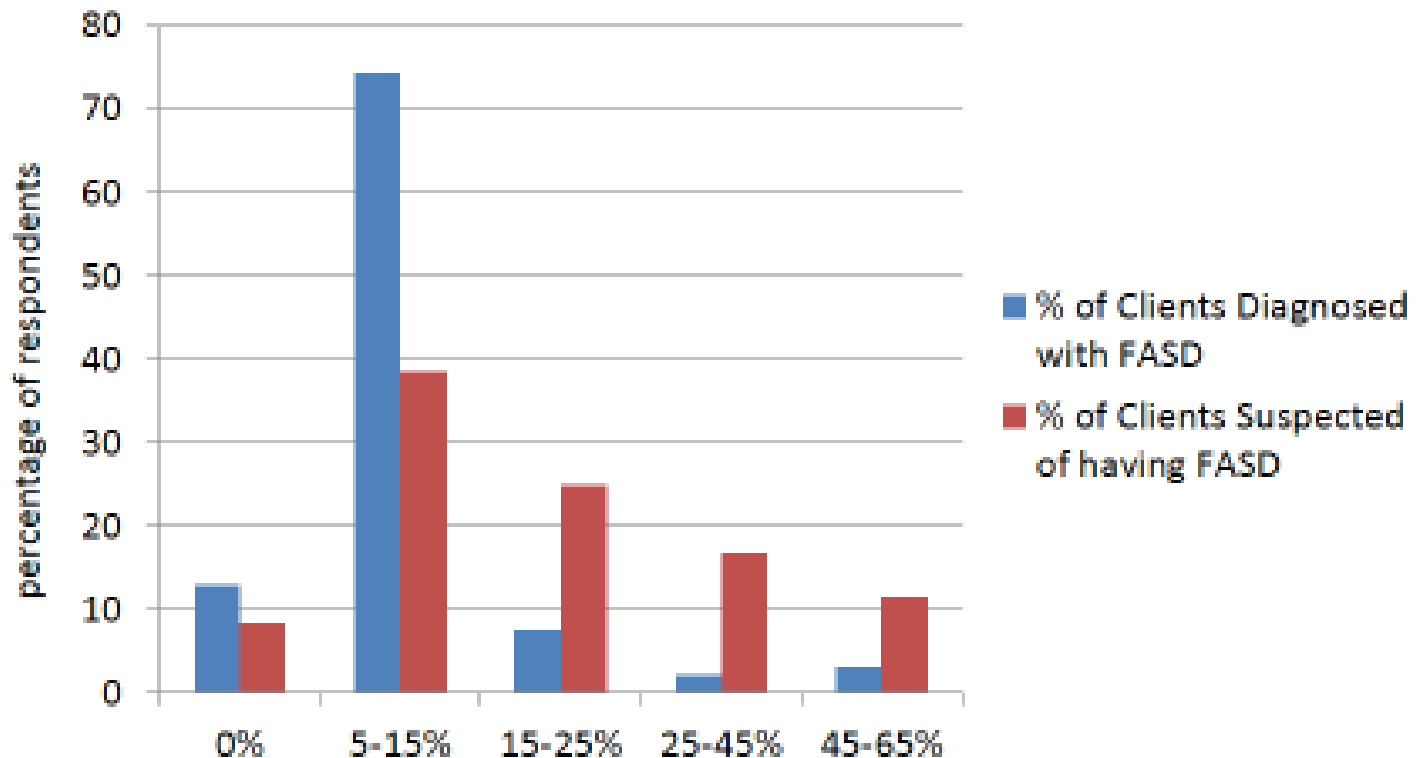
2013-14 initiative

- ▶ Determine perceived prevalence rates of FASD/suspected FASD in justice/related services in Ontario
- ▶ Understand how the justice and corrections sectors track FASD
- ▶ Identify current activities within the province

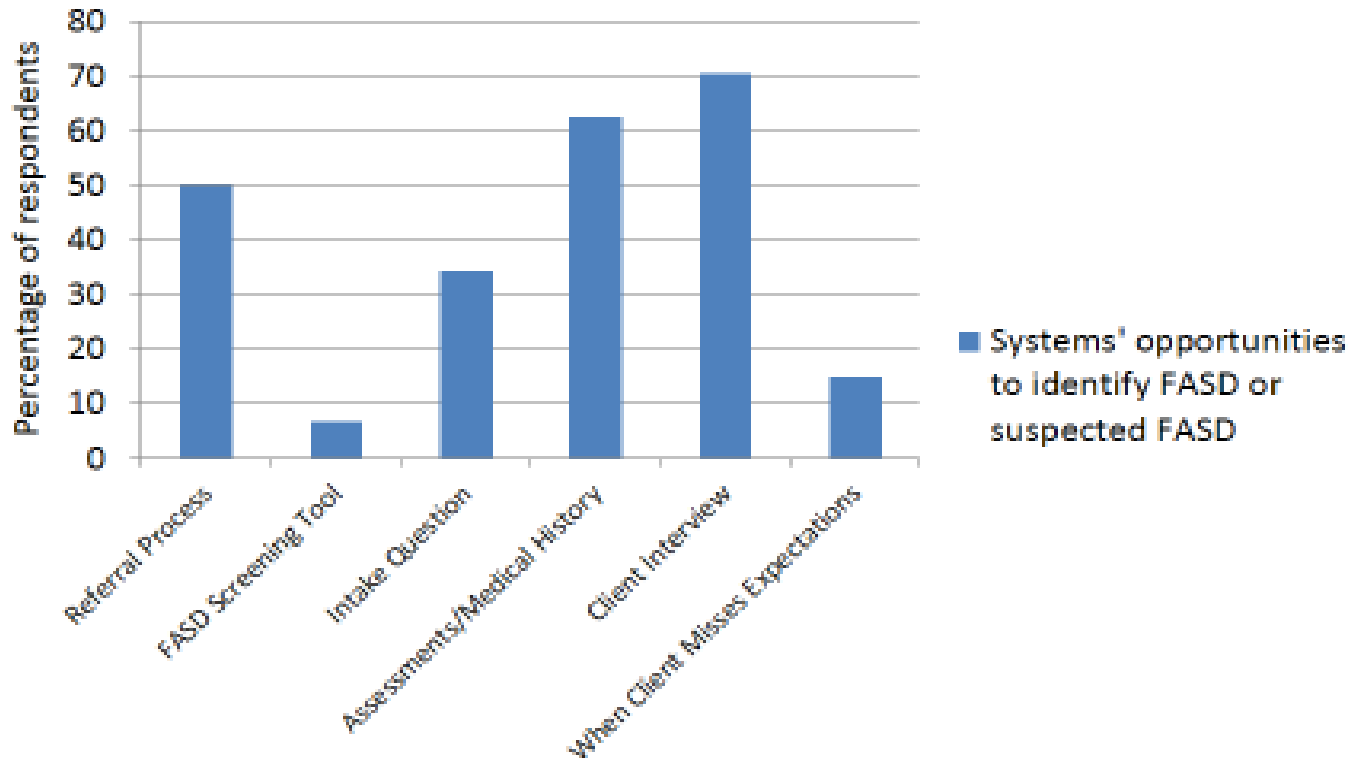
Understanding FASD within the Ontario Justice system

- ▶ 11 question survey developed with support from Southern Network of Specialized Care
- ▶ Survey monkey July to end of September 2013
- ▶ Disseminated through Human Services and Justice Coordinating Committees across Ontario = @ 1100 email addresses n= 109
 - ▶ HSJCC committees are a cooperative effort among the Ministries of the Attorney General, Community and Social Services, Children and Youth Services, Health and Long-Term Care, and Community Safety and Correctional Services and are funded through local LHIN's

Prevalence rates of/suspected FASD



Identifying and Recording FASD Suspected/Diagnosis

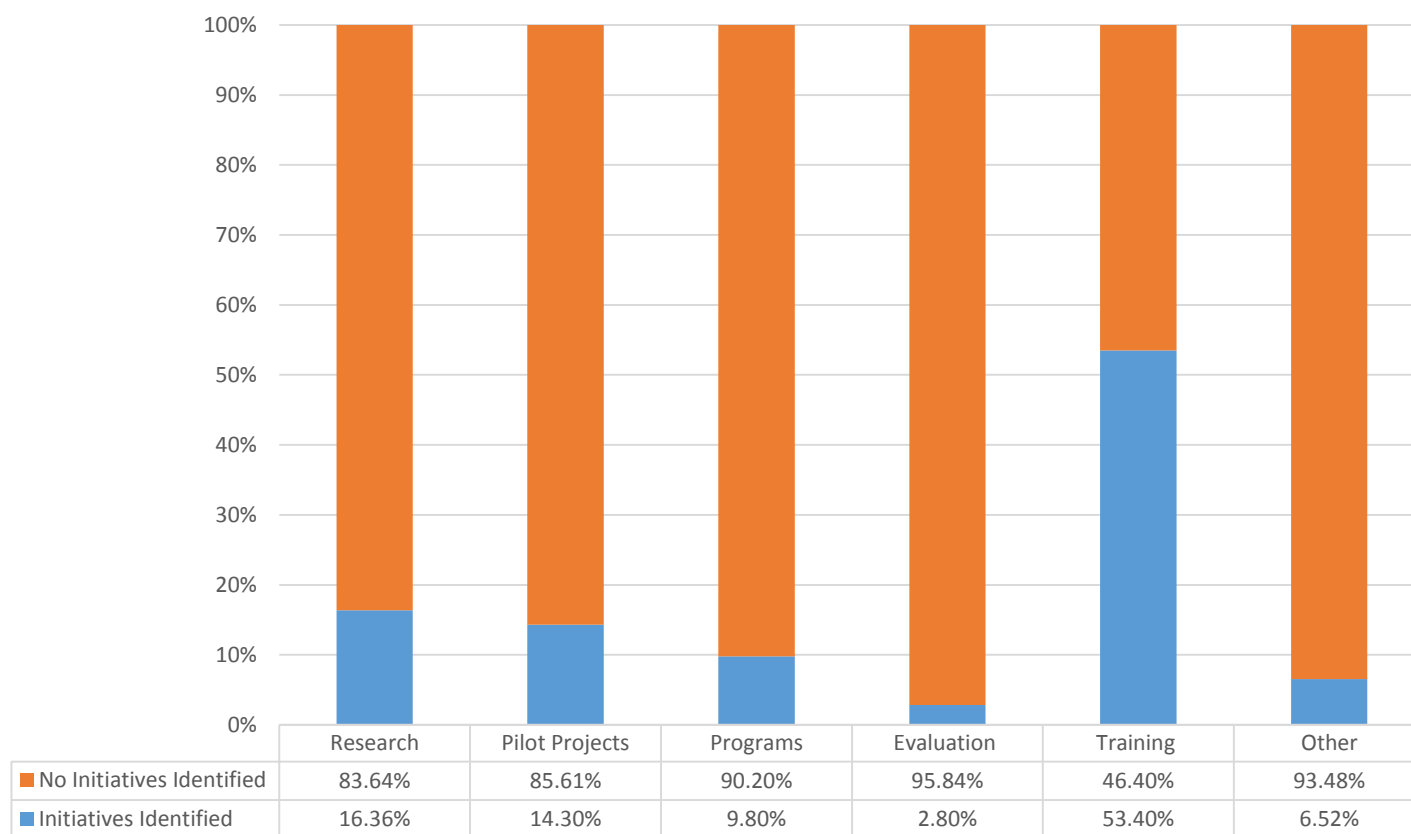


Survey respondents identified many opportunities to track or record existing FASD diagnosis.

More than 30% of agencies either didn't check for an FASD diagnosis or relied only on client self-reports. This limits opportunities to develop appropriate expectations, program accommodations or effectively advocating for their client

Systemic Action: Innovation, Research, Pilot Projects, Evaluation, Training

Respondent Awareness of FASD Justice Related Initiatives



rate of response in each category varied from 42% -55% of overall responses

Highlights of identified evaluation, program innovation, research, and training activities in Ontario

- ▶ Youth Crown Attorneys exploring prevalence rates
- ▶ Enhanced Extrajudicial Sanctions Program for First Nations youth in conflict with the law, expanded to include FASD.
- ▶ Video conferencing for assessment and diagnosis
- ▶ Examples of court diversion to mental health programs
- ▶ Legal Aid Ontario: interaction with clients who have mental health issues/limitations included clients with/suspected FASD diagnosis.
- ▶ Collaborations and community partnerships: includes committees that bridge, coordinate, lead services that address needs of clients with FASD
- ▶ Grey Bruce/Surrey Place research “Exploring the impact of effective practices for adults with FASD living in the community and their contact with the Criminal Justice System”
- ▶ Many awareness/prevention initiatives
- ▶ 60 responses related to training with a wide variety of in-services, workshops and conference cited. Training is imbedded in agency/ministry orientation and on-going professional development

Survey Response: Priorities

Concerns were expressed by many respondents regarding development of or access to appropriate interventions and supports

- ▶ This suggests many opportunities to realign services to reduce recidivism, increase individual and community safety

Training and education – *in the community
and within the legal and correction's system*

Identification **screening, assessment and diagnosis**

Treatment, support **Housing**

Expand options **DIVERSION, BAIL, COURT
SYSTEM & THE USE OF MENTAL
HEALTH COURTS**

In custody programs – skill building

Case management & long term support

- ▶ FASD is a risk factor for involvement in the legal system
- ▶ Agencies are concerned about services for this vulnerable population and see many action opportunities
- ▶ Few examples of FASD specific research, program innovation and evaluation which is not proportional to the prevalence rate or the cost of FASD on the mental health and justice system
- ▶ Training may change individual practice but has not facilitated systemic FASD-informed interventions
- ▶ Cross-sector collaboration is seen as the most effective approach

Summary

- ▶ 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 move into FASD program development supported by FASD-informed policies and practice.
- ▶ Cross-sector FASD-sensitive programming is needed to provide for the lifelong needs of clients.
- ▶ 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.

Recommendations

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Agencies

- ▶ Track FASD diagnosis or suspected cases of FASD
- ▶ Use screening tools and assessment results to facilitate a diagnosis when FASD is suspected
- ▶ Identify referral and diagnostic pathways
- ▶ Develop
 - ▶ Plan of care protocols for clients with/suspected FASD
 - ▶ Develop FASD-informed program components that accommodate treatment, learning and the lifelong developmental needs
- ▶ Coordinate community services with partners in justice, child welfare, addictions, education, mental health, and social services to contribute to stable lives

Ministries

- ▶ Take a leadership role toward the advancement of effective FASD intervention, coordination and accommodation through
 - ▶ Training
 - ▶ Policies
 - ▶ Protocols and programs that coordinate services to bridge the life skills and learning deficits implied by the diagnosis and that recognize the need for lifelong interdependent living supports
 - ▶ Prevention

Consensus Statement on FASD and Legal Issues

Edmonton Alberta, September 2013

Format of event

The primary aim of the consensus development conference was to:

- ▶ Answer a specific set of questions pertaining to FASD-related issues in policy and practice legal issues
- ▶ Assist judges, courts, and policymakers by suggesting actions for improvement based on the findings from the conference.
- ▶ Assist policymakers with evidence of effective means of addressing the needs of individuals with FASD who are involved in the legal system
- ▶ Increase public awareness of legal issues associated with FASD
- ▶ Contribute to prevention of FASD

From Institute of Health Economics

Highlights: findings & jury recommendations

- ▶ Keep people with FASD out of the criminal justice system as much as possible
- ▶ Provide more-stable placements and enhanced transition planning for children with FASD placed in care, as well as FASD-specific training for everyone in the child protection system
- ▶ Mandate training for judges, lawyers, and others in the system to recognize FASD
- ▶ Provide a full medical examination of every child taken into care or into a correctional facility, screening for FASD

Highlights: findings & jury recommendations con

- ▶ Provide access to rapid FASD assessment and diagnosis at critical points in the justice process, e.g. sentencing
- ▶ Adjustments to criminal laws for people with (neurodevelopmental) disabilities including FASD including:
 - ▶ protections for adults with mental disabilities similar to some existing protections for youth in the Youth Criminal Justice Act
 - ▶ increased emphasis on habilitation as a goal of sentencing
 - ▶ recognizing mental disability as a factor in the degree of responsibility of an accused
 - ▶ and more flexibility in sentencing people with mental disabilities

Summary

- ▶ The Consensus Statement and our survey identify common concerns across Canada in terms of how the rights and needs of this disabled and vulnerable population are being addressed including
 - ▶ Training
 - ▶ Screening tools
 - ▶ Reviews of effective/evidence-based practice
 - ▶ Change in policy
 - ▶ Development of FASD-informed programs
 - ▶ Leadership engagement

Follow-up

- ▶ Phase two of our summary (Fall 2014) will include feedback specific to survey responses on program innovation, research, pilot projects, evaluation and training.
- ▶ Working to circulate survey to victims' services and youth and adult custody facilities to ensure their opportunity to participate
 - ▶ This data will be aggregated to strengthen our knowledge of the emerging practice and priorities associated with FASD

Next Steps

- ▶ Engaging community networks and key stakeholders in discussions to improve the systemic response to individuals living with FASD who come in contact with the legal system
 - ▶ Contact info@fasdontario.ca to learn more
- ▶ For a hard copy of the FASD Justice Survey Report email mailing details to info@fasdontario.ca
- ▶ For an electronic copy of the Report or for additional information on FASD ONE visit www.fasdontario.ca

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Questions and Comments

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Acknowledgements

- ▶ The Southern Network of Specialized Care for providing resources to assist in the survey design
- ▶ The Provincial Human Services and Justice Coordinating Committees for dissemination of the survey
- ▶ All survey respondents for sharing information and insights related to FASD
- ▶ FASD Ontario Network of Expertise colleagues

We thank the Public Health Agency of Canada for contributions and acknowledge the opinions expressed in this presentation are those of the authors and do not necessarily reflect the official views of the Public Health Agency of Canada.

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Resources

- ▶ www.fasdjustice.ca
- ▶ www.fasdontario.ca
- ▶ www.peaksupport.ca justice initiative
- ▶ www.davidboulding.com
- ▶ www.canfasd.ca
- ▶ www.asantecentre.org
- ▶ www.community-networks.ca

To view the Consensus Statement on Legal Issues and FASD visit
<http://www.ihe.ca>

Presenters' contact information, and for
permission to use this presentation content

Sheila Burns sheila.burns@rogers.com

Lynda Legge llegge@wgh.on.ca