

Life Stages Transition to Interdependence- Adulthood©

**IHE Consensus Development Conference
Fetal Alcohol Spectrum Disorder: Across the
Lifespan**

Edmonton, Alberta

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FASD Life's Journey Inc.**

The Transition to Interdependence

- ✿ We will examine the risks and protective factors related to the life stage transition to adulthood
- ✿ Coming of age in Canada
- ✿ Current Social trends
- ✿ Terminology & expectations
- ✿ Transition to interdependence with a physical disability
- ✿ Recommendations

Empirical Research

- ✱ Research regarding this life stage transition to adulthood for those affected by FASD is at a neophyte stage
- ✱ Trajectories across the lifespan of those affected by FASD have not yet been identified by research.

Adolescent Markers

- ★ Onset of adolescence is recognized by chronological age – 12 or 13 years of age or physical and social changes such as pubertal development age 11-13 yrs.

Age of Majority

- ✿ The age of majority in Canada is the age at which a person is considered by law to be an adult.
- ✿ The age of majority in Canada is determined by each province and territory in Canada ranging from 18-19 years of age.

Coming of Age in Canada

- ❑ Entrenched in Canadian societal expectations
- ❑ Period of adolescence is recognized as a unique developmental stage in Canada
- ❑ Canadian cultural norm

Coming of Age

- ✿ All citizens (regardless of disability) can enter into contractual obligations – bank loans, mortgages, cell phone contracts, draft a will, etc.
- ✿ Live independently
- ✿ Acquire own finances and be independent financially
- ✿ Choose a partner
- ✿ Engage in family planning
- ✿ Manage their health
- ✿ Acquire housing and sustenance
- ✿ Fulfill responsibilities of dependents

End of Adolescence

Markers of the end of adolescence are less well defined and may include a school to work transition, the attainment of legal adult status (age 18 years) or specific characteristics such as accepting responsibility for ones own actions (Cheah & Nelson 2004)

The Federal government defines youth up to age 29

Adulthood



**Most of us are
biologically and
psychologically equipped
to learn the knowledge
and skills required to
function as adults.**

Current Social Trends

- ✱ The transition from adolescence to adulthood has changed considerably over the past 20 years.
- ✱ Now takes place over a longer period of time. It is now the norm for young people to depend on their parents well into their 20's for emotional, practical, and financial support — as 2006 census data showing that close to half of all BC young adults (age 20-29) live with their families attest.
- ✱ This trend has come about partly in response to a changing economic reality that places high value on education and life long learning. Paralleling and reinforcing these normative trends, new conceptual frameworks on the transition to adulthood **now include an additional life stage known as “emerging adulthood”**.

Supporting Young Persons Transition From Care - Rutman et al 2001

Coming of Age & FASD

- ✱ A person younger than the chronological age of majority is considered a "minor child."
- ✱ With FASD age 18 is going on 10 developmentally and 18 chronologically
- ✱ Typically affected by an array of co-morbidities and contextual factors

Emergence of Adulthood for Those Impacted by FASD

- ✱ Developmental trajectories of FASD have not yet been determined.
- ✱ When does adulthood emerge for those impacted by FASD?
- ✱ They are 18 going on 10 developmentally.

Source: Defining Success-Alberta Ministry of Education

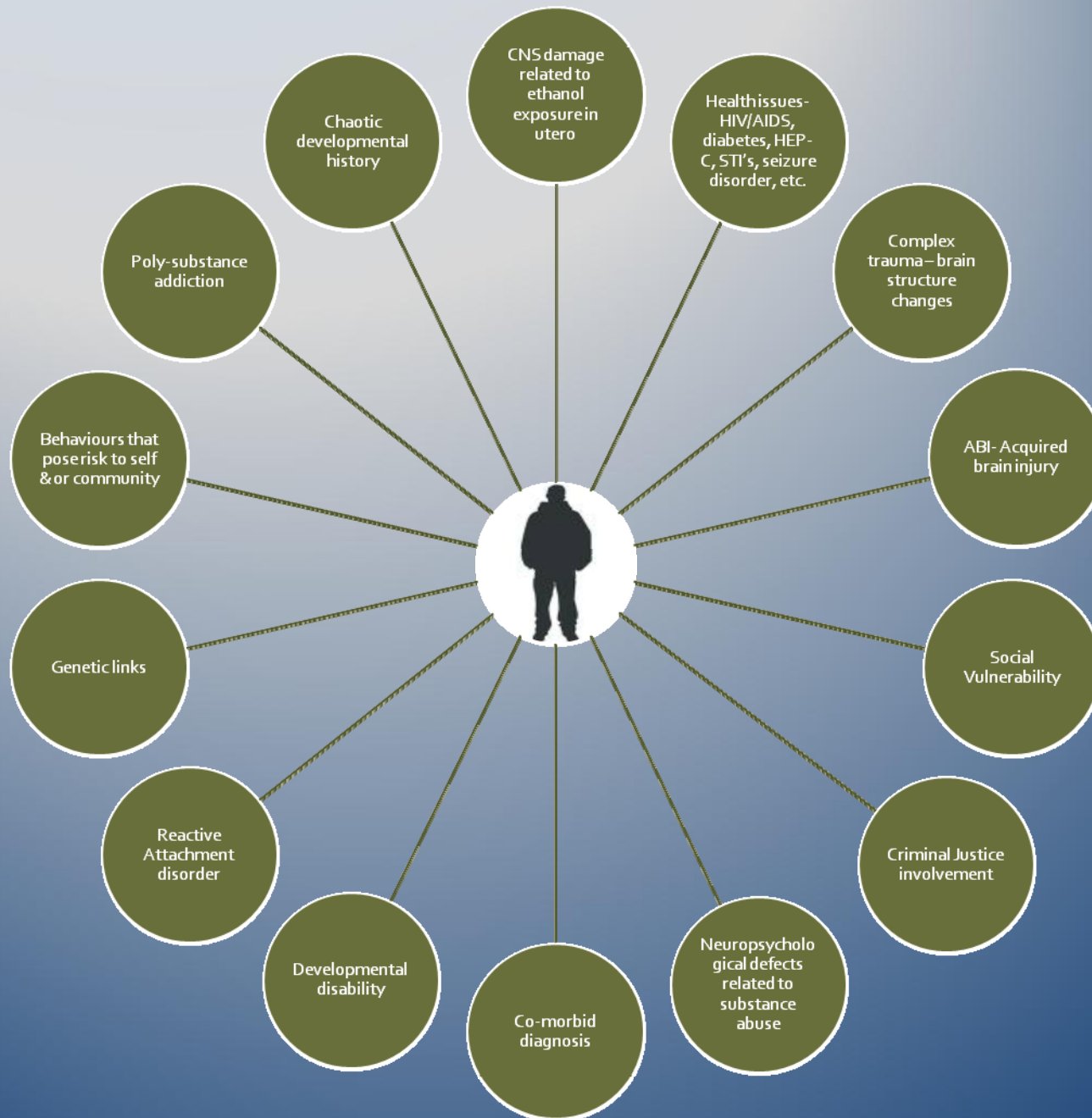
Transition Occurs Within the Context of a Permanent Brain Based Physical Disability

Cognitive processing that is required for:

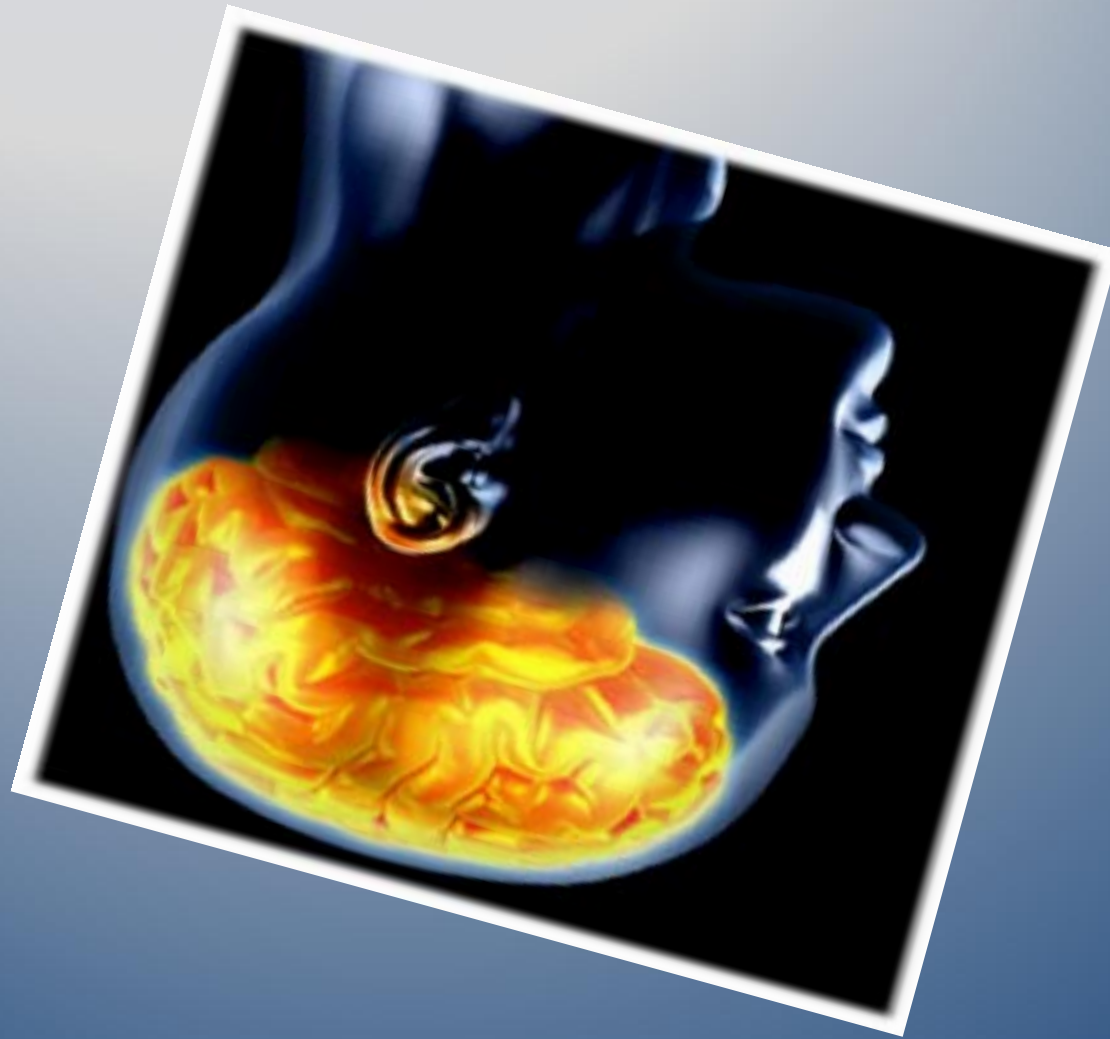
- ❖ learning
- ❖ generalization
- ❖ communication
- ❖ effective decision making
- ❖ sound judgment

Complex Issues

- ★ Many are unlikely to make sufficient change to own internal resources to result in meaningful, observable change
- ★ Autonomic (involuntary) nervous system arousal when dealing with potent content issues
- ★ Neuropsychiatric abnormalities (ADHD)
- ★ Egosyntonic with respect to substance use
- ★ Reactivity, impulsivity and attention problems
- ★ Low stress tolerance
- ★ High risk behaviours that pose risk to self or community



Where to now with this brain?



Surprise After Surprise – Welcome to Adulthood! – Cheryl's Story

They experience significant life experiences for which they are not prepared

- Pregnancy – can't connect the act of unprotected sex with the outcome of pregnancy
- Parenting – "I don't want my kid to grow up in care."
- Victimization – "Why did they do that to me?"
- Exploitation – "I thought he was my friend."
- Loss of job – "I got fired because I was late again – what's with that?"
- Homelessness – "I forgot to pay the rent first!"
- Poverty
- Increased substance abuse
- Without income – "I didn't know that if I didn't return that paper that I would be cut off welfare."
- Illness/injury – "I didn't know I would break my legs when I jumped out the fifth floor window"
- Inability to maintain relationships of importance due to social illiteracy (leaves them vulnerable to street life and gangs)
- Don't know how to change their circumstance – "I don't know what to do."

In Care the Majority of Their Life

- ✿ ...many children with FASD come into out-of-home care, often on a permanent basis (Jones, 1999).
- ✿ Finally both the legal and placement histories confirm that permanent wards with FASD are spending on average close **to three quarters of their lives in the care of an agency**, about 15 % more than any other children who are permanent wards.

Children with FASD Involved with the Manitoba Child Welfare System Final Report - March 2007

When Parenthood of the State Ends...

- ✱ There is a completely different service delivery structure for adults
- ✱ CFS's priority is protection not parenthood
- ✱ Their social support networks are severed when they exit care
- ✱ The permanent wards are less likely to have connections to family & home community
- ✱ Have a history of significant trauma, abuse and neglect including the sometimes neglectful parenting of the government care system (Raychaba 1988, Courtney et al 1988)
- ✱ They became parents at a young age (Courtney et al 2005; Schibler & Mac Ewan-Morris, Tweedle 2005)
- ✱ Youth in care are displaced at a much younger age than those not in care – Rutman et al 2001
- ✱ They are expected to do more sooner, and within the context of a permanent brain based disability that is often invisible
- ✱ They have few material resources
- ✱ They live in poverty and are likely on income assistance
- ✱ Some are transitioned back to home communities (where jurisdictional issues impact availability of services) from placements in other provinces or communities displacing them further

The Magic Wand Discriminates Against FASD...

- ✱ Their vulnerability doesn't diminish after age 18 – they are highly vulnerable to various forms of exploitation and are harmed at significant rates
- ✱ They are socially isolated/excluded due to social illiteracy
- ✱ They struggle with poverty, homelessness and under employment – Leslie & Tare 2000, Mendes, 2003, OACAS McCreary Centre Soc 2007, Tweedle 2005
- ✱ They are lonely – have no reliable emotional support
- ✱ They are anxious, fearful and feel abandoned – “in care/at home I knew someone would always take care of me”
- ✱ Individuals are at the mercy of their environment functioning at their developmental level
- ✱ They lack practical skills of daily living – shopping, cooking, meal prep, etc.
- ✱ Many have not completed their high school education
- ✱ They have extreme difficulty maintaining safe and affordable housing



**The Transition by Default Destination – The
Black Hole in urban and rural settings near you!**

A black and white photograph of a branch with several leaves, overlaid with text. The leaves are semi-transparent, showing the vein structure. The text is in a white, sans-serif font. The background is solid black.


Risk Factors

Not equipped for
Independence



Absence of Empirical Evidence to Support Anecdotal Knowledge

Lack of empirical evidence to support governments to develop and fund programs for adults



Lifelong Trajectories

- ✱ The effects of FASD are manifested throughout the individual's lifespan (Streissguth, Barr, Bookstein, Sampson, & Olson, 1999; Zevenbergen & Ferraro, 2001)
- ✱ Lifelong trajectories need to occur early in life, not when they are transitioning to interdependence

Deleterious Outcomes

Individuals with FASD often require high levels of medical care, residential services, special education supports, adult vocational services, and other social services throughout their lifetimes. The increased risk for deleterious outcomes in adulthood as a result of FASD (i.e. **unemployment, homelessness, poverty, criminal activity, incarceration, and mental health problems**) all have a social cost in terms of the support services, organizational structures, and associated financial costs that must be provided to respond to this vulnerable population (Lupton, Burd, & Harwood, 2004).

As adults, individuals with FASD are vulnerable to mental health problems, conflict with the law, alcohol and drug issues, and problems with employment (Streissguth, Barr, Koga, & Bookstein, 1996).



Unprepared for Employment

- ❖ Few individuals have learned any specific skills while growing up that are of any use in the workforce
- ❖ Training to be a good worker should begin not at age 14 or 18, but when a child is 4-5 years old.
- ❖ Good work habits are taught by imitation at this age when we can capitalize on the desire of young children to please the people they like.

A.P. Streissguth (1996)

Criminalization in the Absence of a Diagnosis

- Criminalization due to disability has a significant impact on youth who do not have a diagnosis
- Codified principles of sentencing require that courts impose sentences that take into consideration any mitigating circumstances relating to offenders.
- The charter of Rights further requires that accused persons are provided with the equal benefit and protection of the law without discrimination on the basis of disability.
- Decisions made in the absence of evidence about how the accused is impacted by FASD, can result in wrongful convictions and inappropriate dispositions that further criminalize the individual.






Lack of Specialized Services & Supports for Adults

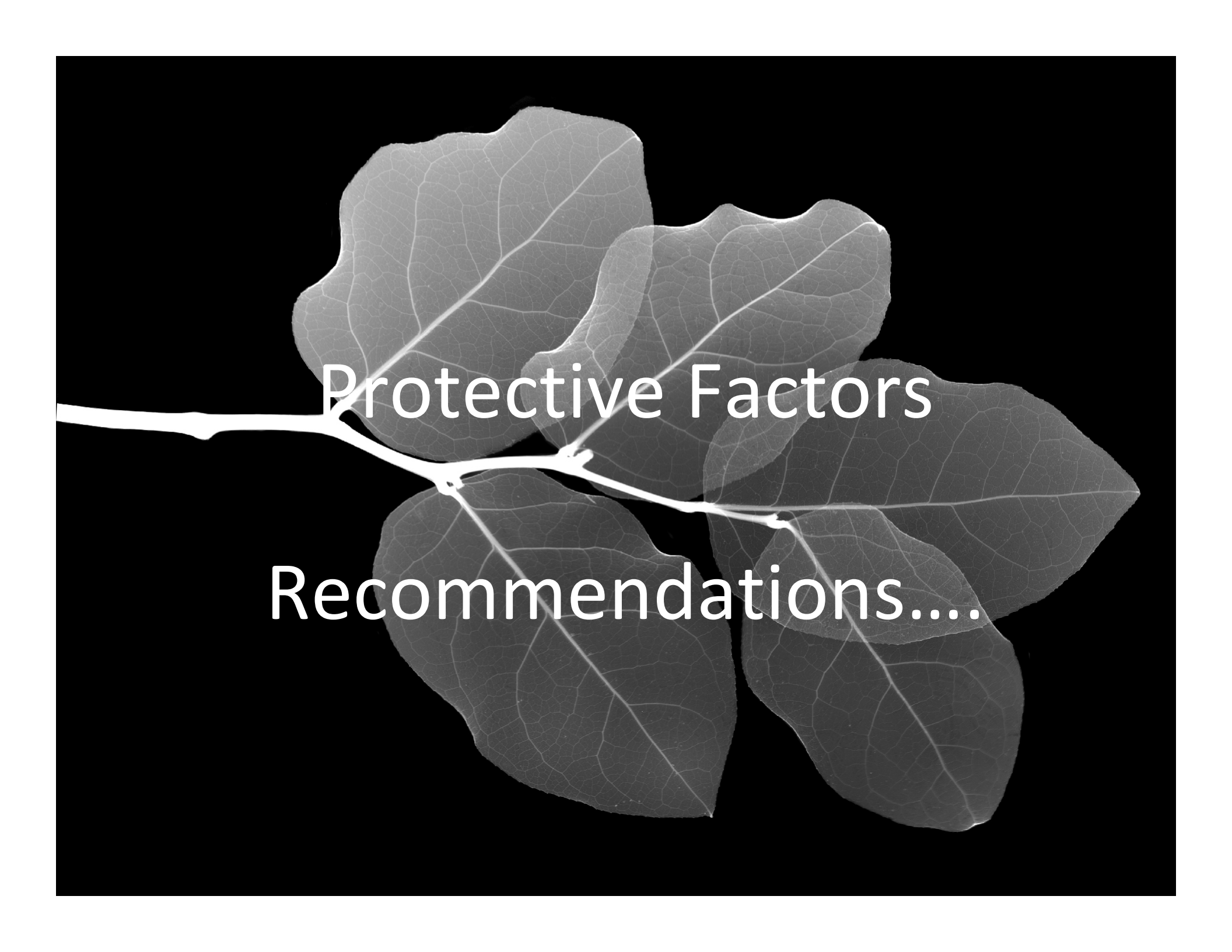
There are few adult services directly related to FASD.

FASD Life's Journey Inc. provides a range of supports for adolescents and adults impacted by FASD.



Invisibility of the Disability



A black and white photograph of a branch with several leaves, overlaid with the text 'Protective Factors' and 'Recommendations....'. The leaves are detailed, showing the veins, and the branch is a simple white line against a black background.

Protective Factors Recommendations....

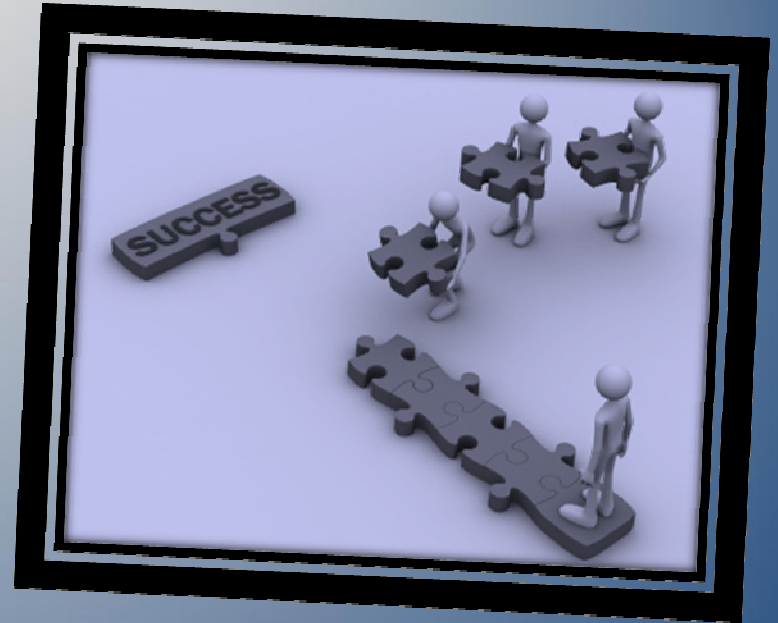
Diagnosis –FASD is an Explanation, Not an Excuse

- Without a diagnosis, individuals continue to mystify systems
- Disability backed up by an official diagnosis, may well be the mediating condition for an improved outcome in people with FAS/FAE.
- An early diagnosis is one of the strongest factors associated with fewer secondary disabilities - Streissguth et al , 1996
- Supports can be informed and tailored by the individual pattern of disability that results from a diagnosis
- Diagnostic clinics need to ask service providers what they need in terms of assessment information so that adult /youth supports can be individually tailored.
- **Need universal availability of FASD diagnostic services for all Canadians regardless of age.**



The Social Safety Net - Spectrum of Interdependent Supports for all Affected by FASD

- ✱ A range of specialized supports and services, including access to a mentor to provide adolescents with assistance and guidance when needed, and appropriate housing, health, addictions and mental health services e.g. Spectrum Connections Program
- ✱ Individualized, flexible, strengths based integrated case management and mentorship for all individuals living with FASD regardless of I.Q. or other qualifying factors



Disability Sensitivity

Neurobehavioural sensitive service system
– ethical principles drive the
work/involvement of collaterals and
systems, however this can significantly
interfere with the FASD specialists ability
to provide supports to youth and adults

Remove intelligence as the focus/purpose
of the brain and shift to functionality and
understanding individual uniqueness

Disability sensitive bail and probation
orders

Harm Reduction

- ✱ Not cognitive behavioural model
- ✱ Recognize and treat all co-morbidities at the same time as they overlay one another
- ✱ Adapt Motivational Interviewing to accommodate for brain differences
- ✱ Accommodate primary disability first – the affected brain domains
- ✱ A neurobehavioural model where “treatment” can be supported through its integration into the day to day life of the individual.
- ✱ Harm reduction includes primary FASD prevention

Housing

Not transitional
housing

Structured housing
that is interdependent,
sustainable and
supportive based on
level of individual need



Employment

- Lifelong apprenticeship, not transitional support
- Specialized job training program to equip them for appropriate and sustained employment.
- Start early in junior high when academic work is reaching a plateau – shift to an apprenticeship model & focus on developing useful job skills that will lead to enhanced image of self, more structured time and success.

Extend Transition to Interdependence (Adulthood)

- ✱ Extending the age at which youth in care can access supports and services, needs to be practiced in jurisdictions where it exists and extended to jurisdictions where it is not currently available. It is also needs to be extended beyond those with permanent orders e.g. Voluntary Placement Agreements, etc.
- ✱ Extending the age at which youth could remain in care and have access to foster care and guardianship services resulted in better outcomes for youth in health, mental health, education and employment domains (Courtney et al, 2005) and resulted in dramatic cost savings at a societal level (Raman et al, 2005).
- ✱ Youth in care need to have a gradual and extended transition process to interdependence based on their individual (sub type) trajectories.

Spectrum of Trajectories to Achieving Interdependence (Adulthood)

- ✿ Recognize that adulthood cannot be framed by typical trajectories
- ✿ Emerging adulthood, according to Arnett (2007), has particular features that distinguish it as a period between adolescence and adulthood. **We need to determine when adulthood emerges for those impacted by FASD?**
- ✿ It should be referred to as interdependence not adulthood

Empirical Exploration

- ✿ Establish life trajectories for those impacted by FASD so that we can understand how to influence optimal outcomes across the lifespan and through life stage transition periods
- ✿ Determine sub patterns of disability to assist in determining how to work with these specific sub groups to further develop life trajectories and best practice
- ✿ In order to inform policy, we need a cost analyses of the benefits of extending care for those impacted by FASD

Lessons From the Elders...

- ✿ Learn from cultures where there is no transition to adulthood – there is lifelong inclusion, support, acceptance and love
- ✿ Learn from our First Nations people

Let's Put an End to Black Holes in our Communities!!!

