Human Services and Justice Coordinating Committee Ontario

Fetal Alcohol Spectrum Disorder & Justice Related Services

Wednesday, November 26, 2014

Sandie Leith, Provincial HSJCC Co-Chair
Cheryl Neave, Chair FASD ONE
Sheila Burns, FASD ONE Justice Action Group

@HSJCC

HSJCC Webinar

- To ask a question, please type your question in the chat box.
- Power-point presentation will be emailed to you following the webinar.
- Please complete the brief evaluation survey following the webinar.

Overview of Webinar

1. About the HSJCC
2. FASD ONE Presentation
3. Open Question & Answer Period

Presenters

- **Sandie Leith,** Director of Clinical Services, Canadian Mental Health Association, Sault Ste. Marie Branch and Co-Chair of the Provincial HSJCC

- **Cheryl Neave,** Chair, FASD Ontario Network of Expertise

- **Sheila Burns,** FASD Ontario Network of Expertise Justice Action Group

HSJCC Network

- Responding to a recognized need in the province to coordinate resources and services, and plan more effectively for people who are in conflict with the law

- HSJCCs established based on the *Provincial Strategy to Coordinate Human Services and Criminal Justice Systems in Ontario* (1997)

- Priority consideration is for people with a serious mental illness, developmental disability, acquired brain injury, drug and alcohol addiction, and/or fetal alcohol spectrum disorder

HSJCC Network

HSJCC Network is comprised of

- 43 Local HSJCCs
- 14 Regional HSJCCs
- Provincial HSJCC

- Each HSJCC is a voluntary collaboration between health and social service organizations, community mental health and addictions organizations and partners from the justice sector including crown attorneys, judges, police services and correctional service providers
- Funded by the Ministry of Health and Long-Term Care

Provincial HSJCC

Provincial HSJCC consists of

- Regional HSJCC Chairs representing their Regions

- Ex-officio members from important stakeholder groups such as Correctional Service of Canada, Ontario Provincial Police and Ontario Association of Chiefs of Police, Legal Aid Ontario, and Community Networks of Specialized Care

- Ex-officio representatives from 5 Provincial Ministries:
  - Attorney General
  - Children and Youth Services
  - Community and Social Services
  - Community Safety and Correctional Services
  - Health and Long-Term Care

Contact Information

For more information about the Provincial HSJCC and to join the mailing list, visit:
www.hsjcc.on.ca

FASD: A Call to Action in Ontario
FASD and the justice system

P-HSJCC webinar learning series: November 2014

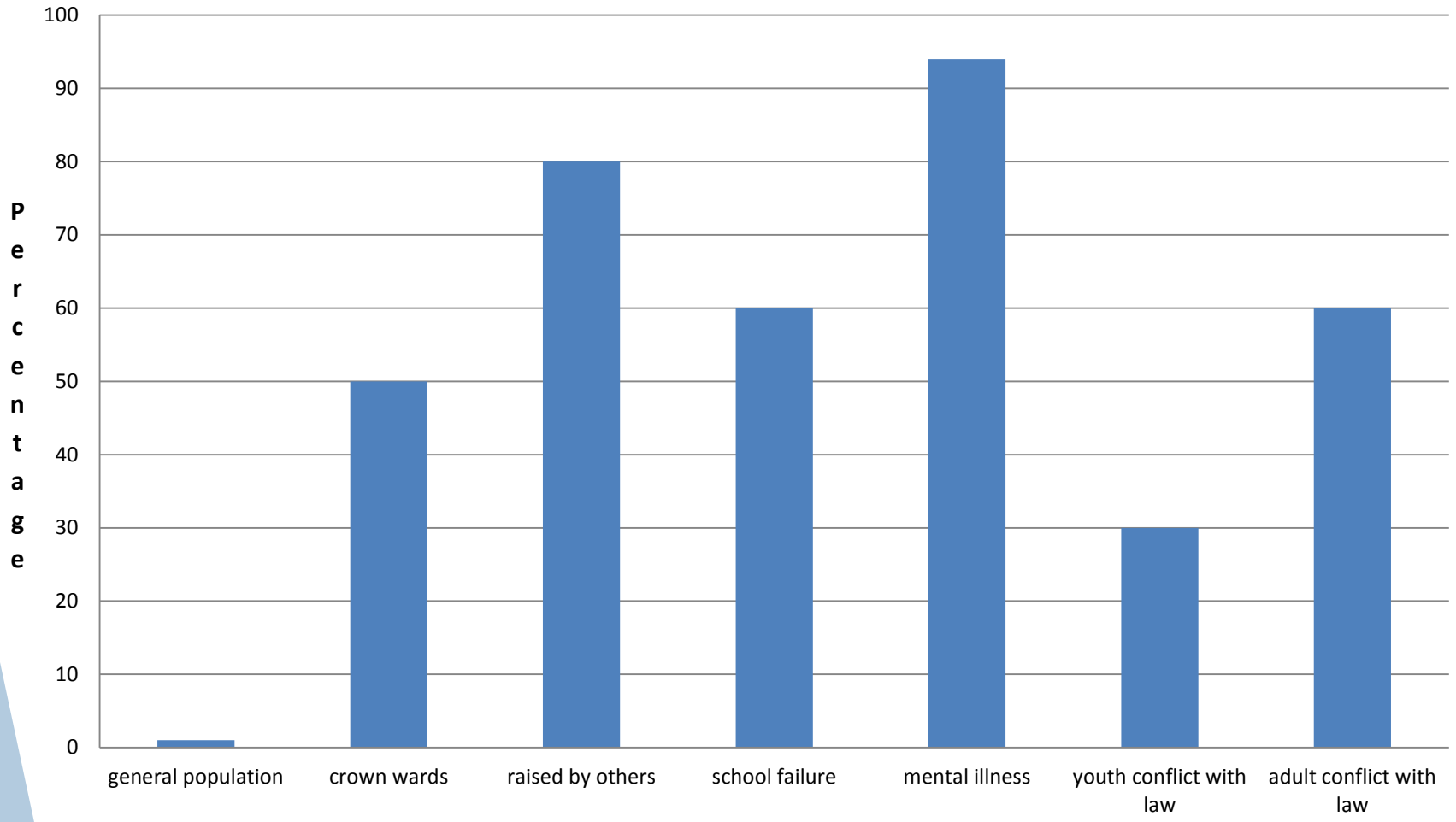
Presenters: Cheryl Neave, Chair FASD ONE

Sheila Burns, FASD ONE Justice Action Group

Learning objectives

- A Call to Action
- Quick primer on FASD
- FASD and Justice
- Relevance of the mandate of HSJCC
- Q&A

FASD Incidence & Prevalence Rates



Adverse outcomes for children, youth and adults with FASD

Individuals with FASD are heavy users of the system.

Adverse outcomes reflect a poor fit for services vs needs rather than innate disorder traits.

These poor outcomes contribute to stigma associated with the disability.

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

FASD | ONE

Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

- FASD ONE was founded in 2005 (formerly FASD Stakeholders for Ontario) with funding from Public Health Agency of Canada
- Aim is to improve the response to FASD in Ontario towards the
  - Prevention of FASD
  - Better outcomes for individuals living with the disability by advancing the development and dissemination of best practices
- It's a volunteer collaborative of
    - caregivers
    - practitioners
    - specialists

The building of “A Call to Action”

- Informed by stakeholders from across the province including individuals with FASD, caregivers and a wide spectrum of service providers.
- Reflects the growing understanding that a multi-sector coordinated and collaborative response is required to address the complex issues of FASD prevention and effective intervention.
- Addresses the need for parallel and concurrent action to shift programming parameters, and protocol and policy frameworks to ensure adequate accommodation and interventions for optimal outcomes.
- Highlights action toward FASD
  - Awareness and prevention
  - Assessment and diagnosis
  - Supports and interventions
  - Knowledge transfer
  - Research and evaluation

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Fetal Alcohol Spectrum Disorder
Ontario Network of Expertise

A Call to Action

1. Prevent FASD by providing evidence-based information and accessible, comprehensive services to pregnant women and all women of childbearing age;

2. Ensure timely access to assessment and diagnostic services to children, youth and adults who may be affected by FASD;

3. Support children, youth and adults who are affected with the disability through evidence-based interventions that stabilize home life and maximize potential.

About alcohol, pregnancy

and Fetal Alcohol Spectrum Disorder

Alcohol's biological impact

Alcohol

- Kills cells so there aren't enough of them
- Diverts cells so they aren't where they need to be
- Alters cells so they don't become what they should
- Affects the expression of genes
- ***Because the brain develops throughout gestation (and beyond) it is most vulnerable to alcohol's impact***

Degree of damage depends on

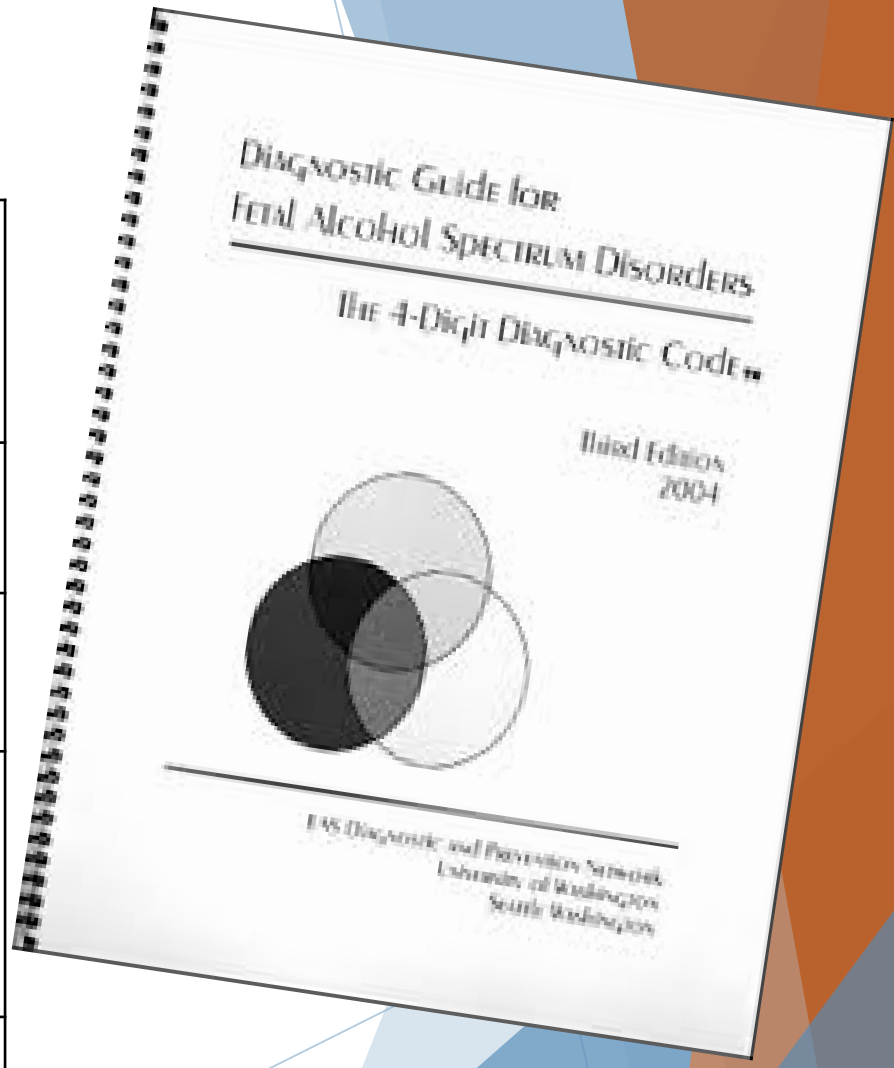
- Timing
- Dose
- Genetics
- Nutrition
- Maternal health

- ***Can result in permanent, organically-based neurodevelopmental disorder: Fetal Alcohol Spectrum Disorder***

A bit about the diagnostic process

Diagnosis	Growth Clinician	Face Clinician	Brain psychologist, OT, speech pathologist	Alcohol (anyone)
Fetal Alcohol Syndrome FAS (1-3:1000 births)	x	x	x	x/o
partial-FAS (pFAS)	some but not all of these		X	x
Alcohol Related Neurodevelopmental Disorder (ARND) (6-8:1000 births)	0	0	x	x
Alcohol Related Birth Defects (ARBD)	organ, joint, limb anomalies			x

X=required for the diagnosis; 0=not required

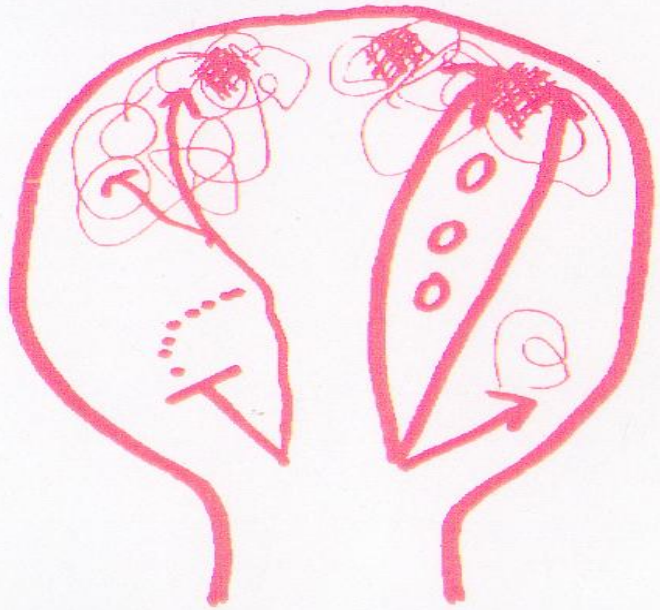


FASD: primary disability

- **Executive function** – age appropriate cognitive dexterity to remember, adjust, accommodate, plan anticipate, revise, modulate actions/emotion/behaviour & problem solve
- **Adaptive function** – age appropriate self-care, hygiene, housing, food, time, $$
- **Sensory** regulation - hypo/hyper to touch, sound, visual
- Social **communication –** interpretation and response to verbal and non-verbal language
  - Expressive language > than comprehension or performance (doing what they say they'll do)
  - May mimic, parrot or embellish ideas or language without comprehension or understanding implications
- **Processing deficits** = following directions, hearing all language content/meaning, retrieval of meaning
- **Memory** and sequencing = what happened when/where (fantasy/reality, filling in the blanks)

Visual Model for Rethinking Behaviours

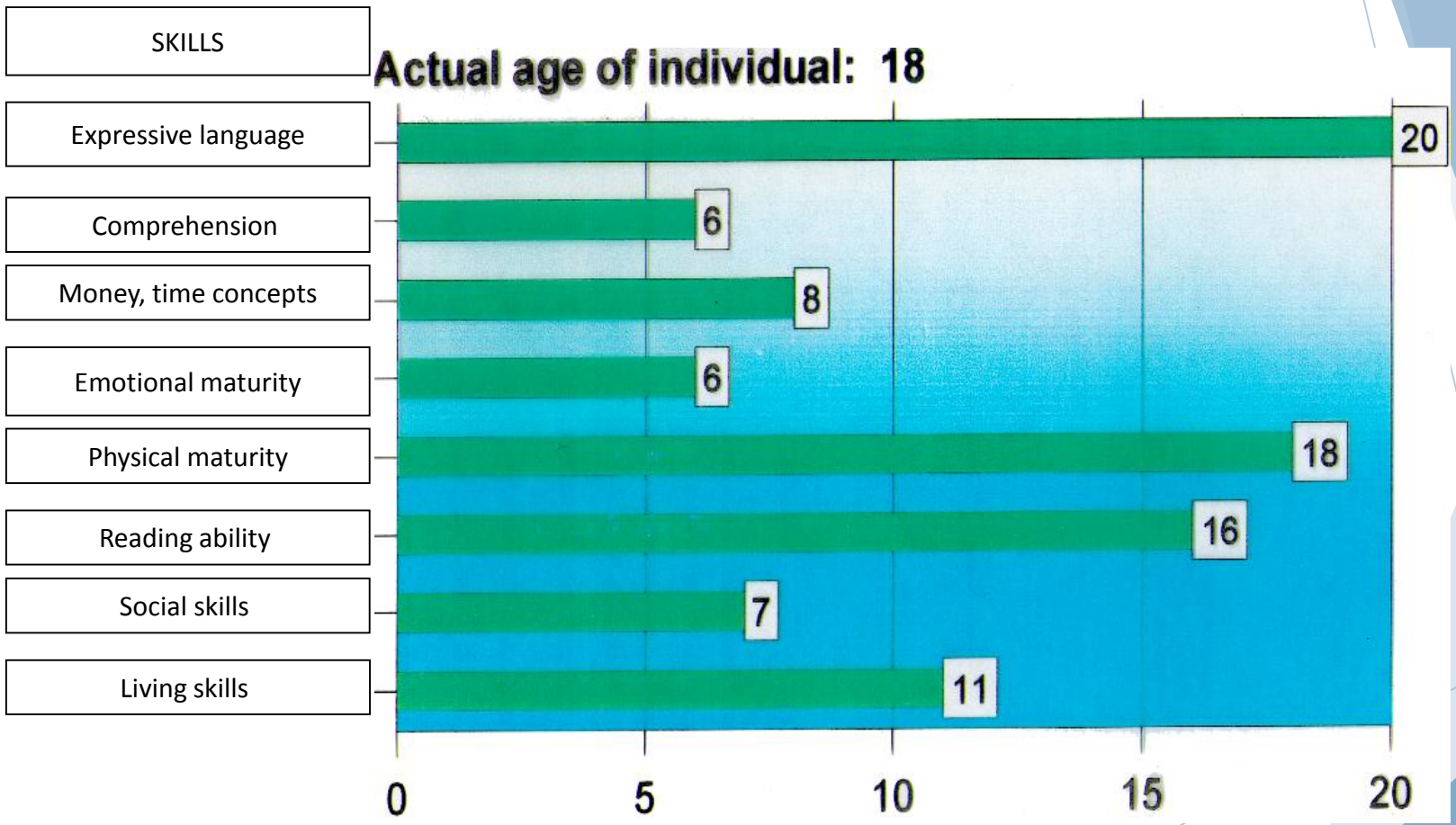
Normal brain development is orderly sequential. Rich neural networks provide opportunities to link, integrate, associate.



FAS/E: Undergrowth, over-growth, gaps and tangles. Fewer physical links for retrieval, integration and other options.

Diane Malbin

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 incarcerate (Popova 2011)
- Adults with FASD are 28x more likely to be incarcerated
- Recidivism rates among individuals is high; the severity of offenses don't typically escalate
  - A repeat of the same offence
  - Breach probation, violate parole, miss court dates (MacPherson, Chudley 2011)

- Offences occur while in custody
  - Manipulation by other inmates
  - Overwhelmed by/unable to manage institutional demands and environment
- While incarcerated
  - They meet bad people and learn bad things
  - Programs aren't designed for complex communication, executive and/or adaptive function deficits
    - assumes they aren't trying or committed
    - they cannot organize themselves to get reclassified, paroled or released

2013-14 initiative FASD ONE Justice Action Group FASD and Justice Survey *The Call to Action through the Justice Lens*

11 question survey disseminated through HSJCC 2013 - 10% response

- 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 FASD activities within the province
- Identify priority issues

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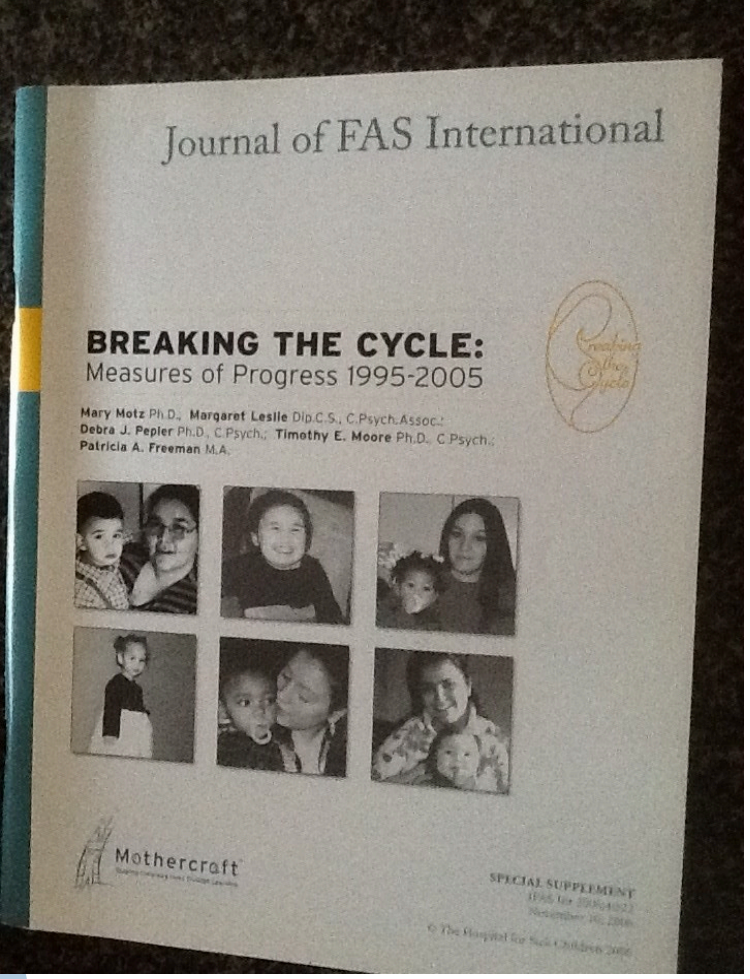


Poor outcomes associated with the disability appear to have contributed to stigma and blame rather than the advancement of effective intervention

- Maternal death of women who have had a child with FASD (from accident, suicide, violence and disease) is 45x greater by age 50 Li Q, et al 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
- Programs like BTC offer alternatives for parenting support and treatment of women w/without FASD.

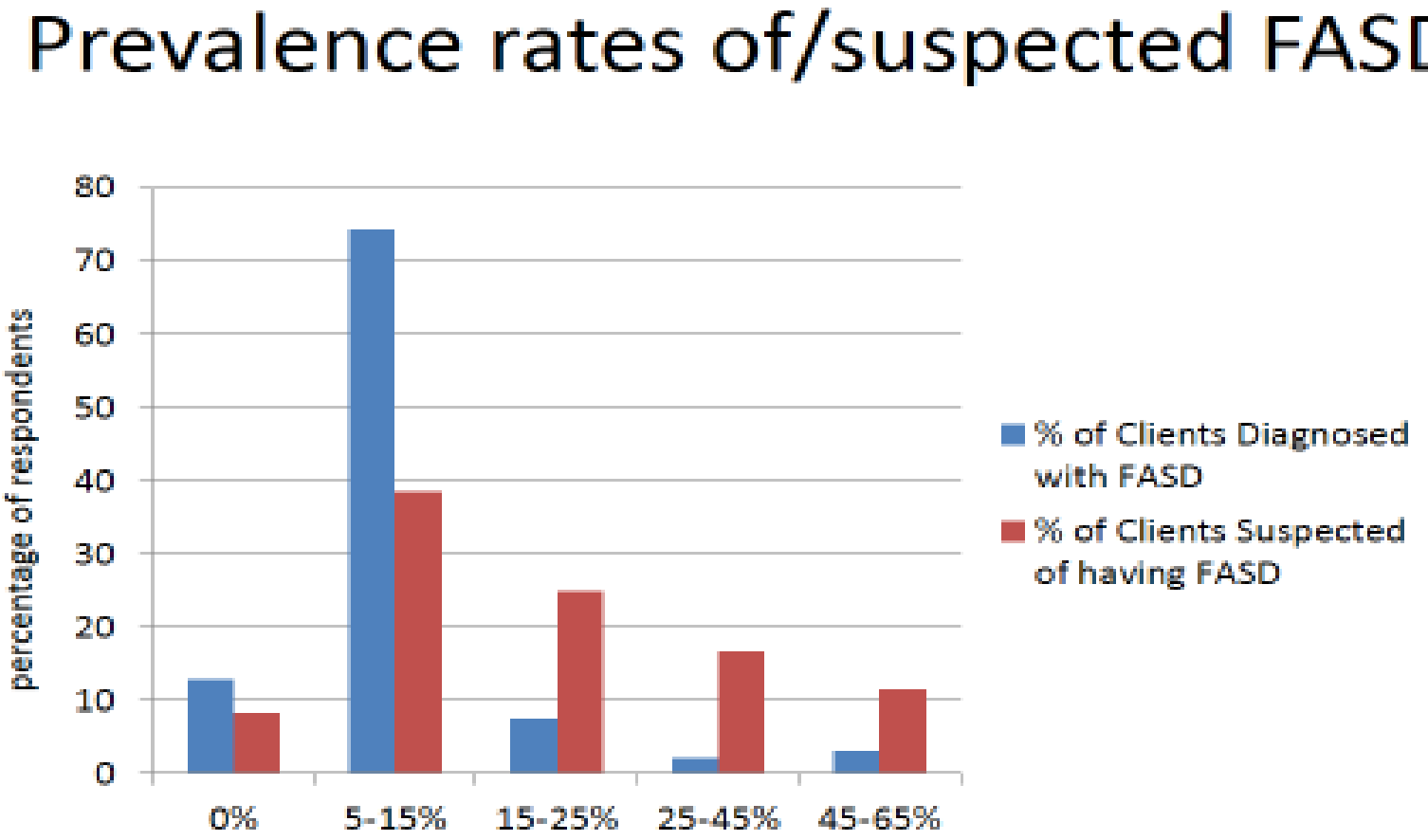
A Call to Action: Justice Lens

AWARENESS and PREVENTION

Ontarians will receive accurate information regarding the risks of alcohol use during pregnancy, together with timely access to the services they require to abstain from or limit alcohol use in pregnancy.

- FASD is preventable but messages are women-focused, limited and often missing the importance of planning pregnancies
- The needs of women with substance use issues are under served and/or misunderstood
- Women with FASD are under served and/or misunderstood

FASD and Justice Survey Findings



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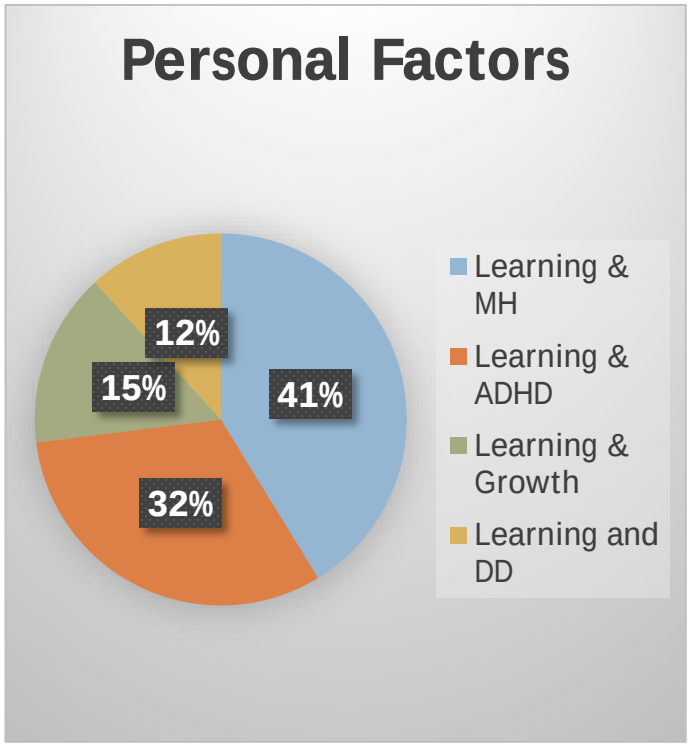
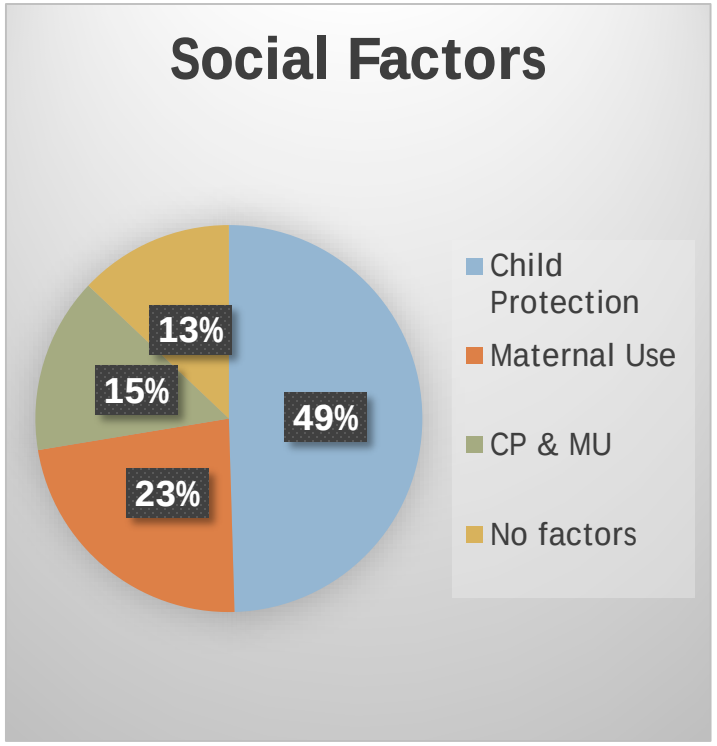
Risk indicators for FASD

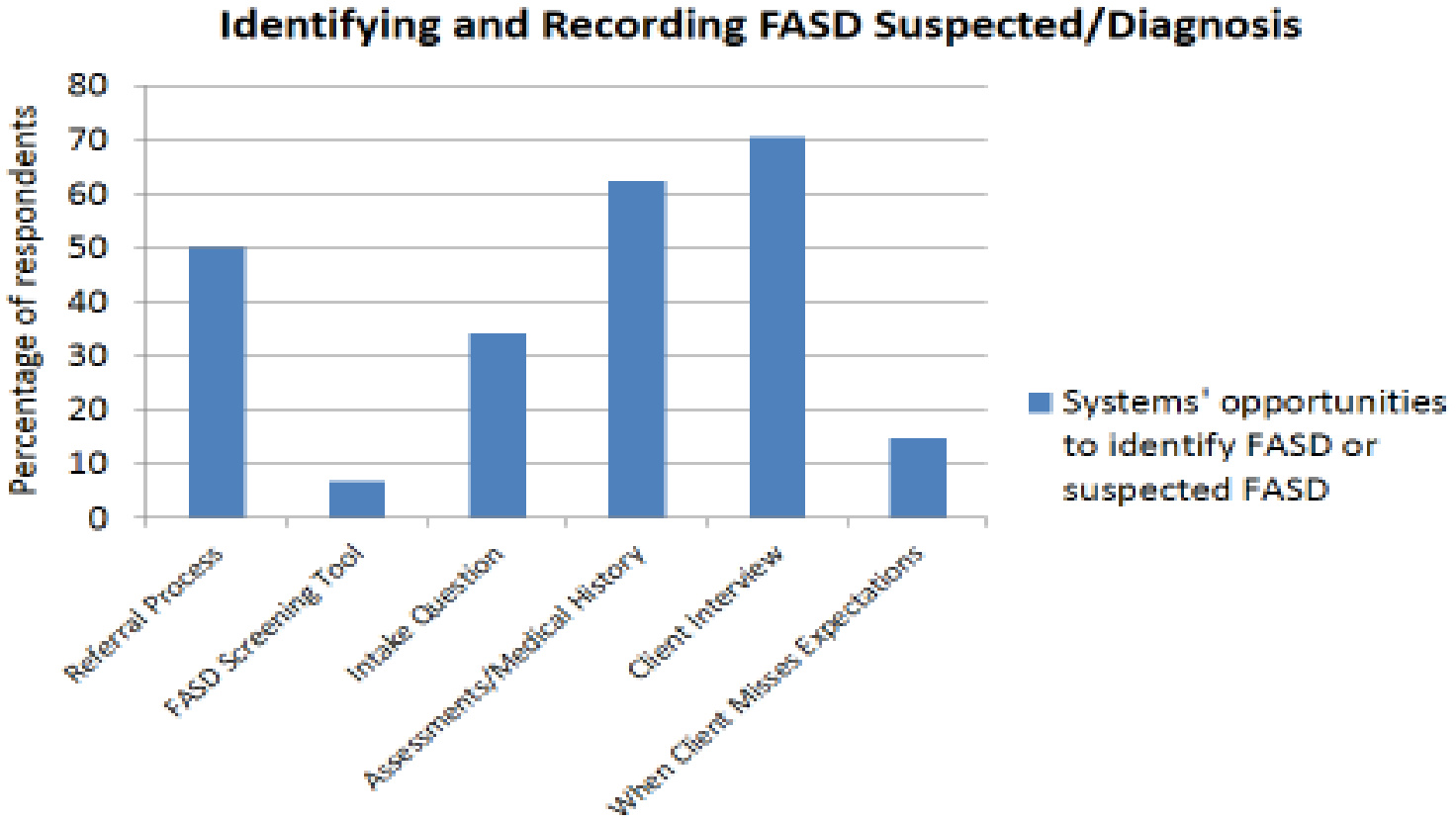
Asante Centre FASD Screening and Referral Probation Officer Dr. J. Conry





Research directs screening to common factors associated with longer-term poor outcomes: maternal substance use, child protection incl foster/adoption, and school-based issues: mental health, ADHD, developmental delays

FASD and Justice Survey Findings



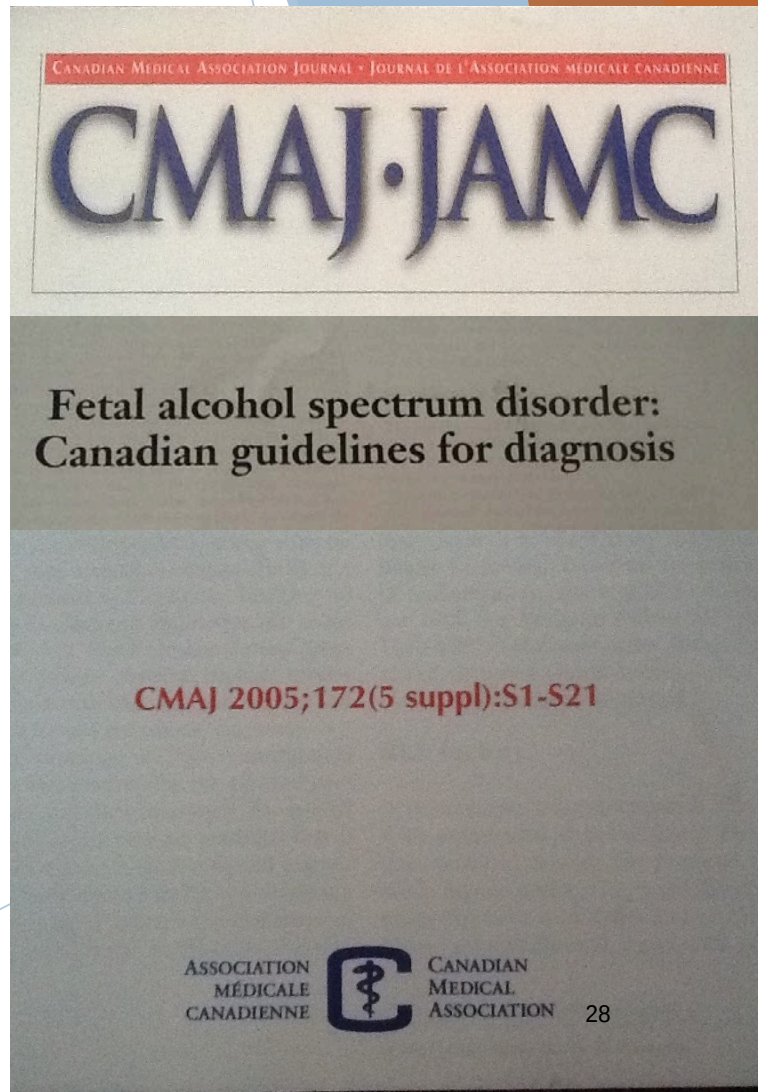
Survey respondents identified many opportunities to track or record existing FASD diagnosis.
Relying on self-report or not asking (30% of respondents) misses diagnosed clients
- self reporting requires clients to know/the importance of their diagnosis
- miss opportunities to structure service effectively including better release plans, plans of care

A Call to Action: Justice Lens
ASSESSMENT and DIAGNOSIS

Individuals with prenatal alcohol exposure, regardless of their age, will have access to timely assessment and diagnostic services and a coordinated, informed response that is appropriate, effective, and linguistically and culturally sensitive.

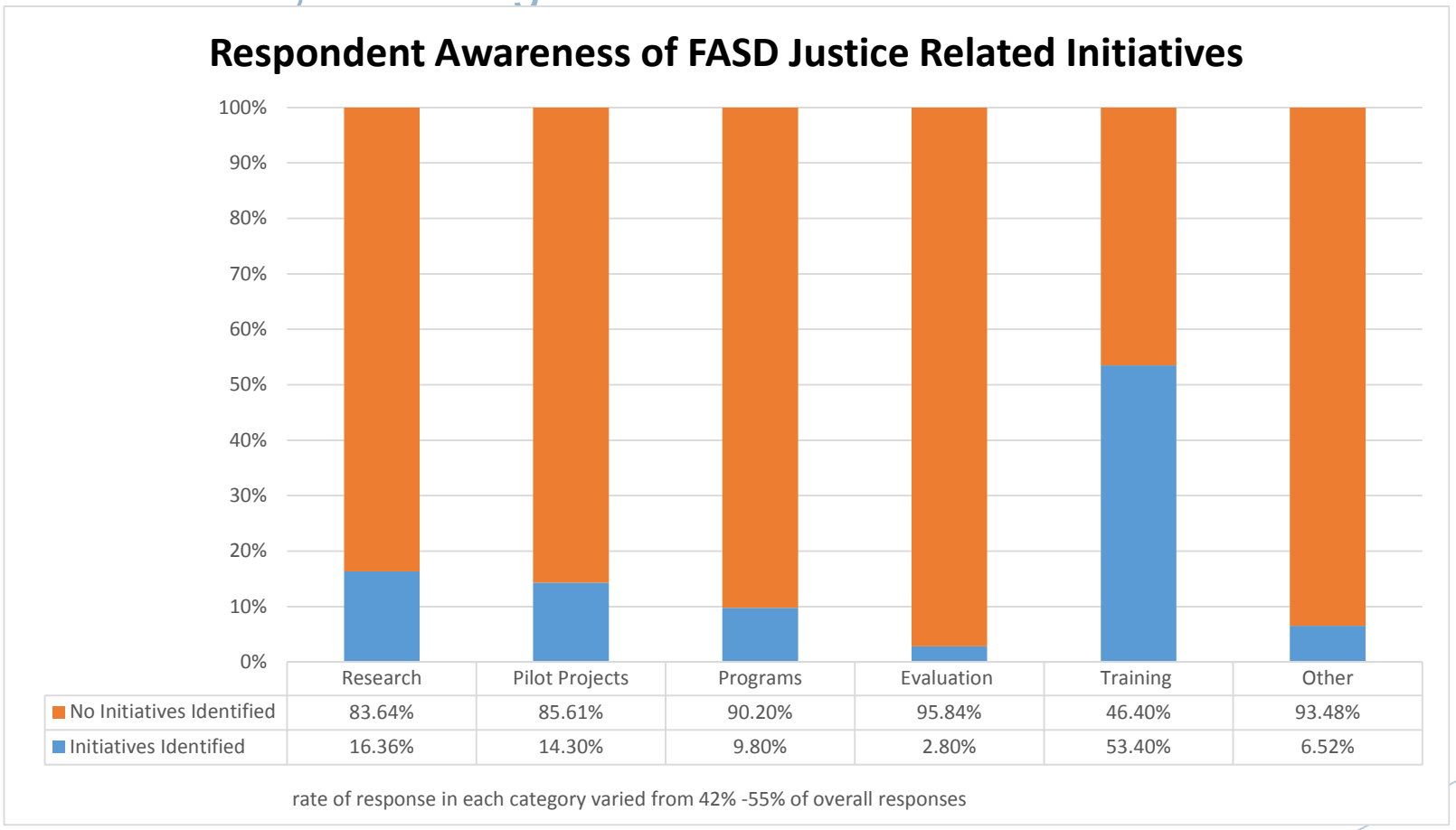
Survey findings:

- Suspicion of the diagnosis need to be acted on. There are opportunities for assessments at multiple points in the health, education and justice systems.
- Pathways for diagnosis can use existing service system streams
- Protocols are needed to track **existing diagnosis** that are not solely reliant on the individuals themselves



FASD and Justice Survey Findings

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



	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

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FASD and Justice Survey Findings

Identified evaluation, program innovation, research, and training activities in Ontario Highlights coming in a summary report

- 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
- Collaboration with MCYS—YJO and Firefly in 2012-13 hosted 2 Youth Justice FASD clinics in the Kenora Rainy River Districts
- Court diversion to mental health programs
- Research into impact of training and a screening tool
- 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"
- 60 responses related to training with a wide variety of in-services, workshops and conference cited

A Call to Action: Justice Lens
INTERVENTION and SUPPORT

Children, youth, adults and their caregivers will have ready access to culturally sensitive resources and services designed to address and accommodate their individual lifelong needs.

- Considerations of issues of
  - Moral blameworthiness, proportionality/crime, breaches etc
  - The rights of victims, accused and offenders with FASD (and other neurodevelopmental disorders (ND)) need to be respected
- The needs of victims, accused and offenders with FASD (and other ND) and fit with speciality models
  - Mental health courts
  - Diversion programs
  - Gladue reports/courts
- This will keep our communities, our vulnerable, and offenders safer and ensure efforts results in the best outcomes possible.

FASD and Justice Survey Findings

Priorities

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

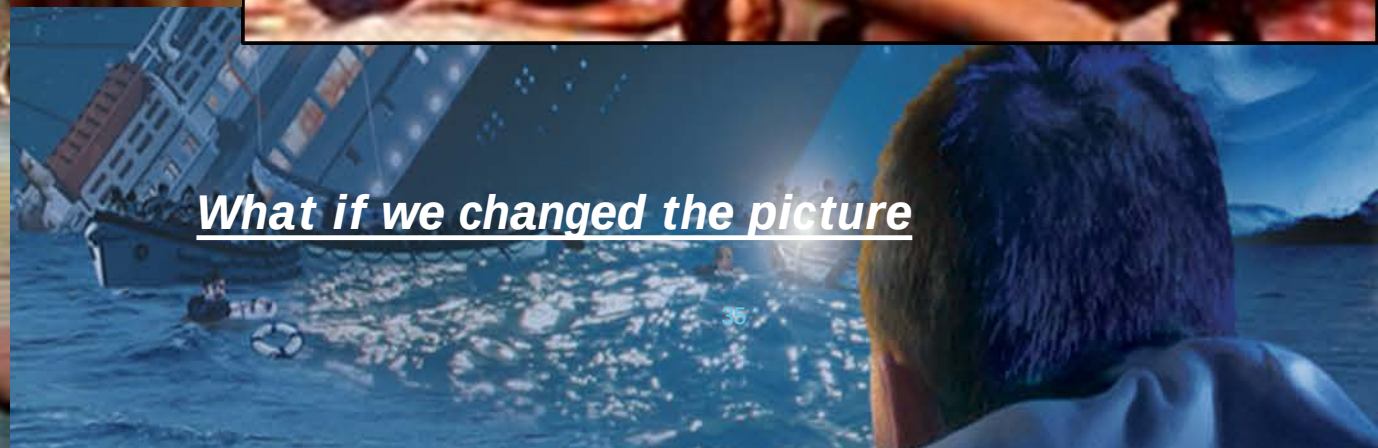
A Call to Action: Justice Lens
KNOWLEDGE TRANSFER and CAPACITY ENHANCEMENT

FASD education and training will be made readily available to both current and future families/caregivers and service providers in all service sectors.

- Understanding the origins of challenges ensures the responses and programs align more closely to client needs. Sharing what we know/what is working is vital.
- Learning about FASD is not hard; on-going *coaching* is needed to solidify the transition from theory to practice
- Information/knowledge is not enough. Systems' change is required
  - Flexibility (and permission) is needed to change programming components to address the client "consumer"
  - Policies need to reflect individuals on the spectrum

FASD and Justice Survey Findings
Respondents reported significant concerns

- Perception of vulnerable clients/offenders
- Concern about victimization inside and outside institutions
- The wonderful qualities in clients with FASD
  - Earnest and loyal
  - Creative and artistic
  - Kind and helpful



What if we changed the picture

A Call to Action: Justice Lens
RESEARCH and EVALUATION

Services and resources will be evidence based, effective, culturally appropriate and inclusive of those affected by FASD.

- Evaluation of existing programs has helped highlight what isn't working for those with FASD
  - The status quo can't continue without breaching Charter Rights (of the disabled)
  - We can't afford to keep doing what we know doesn't work
  - Improved outcomes occur when we accommodate the disability and reframe the work and expectations to incorporate client capacity
- Research and evaluation will steer us in the right direction and validate programs

FASD and Justice Survey Findings

Recommendations

- Track FASD diagnosis or suspected cases of FASD
- Use screening tools and assessment results – including section 34 assessments to facilitate a diagnosis
- Identify referral and diagnostic pathways
- Develop:
  - Plan of care protocols for clients with/suspected FASD
  - In the absence of prenatal history, develop plan of care protocols for clients considering neurodevelopmental disorder – cause unknown
  - 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

FASD is a neurodevelopmental disability. It feels complex because of uneven skill sets that distract and confuse: expression and comprehension, memory and IQ.

- Models already exist that will improve outcomes
- Government leadership has begun to move us toward more effective FASD intervention, coordination and accommodation (2014)

Local Call to Action

- Put FASD on the agenda of your HSJCC
  - Strike working groups
  - Identify priorities
  - Engage stakeholder partners to address gaps or systemic barriers
  - Address obstacles in policy and programs
- Changing outcomes for those with FASD happens when we change their environment
  - FASD ONE justice action group members may be available to facilitate discussion and support your planning needs

Q&A

Resources

- www.asantecentre.org
- www.fasdjustice.ca
- www.fasdontario.ca
- www.canfasd.ca
- www.community-networks.ca
- www.peaksupport.ipage.com/fasd-justice-initiative
- www.connections

To view the 2013 FASD Justice Consensus Statement visit

- http://www.ihe.ca

Presenters' contact information

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