

Ontario Senior Caregiver Action Network (OSCAN)

FASD Resource Guide 2022



Supported by



OSCAN is grateful to Health Nexus for sponsoring creation of this support and education group and development of this resource guide.

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Group Leaders: Nancy Lockwood, Elspeth Ross, Barbara Sabourin

Registered Social Worker: Angela Geddes, MSW, RSW, YTT

Group Facilitator: Nancy Lockwood

Introduction:

In 2021, Ottawa FASD advocates Nancy Lockwood, Elspeth Ross, and Barbara Sabourin were brainstorming ways to support older caregivers of adults with FASD. Older caregivers were telling them they felt their needs were not being addressed by regional services: the Ontario FASD Worker program only supports children and youth, and local support groups tend to focus on the challenges experienced by younger families such as navigating the school system.

Nancy and Elspeth applied to Health Nexus for funding to start a provincial group for senior caregivers through the Ministry of Children, Community and Social Services' FASD Family / Caregiver Support Group Project and received a one-year grant. Goals of the group were to explore and share resources in Ontario to address the needs of senior caregivers of adults with FASD in order to reduce caregiver stress; build peer support; and assist with lifetime planning. A Social Worker was hired to co-facilitate monthly group meetings. Topics were chosen based on the most common challenges facing group members. At the end of the grant cycle, the group would create a resource guide with information shared at meetings by members, facilitators and guest speakers.

Positive outcomes of the sessions were increased connections and peer support, feelings of belonging, and relief seeing others experiencing similar situations. On the downside, the needs and challenges far outweighed available resources. Members did share some ideas of programs and strategies that had worked for them, and the facilitators and guest speakers did share helpful resources, but the journey also highlighted the fact that we have a very long way to go in developing resources and support for older caregivers and their adult children. The vast majority of suggestions in this guide were brought forward by the two group facilitators, Angela Geddes and Nancy Lockwood, gathered through their own work in the FASD field.

The members of the Ontario Senior Caregiver Action Network for FASD strongly urge governments, policy makers, agencies and community partners to invest in resources and supports for adults with FASD and their parents / caregivers. Not only will this improve outcomes for adults with FASD, it is a wise investment. Building supports related to employment, housing, caregiver respite, health, mental health, social connection, and lifetime planning for adults with FASD will reduce many of the costs associated with FASD, including those associated with homelessness, justice, welfare and addictions. It will demonstrate that Fetal Alcohol Spectrum Disorder, affecting an estimated 4% of our population, is a health equity issue worthy of attention and investment.

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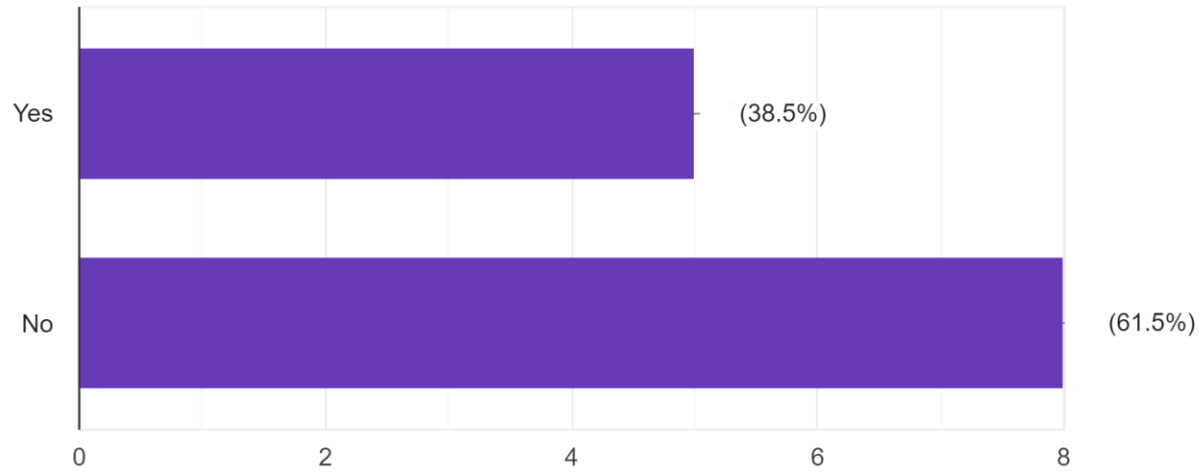
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What is OSCAN

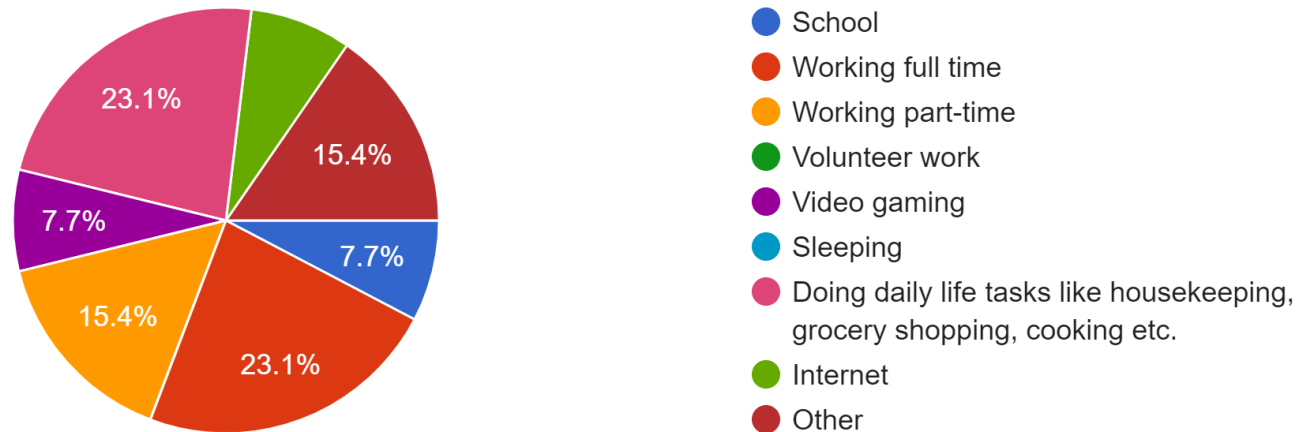
- 20 group members from across Ontario
- Range in age from 55-85
- All have adult children with FASD, ranging in age from 18 to 48
- Felt unique needs weren't adequately addressed by other groups
- Worried to share experiences with younger parents, as might frighten them
- Expressed relief having group geared to their ages and stages



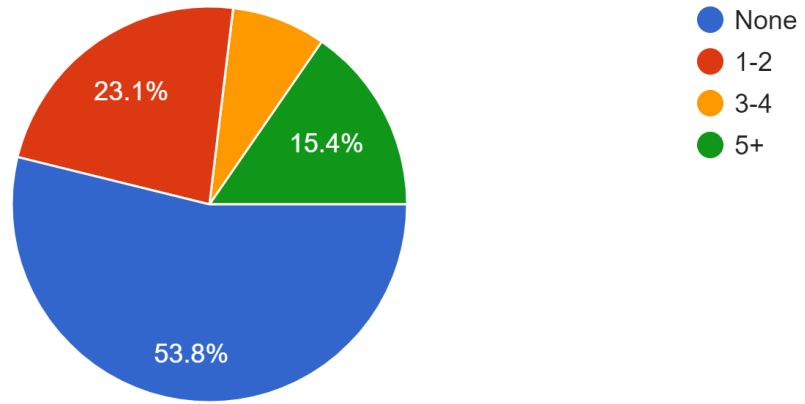
1. Does your adult child live with you?



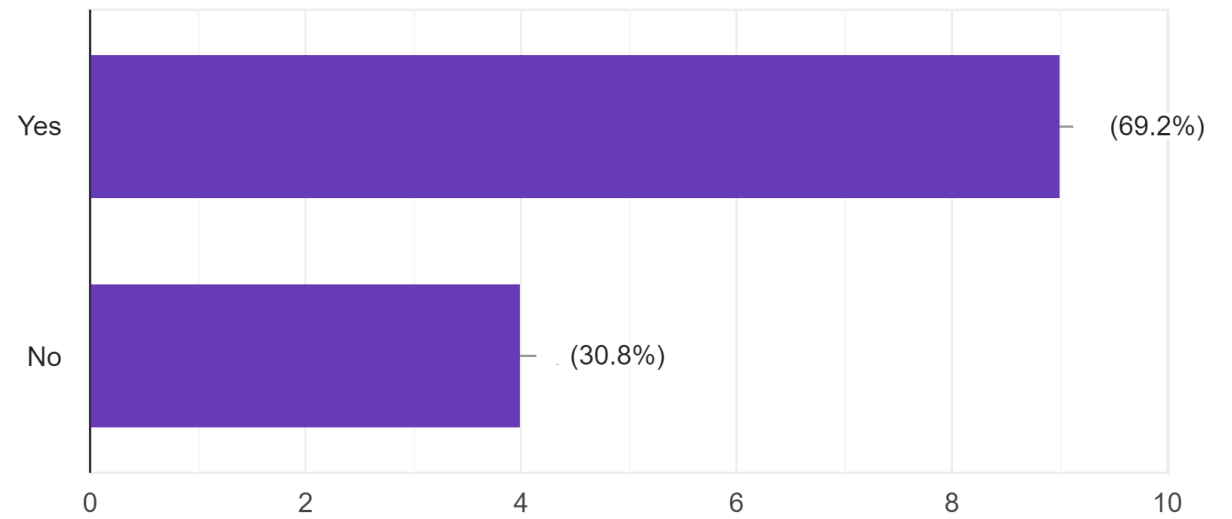
2. How does your loved one with FASD spend most of their days? Please choose one.



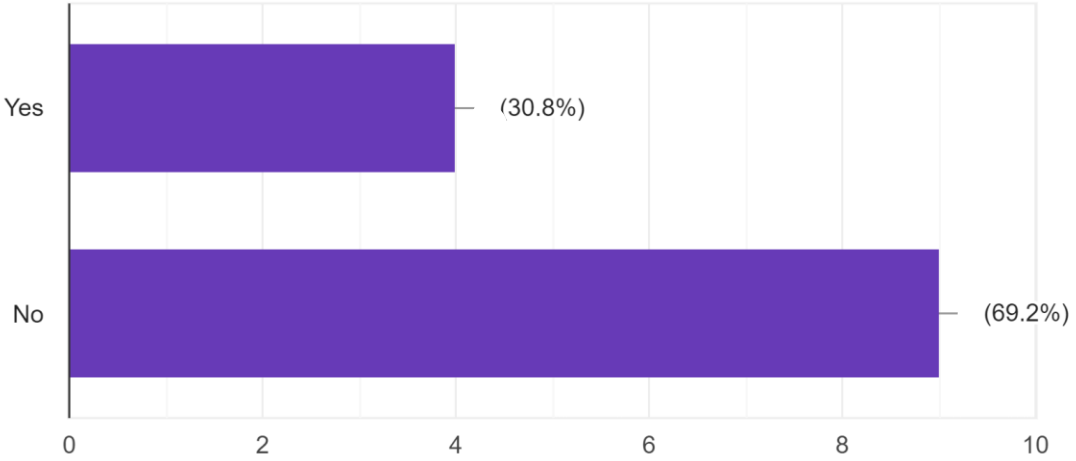
3. How many family, friends or front-line workers provide support to you and/or your adult child on a regular basis?



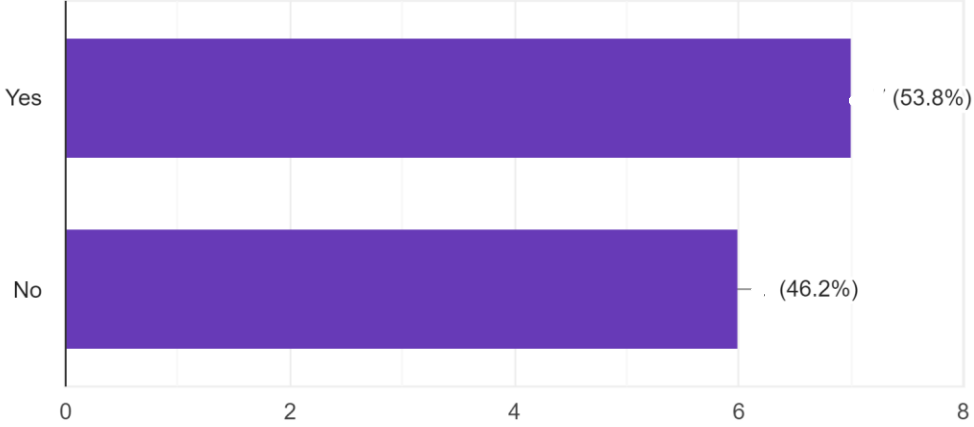
4. Does your adult child receive support from the Ontario Disability Support Program (ODSP)?



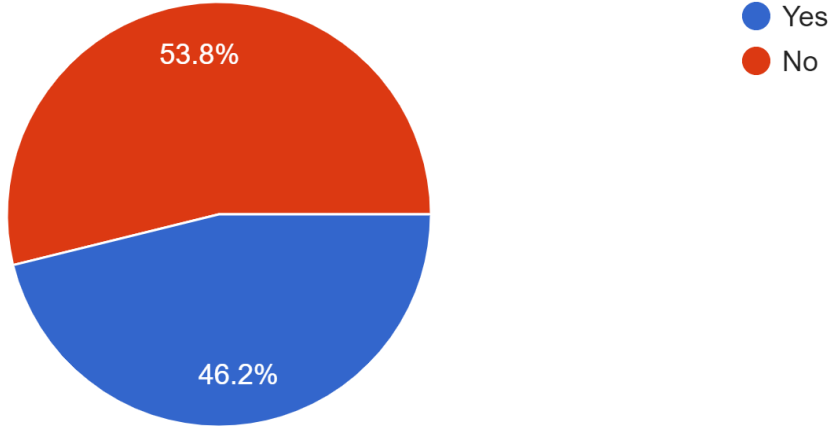
5. Does your adult child receive any supports through Developmental Services Ontario (DSO) such as Passport Funding?



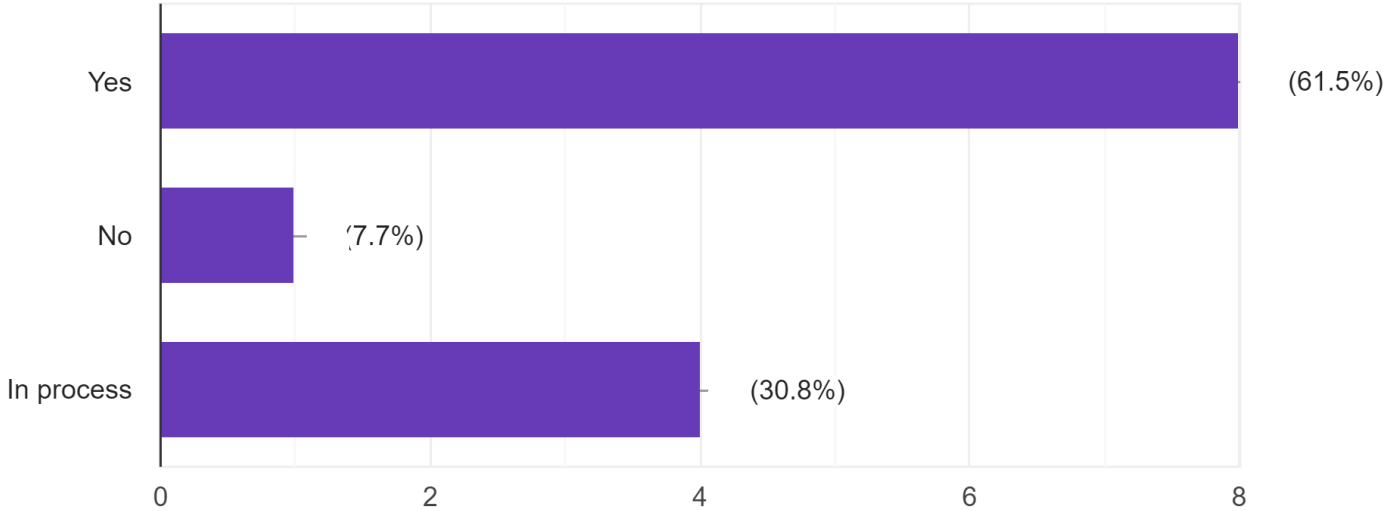
6. Does your adult child receive Canada's Disability Tax Credit?



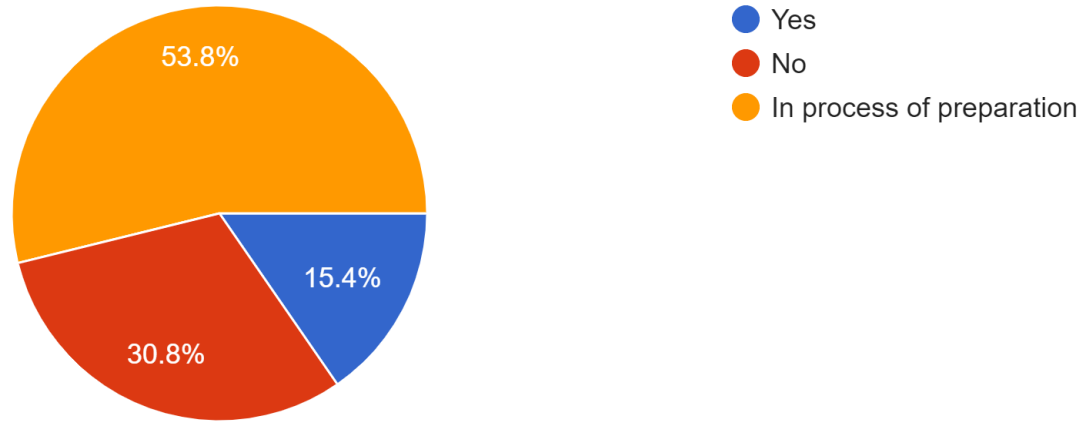
7. Does your adult child have a Registered Disability Savings Plan (RRSP)?



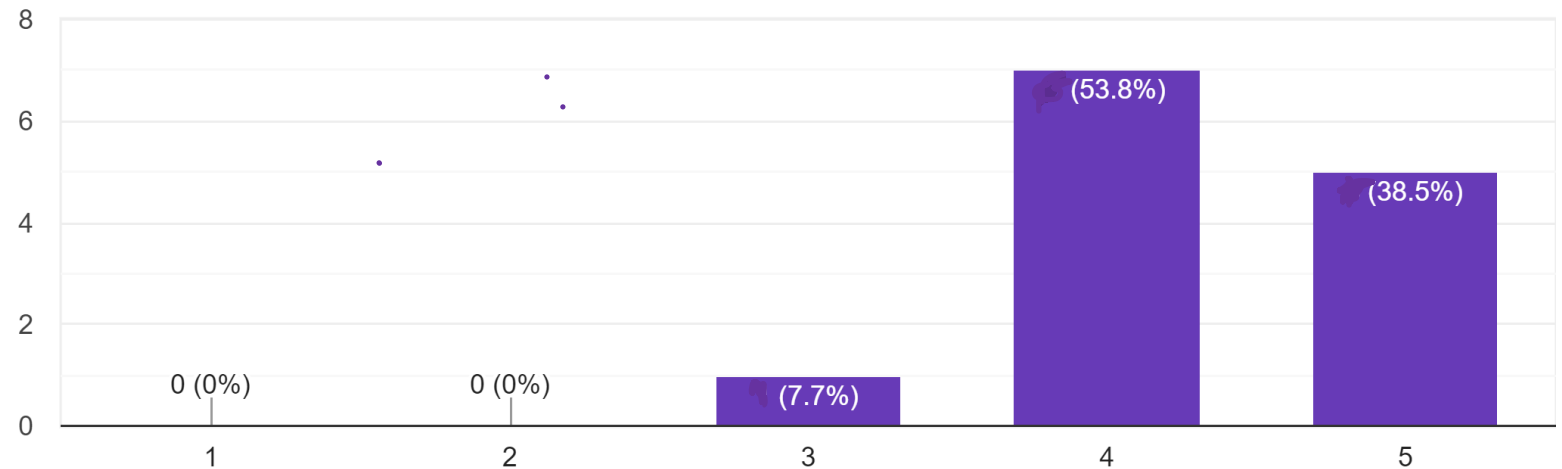
8. Do you have an up-to-date will?



9. Do you have a plan for your adult child after you are no longer living?



10. Please rate your level of concern for the future of your loved one



Primary concerns of OSCAN members

Members who are widowed; single; terminally ill

Justice issues

Personal safety related to aggression / violence; child's lack of emotional control

Managing child's finances, health care, appointments, nutrition, etc.

Financial / lifetime planning; accessing social supports & workers

Who will care for them after we are gone?

Lack of safe, affordable housing

Vulnerability to people posing as friends

Health / mental health / addictions issues among children

Caregiver health issues resulting from stress and PTSD

Caregiver grief, & social isolation

Finding / keeping work; learning life skills

Child's romantic relationships, issues re sexuality, parenting with FASD

Sandwich generation, supporting multiple generations

Caregivers raising grandchildren

Worry for siblings

Physical & Mental Health: Topics discussed by group

Presenter:
Angela Geddes,
MSW, RSW, YTT

Physical & mental health of adults with FASD:

- FASD as a whole-body disorder
- Nutrition
- Sleep
- Prevalence of mental health issues
- Substance use disorders
- Medications
- How brain impairments affect health care (remembering to take meds, appts.)
- Need for advocate at medical appointments

Physical and Mental Health of Senior Caregivers:

- Chronic stress, PTSD
- Social isolation
- Sleep issues
- Trauma, depression
- Catch 22 of worrying stress will shorten parents' lives but our adult children need us
- Lack of respite to enable self care
- Approaches showing promise: ACT; polyvagal theory

Physical & Mental Health Resources:



Many health professionals are not aware that FASD is a whole-body disorder, and that prenatal alcohol exposure has the potential to affect every organ and system in the body. Consider sharing resources with your health professional:

“Comorbidity of fetal alcohol spectrum disorder” -Popova et al, 2016
https://fasdontario.ca/wp-content/uploads/2016/01/Popova_etal2016_TheLancet.pdf

Watch: FASD Changemakers’ “The Lay of the Land: Final Results of a Health Survey of 500+ Adults with Diagnosed FASD” with *Myles Himmelreich, CJ Lutke, Emily Travis*

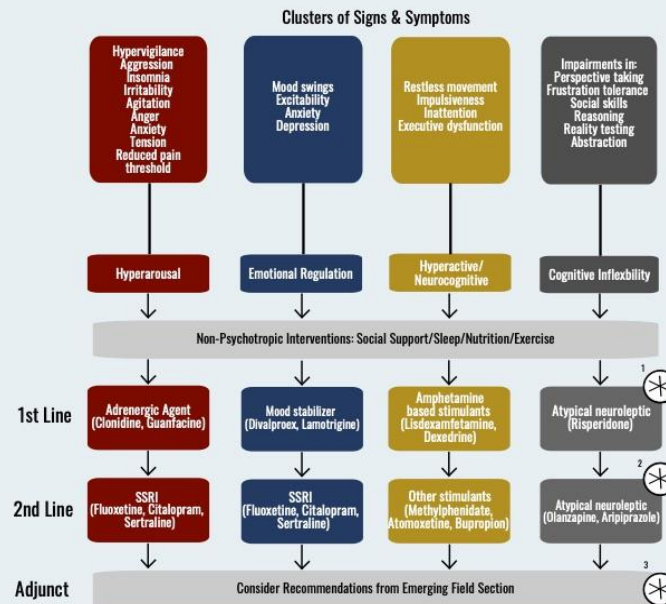
<https://interprofessional.ubc.ca/webcasts/fasd2017/> (last video)

Medications often work differently for people with FASD. Physicians must remember that FASD is a whole-body disorder when prescribing medications: there may be undiagnosed issues related to organs / systems in the body that could be impacted. General rule is to “start low, go slow”

Psychotropic Medication Algorithm for FASD/ND-PAE

Dr. Mansfield Mela et al., 2018 (all rights reserved)
Do not reproduce without permission

<https://research-groups.usask.ca/psycholegal-fasd/psychotropic-medication-algorithm-for-fasd.php>



Important Notes:

- 1 - This group of medications should not be used with preschool children and should only be used with children in consultation with child psychiatry.
- 2 - The studies showing evidence for Citalopram came before the new warnings of QTc problems. The experts recommend that Escitalopram be considered favorably ahead of Citalopram.
- 3 - The Adjunct section is only for adults and should not be used with children.

If you are a prescriber seeing patients with FASD/ND-PAE, your feedback on the algorithm is extremely valuable. Please share your experiences with using the algorithm by clicking on the survey link below.
This research has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board.

<https://canfasd.ca/algorithm/>



You can print / share the Psychotropic Medication Algorithm for FASD at this link with your loved one’s medical provider. It provides decision-tree guide for prescribers supporting patients with FASD.

Researchers encourage feedback on usefulness from prescribers and patients to “tweak” algorithm in the future.

<https://canfasd.ca/algorithm/>

FASD & Nutrition

Common challenges

- Issues related to nutrition often become more complicated during the adult years, as individuals with FASD take more responsibility for meal planning and prep
- They may not recognize when they are hungry or full due to challenges with interoception: may forget to eat or overeat
- May have strong sensory issues related to smells, taste and texture of foods
- May develop addictions to certain foods e.g. salty, sweet, caffeinated

Strategies

- Support workers or anchor people to assist with meal planning, grocery shopping, meal prep
- May need help with food budget
- Develop routines re eating; schedule reminders to eat on devices
- Teach food safety including expiry dates, refrigeration
- May need support / anchor person to help with cleaning out fridge

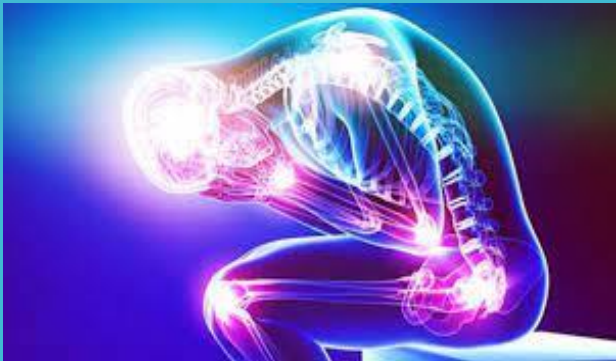
Helpful Resource:

<https://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf>

Pain in People with FASD

CanFASD Webinar

https://www.youtube.com/watch?v=WjebnXZ3_kM&t=2174s



May have very high or very low threshold; caused by effects of PAE on brain neurotransmitters (dopamine and serotonin)

Can be further affected by meds for mood disorders

May not recognize when sick or injured

May have challenges communicating about pain

Physicians may not believe them; may not know about FASD as a whole-body disorder; may hesitate to prescribe pain relievers

Important for people with FASD to self-advocate or have anchor person to advocate for them

"SKIP" (Solutions for Kids in Pain): knowledge mobilization network; working toward effective treatments <https://kidsinpain.ca/>

Dental Issues

Hygiene issues relate to sensory and memory challenges

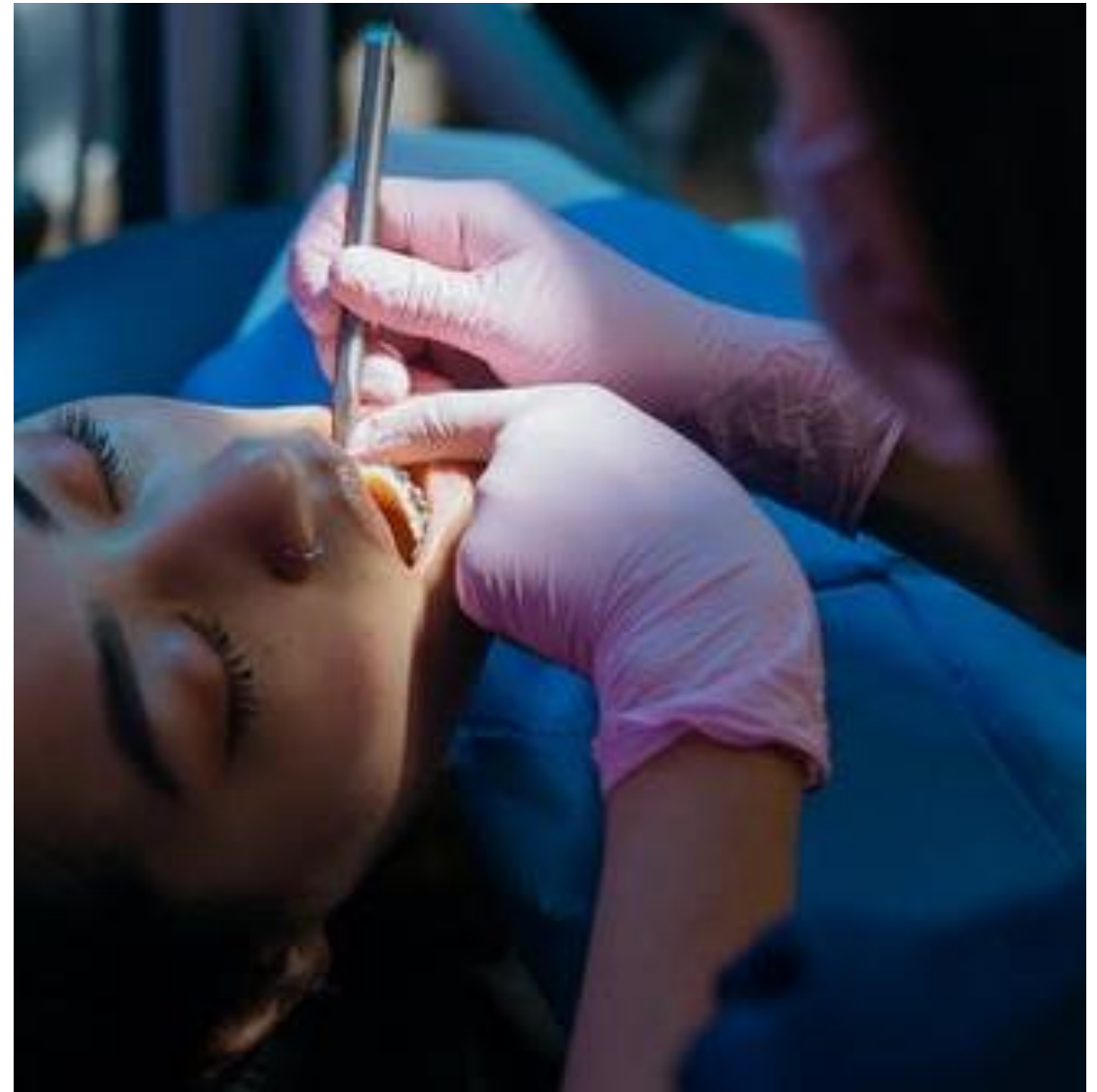
May crave sugary drinks and snacks; may be vulnerable to cavities

May forget appointments, be late, or need to reschedule at last minute

Anxiety may present barrier to getting to appointments

At appointment, may seem rude, angry or have flat affect

Dental offices may cause sensory overload



Strategies for Caregivers and Anchor People

- Provide advance warning
- May be best not to take siblings
- May be only thing they can manage that day
- Provide sensory supports
- Share FASD diagnosis with staff
- Recommend FASD training by provincial workers
- Age 18+, ODSP dental coverage or request coverage under private plan
- “Prevident” toothpaste



Strategies for Dental Office Staff

- Check for other health issues
- Remember meds such as antibiotics may work differently
- Freezing / anesthetic may work differently
- Have patience with family members / emotional mirror
- Explain what is happening
- Allow time for questions
- Provide time for breaks
- Welcome caregiver to join
- Give brain time to catch up with emotion
- Expect lateness / rescheduling

Sleep Issues are Common

- Difficulty falling asleep / staying asleep / fragmented
- May increase anxiety and challenging behaviors
- Can be exacerbated by mood disorders
- 80% have abnormal melatonin profile (Goril et al, 2016)

Strategies:

- FASD diagnosis / intervention plan (doctors / OT's)
- Allow time for naps / catnaps
- Plan challenging activities during times of alertness
- No screens for min. 30 minutes before bed / no screens in bedroom
- Keep sleep schedule

FASD & Mental Health: What does the research say

- Over 90% of people with FASD experience mental health issues (CanFASD, 2020)
- 20 times more likely to have substance use problems (Flannigan et al, 2020)
- Tend to have elevated baseline cortisol level; cortisol levels rise quickly; take longer to come down (Hellemans, 2010)
- Lifetime rate of suicide attempts 10X higher than general population (Merrick & Kandel, 2007)
- 43% have expressed intent to commit suicide; 23% have attempted suicide (CanFASD, 2020)
- May not understand the finality of death; “suicide talk” is often driven by a desire to escape painful experiences (Badry, 2021)



Mental Health Protective Factors

- Multidisciplinary FASD assessment to determine strengths and challenges
- Mental health professionals trained in FASD
- Goal is prevention instead of crisis intervention
- Stable loving family
- Absence of exposure to violence
- Support with life transitions (transition to adulthood, moving out of family home, starting a job, losing a parent)
- Circles of support; anchor people



Effective Mental Health Interventions

Individualized interventions that capitalize on strengths and support challenges

Modify environment to fit the person with FASD, not the other way around.

Teach people with FASD skills to improve emotional regulation and stress management ; engage peer mentors; navigate to groups for adults with FASD

Foster relationships that are supportive, loving and nurturing; build sense of belonging & purpose

Addressing Mental Health

Caregivers of children with FASD have been shown to experience higher levels of stress than other disabilities.

Barriers to self care:

- Time restraints / busy schedules
- Lack of resources (money / costs, lack of support from family)
- Family needs and challenges
- Exhaustion; mood; motivation
- Health issues
- Logistics (friends unavailable, geographic location)
- Pride: it's hard to ask for help

Those who are confident in practicing self-care have lower rates of stress.

Useful strategies include:

1. Yoga, meditation, mindfulness
2. Exercise, sleep, healthy eating
3. Social supports
4. Hobbies
5. Small luxuries

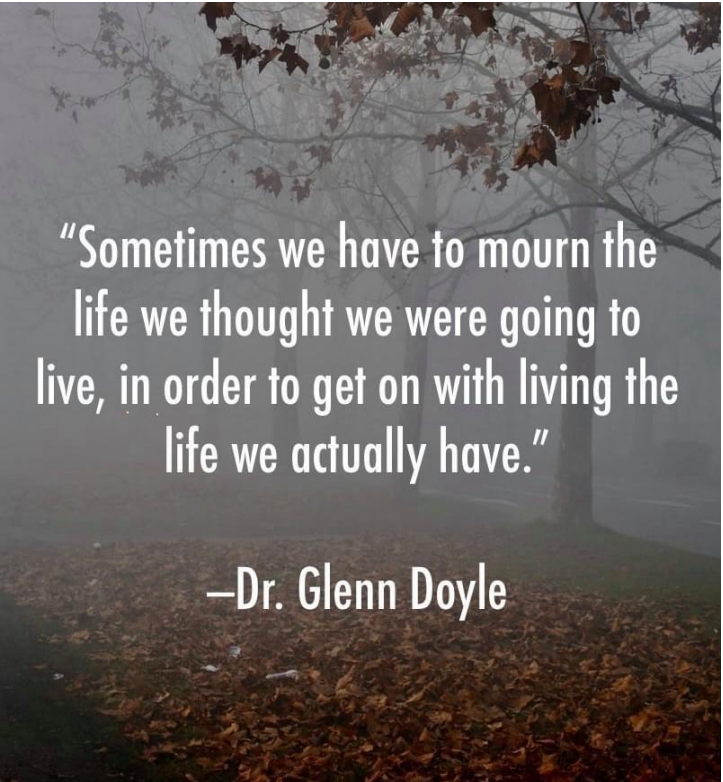
-(*CanFASD, 2020*)

Self care for caregiver needs to be scheduled and valued by other family members.



GRIEF

- OSCAN members spoke of a new stage of grief in the senior years, as peers retire, travel, spend time with grandchildren, etc.
- Grief is exacerbated when professionals, family and friends don't understand the daily requirements to support adults with FASD.
- OSCAN's Social Worker Angela Geddes shared information about Acceptance and Commitment Therapy (ACT) for supporting grief in carers.
- CanFASD also reporting ACT as useful. See <https://canfasd.ca/2020/04/22/acceptance-and-commitment-therapy-for-caregivers/>
- OSCAN's group facilitator Nancy Lockwood spoke of therapeutic support groups she is running with Psychotherapist Tanya Eichler based on polyvagal theory and regulating caregivers' autonomic nervous systems to manage and improve symptoms of stress, grief and PTSD.



"Sometimes we have to mourn the life we thought we were going to live, in order to get on with living the life we actually have."

—Dr. Glenn Doyle

Substance Use Disorders

- At increased risk due to damage to Central Nervous System (Popova, 2013)
- May be self-medicating for mental health issues
- More prone to engage in high-risk behaviors
- Intergenerational effects

Strategies & Resources:

- Ensure support workers are trained in FASD
- Program needs to be concrete and individualized: 12 step programs tend to be abstract; group therapy may be challenging due to impulsivity issues
- Helpful resource:
<https://ontario.cmha.ca/addictions/>

Types of Behavior Addictions



Relationships: topics discussed by OSCAN

Guest Speaker:
Tanya Eichler,
Psychotherapist
/ FASD Educator

Friendships

Romantic relationships

Social isolation of adult children

Social isolation of caregivers

vulnerability to predators

Sexual relationships

Parenting with FASD

- <http://knowfasd.ca/> A searchable database of FASD resources across the lifespan
- https://www.bsec.ab.ca/pdf/So_You_Have_Been_Diagnosed_With_FASD_Now_What_Education_Resource.pdf
- <https://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf>
- <https://edmontonfetalalcoholnetwork.org/2018/11/14/tips-dating-sexuality/>

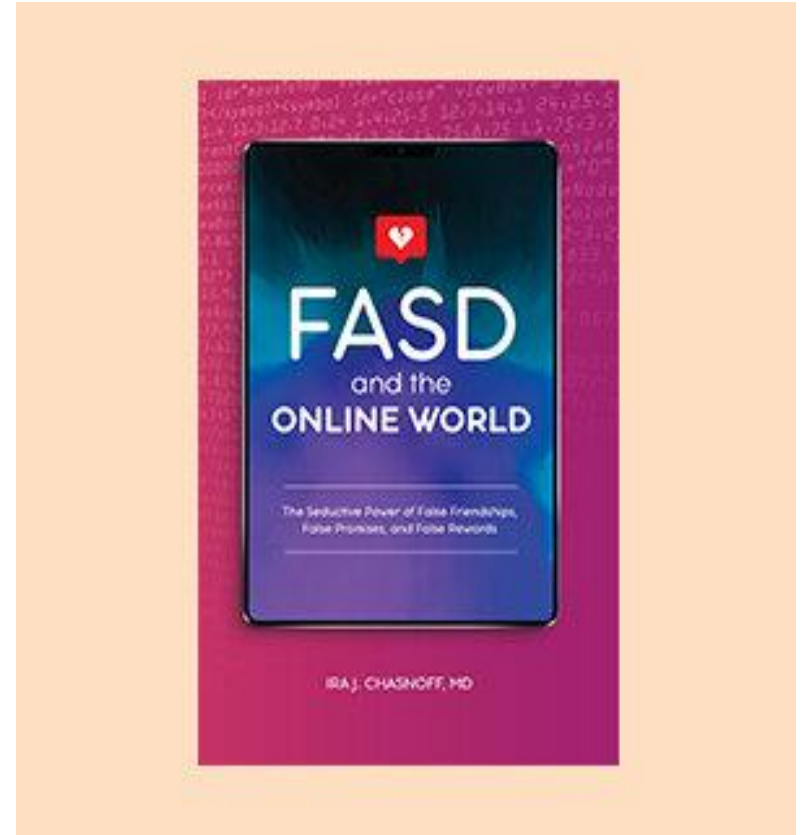
Resources about FASD & relationships

FASD and the Online World

by Dr. Ira Chasnoff

<https://www.ntiupstream.com/books/fasd-and-the-online-world-digital-book>

“The online world is very real, but the friendships, promises, and rewards young people with FASD find there are for the most part false. This book is for any parent or professional who must find a balance between the young person’s quest for independence and the need to protect that young person from harm in the online world.”



1. Only have sex with people the same age as you.
2. Make sure every person says “yes” out loud before you have sex.
3. Consider strong role of peer influence.

http://www.davidboulding.com/uploads/2/4/1/4/24146766/fetal_alcohol_and_the_rules_for_sex.pdf

David Boulding's “Fetal Alcohol & the Rules for Sex”

David Boulding's 7 R's

- 1. Relational:** build relationship; get comfortable talking about sex
- 2. Respectful:** avoid a power dynamic
- 3. Repetition:** to support memory issues; across the lifespan
- 4. Relevant:** use simple, clear concrete language; these rules will keep your loved one out of jail
- 5. Rhythmic:** keep the information fresh; present in different ways
- 6. Rewarding:** the reward is the connection / trust you build
- 7. Recognize:** the brain before you

Responding to Inappropriate Sexual Behaviors

-Pascal Gagne,
2020

Not Recommended

- Not Taking the Disability Into Account
- Cognitive Behavioral Therapy / Talk Therapy
- Professionals not trained in FASD
- Strictly punitive measures that focus on guilt, crime
- Responses that include shame, anger, shock

Recommended

- Prevention Strategies: assessment / early interventions
- Very clear rules, repeated often
- Privately tell them what they *can* do (when and where)
- Professional help: FASD Workers; sexual behavior clinics; mentors; peer support
- Dyadic Developmental Psychotherapy (DDP)
- Social Stories
- In some cases, safely prescribed medications

Know the Laws: Age of Consent to Sexual Activity in Canada

[https://www.justice.gc.ca/
eng/rp-pr/other-
autre/clp/faq.html](https://www.justice.gc.ca/eng/rp-pr/other-autre/clp/faq.html)

“The age of consent is the age at which a young person can legally agree to sexual activity. Age of consent laws apply to all forms of sexual activity..from kissing..to sexual intercourse.”

- All sexual activity without consent is a criminal offence, regardless of age.
- The age of consent to sexual activity is **16 years**.

Close in age exceptions:

- Age 14 or 15, can consent to sexual activity if the partner is **less than five years older** and there is no relationship of trust, authority or dependency or any other exploitation of the young person.
- Age 12 or 13, can consent to sexual activity with a partner if the partner is **less than two years older** and there is no relationship of trust, authority or dependency or any other exploitation of the young person.

<https://www.justice.gc.ca/eng/rp-pr/other-autre/clp/faq.html>

How Do You Know if Someone Wants to Have Sex with You? | Planned Parenthood Video



Consent means actively agreeing to be sexual with someone. Consent lets someone know that sex is wanted. Sexual activity without consent is rape or sexual assault.

CONSENT



- Freely Given
- Reversible
- Informed
- Enthusiastic
- Specific

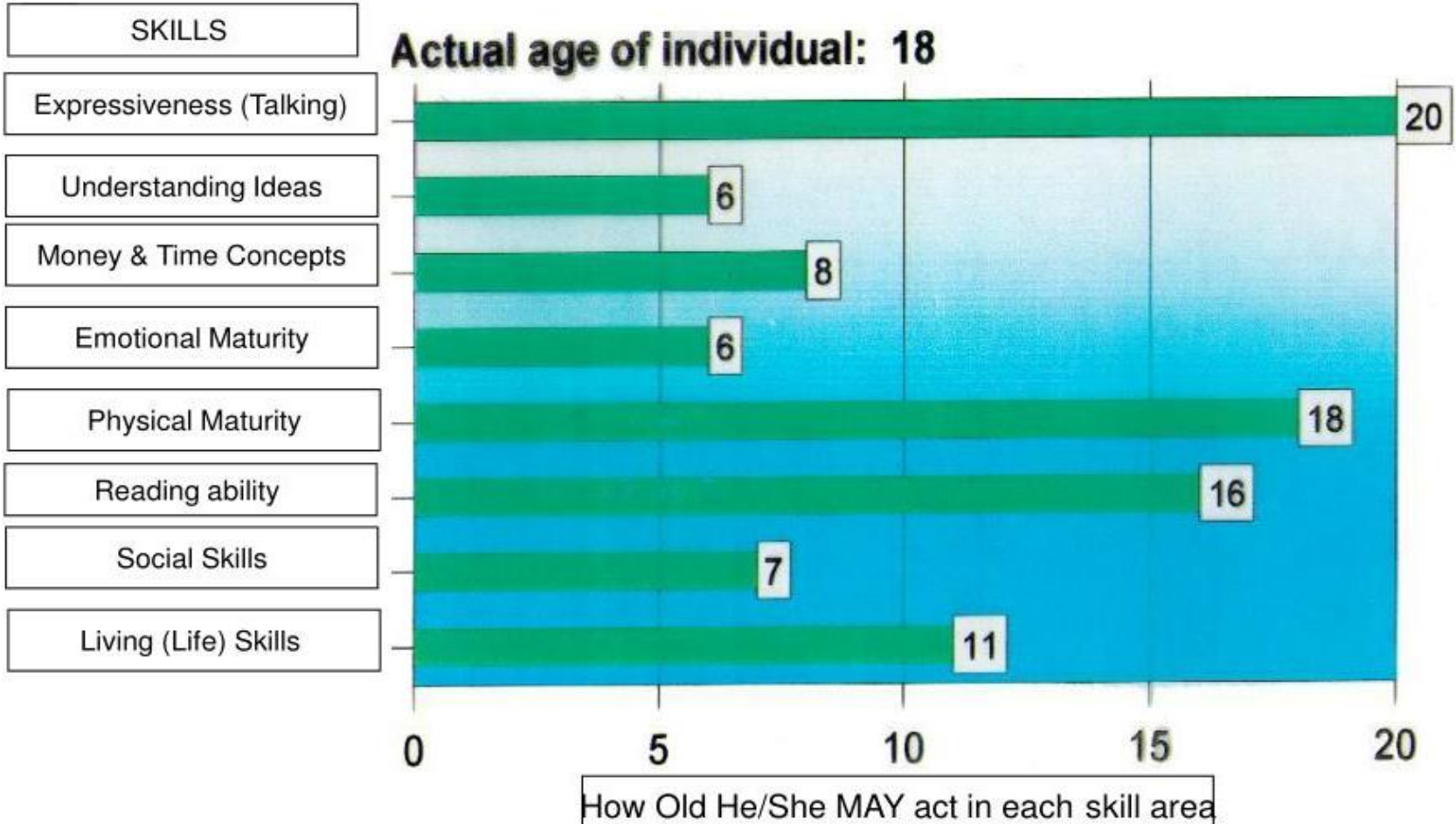
Planned Parenthood®

Understanding Consent

<https://www.plannedparenthood.org/learn/relationships/sexual-consent>

Remember role of dysmaturity as it relates to social connections and sexual behaviors: may do better socializing with those younger than themselves but may require supervision.

Dysmaturity Concept – Students with FASD Frequently Show Many Different Ages



Cunningham www.fasout.ca
Adapted from research findings of Streissguth, Clarren et al by D. Malbin 94
2008



Human Trafficking

People at greatest risk of being trafficked include females under age 24 and members of marginalized populations including:

- People with disabilities
- Those involved in the child welfare system
- Indigenous women and girls
- People who are socially and economically disadvantaged

<https://canfasd.ca/2022/02/23/human-trafficking-and-fasd/>

- *Engage anchor people to assist in keeping the individual with FASD safe from traffickers*

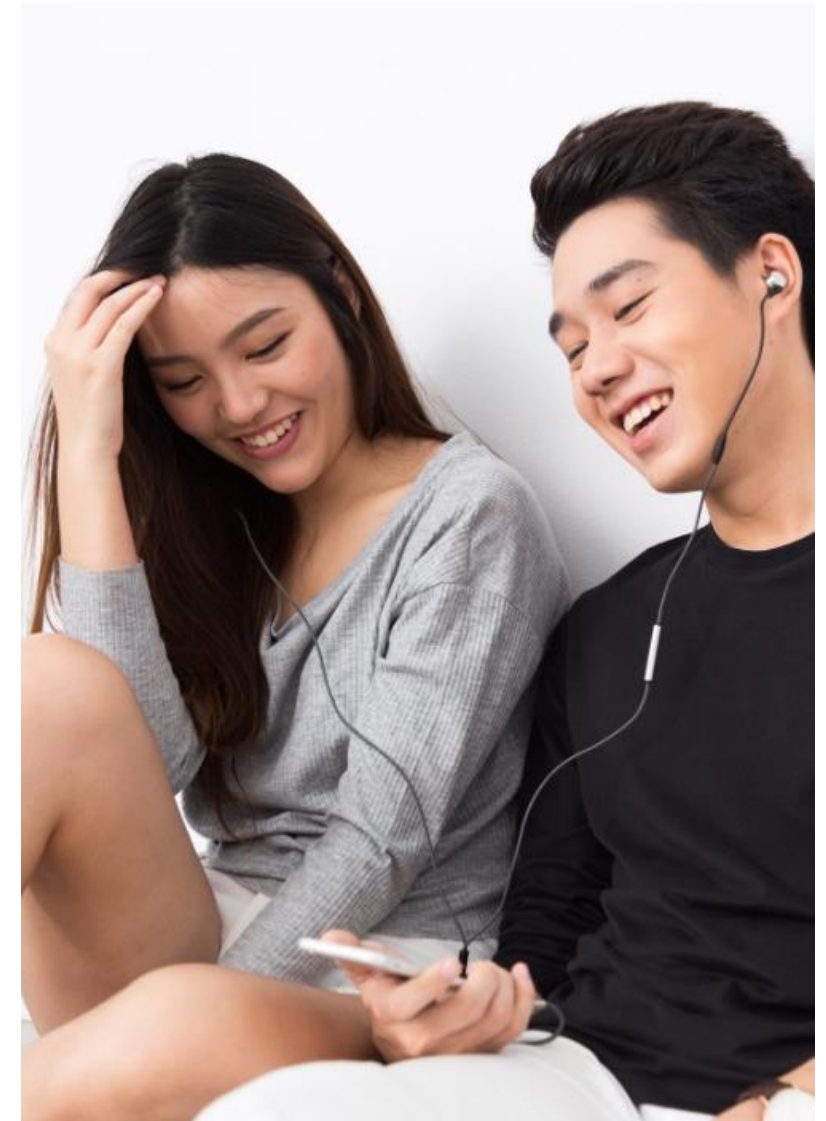
Sexuality, Technology and Media

Their online lives are often as important / more important to them than their in-person lives

Tips:

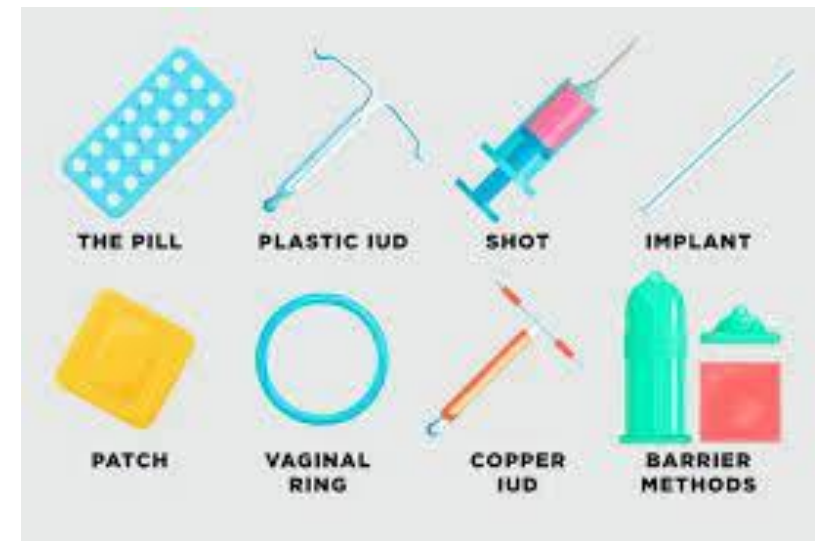
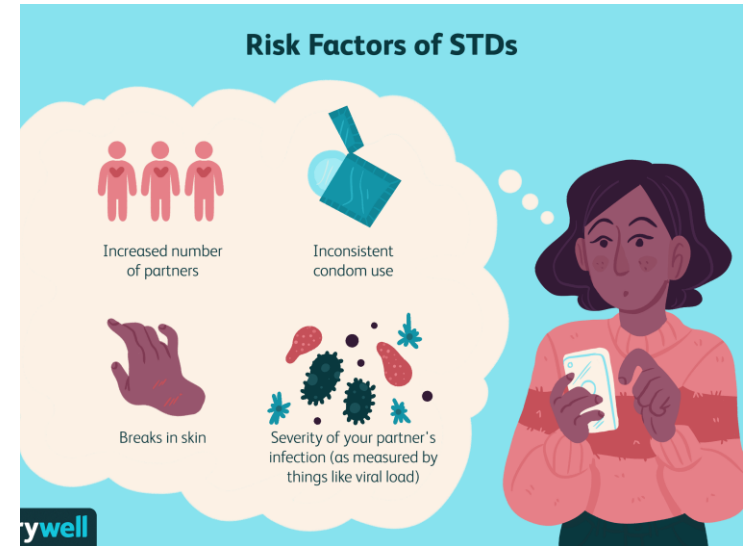
- Promote healthy online relationships; teach self-respect and how to behave respectfully online.
- Discuss privacy and online safety, and their role in protecting other people's privacy.
- Communicate your values.

<https://teachingsexualhealth.ca/parents/information-by-topic/technology-media/>



REPRODUCTIVE HEALTH:

- Need clear instructions; reminders to take meds
- May need help with accessing and paying for birth control, and remembering to take it
- Provide a trusted anchor person for support
- May experience side effects with birth control medications



FASD & Sexuality Resources for Caregivers



Teaching Sexual Health

- Parent and teacher portals; videos, resources, sections for differing abilities; resources re gender and sexual diversity; technology and media; parent guides by age
- <https://teachingsexualhealth.ca>

Sex & U

- Created by the Society of Obstetricians and Gynecologists; facts re sex & sexuality
- <https://www.sexandu.ca>

Understanding Consent Video

- <https://www.youtube.com/watch?v=raxPKklDF2k>

Safe Sex & Fun Booklet and Video

- https://www.fpnsw.org.au/sites/default/files/assets/sex_safe_and_fun_booklet_a5_.pdf <https://www.youtube.com/watch?v=cD6xvQpdgzE&t=268s>

Healthy Bodies, Safer Sex Booklet

- For trans & non-binary People
- https://lgbtq.unc.edu/sites/lgbtq.unc.edu/files/documents/healthybodiessafe_rsexnatl.pdf

Action Canada for Sexual Health and Rights

<https://www.actioncanadashr.org/resources/sexual-health-hub>



Sexuality & sexual health

Reproductive health

Sexual relationships

Aging & sexuality

STI's

Sexual rights

Info for healthcare providers

Filling Their Days December 2021

Guest speaker:
Krista Gibson,
North Bay Community
Living



OSCAN Session Agenda and notes

December 15, 2021



1. Welcome and brief overview of today's topic
2. Introduction to Krista Gibson - North Bay Community Living
3. Ways to fill our days - different for everyone.. but there are some commonalities. Some considerations:
 - a. Weekly plans- routines- jobs around the house - exercise, meal planning, self-care, visits, social interactions, volunteering,
 - b. Employment - part time vs full time?
 - c. Finding areas of interest
 - d. Strength based
 - e. A feeling of belonging - "normal" social settings, how to support safety and harm reduction?
 - f. Intrinsic desire to be helpful and to have purpose
 - g. Video games - virtual worlds- important social interactions
 - h. Community supports - DSO applications - focus on challenges on difficult days and without any supports.. ie can do laundry, but not without visuals and reminders.
 - i. Passport funding
 - j. Community Living
 - k. Day programs for Seniors and adults with disabilities in towns/municipalities
 - l. Housing for seniors and disabled adults.
 - m. Community Health Centres - programs for seniors and disabled adults. Friendly visiting, congregate dining, meals on wheels. Other health promotion activities
 - n. Acquired Brain Injury Supports - ie. Dale Brain Injury
 - o. others ?



London Middlesex Community
Support Network



Developmental
Services Ontario



Community Living
North Bay



Ottawa East Community
Health Centre

FASD Resources for Employers

- Supporting Employment in Adults with FASD
<https://canfasd.ca/wp-content/uploads/publications/Guide-for-Employment-Professionals-Supporting-Employment-in-Adults-with-FASD.pdf>
- FASD: A Practical Guide for Employers
https://inclusionnwt.ca/wp-content/uploads/pdf/FASD-A_practical_Guide_for_Employers.pdf
- March of Dimes www.marchofdimes.ca
- Understanding employment success in adults with Fetal Alcohol Spectrum Disorder
https://worksupport.com/research/documents/pdf/jvr_2019_513_jvr513jvr191053_jvr51jvr191053.pdf
- Hiring Someone with FASD <https://neafan.ca/hiring-someone-with-fasd/>

Resources for people with FASD: Filling Your Days

- Supporting Adults with FASD
<https://www.communitylivingbc.ca/wp-content/uploads/Supporting-Success-for-Adults-with-FASD.pdf>
- Ontario Disability Support Program (ODSP) Employment Supports
<https://www.ontario.ca/page/ontario-disability-support-program-employment-supports>
- Developmental Services Ontario (DSO) Passport Funds can be used to hire a support worker to assist with life skills training and employment searches. Passport funds can be used for activities, events, gym memberships, museum passes and so much more. Funds can also be used for a friend, relative or support worker to join these activities <https://www.dsontario.ca/passport-program>
- Join an in-person or virtual group for people with FASD, such as one of these https://fasdinfotsaf.ca/wp-content/uploads/2021/08/FASDSupportGroups_ListForWebsite_2021-222.pdf

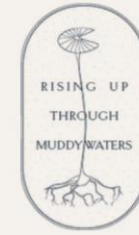
Housing January 2022

Guest speakers:
Jessica Mostert-Thiessen,
of Indwell &
Mel Quevillon,
of L'Arche London



OSCAN Session Agenda and notes

January 19, 2022



- 12:00 Welcome and brief overview of today's topic:
Supportive Housing -Options and realities re: housing
needs vs accessibility
- 12:15 Introduction to Jessica Mostert-Thiessen- Indwell
who will speak to new housing initiatives which do not
exclude FASD- opportunities a more FASD informed
approach from layout to program plans.
- 12:45 Introduction to Mel Quevillon - L'Arche London who
will speak to their day program and ways to access
community supports
- 1:00 Creative Housing options: What are people doing?
Whitcrowvillage
Wisconsin communities/housing
Housing Trust - Nancy Lockwood
Aroha's - Supporting people with disabilities
Housing research paper - CanFASD
- 1:25 Wrap Up, and Next meeting date: February 16, 2022



Whitecrow Village



Developmental
Services Ontario



Wisconsin Communities



Aroha's

Creative Housing Models and Ideas

Bissell Centre: FASD Permanent Supportive Housing (Edmonton)

<https://bissellcentre.org/programs/individual/fasd-permanent-supportive-housing/>

- Canada's first apartment complex providing 24/7 support services for people with FASD.
- Staff are on site and trained in FASD
- Assist with integration in the community, goal setting, attending medical appointments, mental health and justice related supports and more.

Aloha Community Platteville, Wisconsin

<https://fasdcommunities.org/housing/>

- Home on four acres outside Platteville, Wisconsin.
- Provides young adults with a structured, calm and safe environment
- 24-hour staff
- Each resident has a bedroom and access to communal spaces
- Large outdoor spaces with a hobby farm.

Housing models continued

Whitecrow Village

<https://www.whitecrowvillage.org/>

- Interdependent community and programs for adults with FASD
- All people and the contributions they make are valued and respected equally
- Fosters life skills, addictions recovery, education and employment skill training.

Note: no longer in operation but interesting model

The Kelsey (California)

<https://thekelsey.org/projects/>

- Mixed-income, mixed-ability residential communities created by affordable housing developers.
- Attract new sources of capital and unrealized land value to accelerate development.
- Affordable to people at the very lowest and moderate-income level.
- Accessible and inclusive culture and staffing

**CREATING INTERSECTIONS:
A SYSTEMATIC AND PERSON-
CENTERED HARMONIZING
FRAMEWORK FOR HOUSING
INDIVIDUALS WITH FETAL
ALCOHOL SPECTRUM
DISORDER (CanFASD,2018)**

“...This project was catalyzed by service providers and individuals with fetal alcohol spectrum disorder (FASD), as well as their caregivers, all of whom described challenges navigating conventional housing support systems. In particular, current housing models were described as not yet meeting the unique and ever-changing needs of individuals with FASD—we can do better. Our community partners spoke of the need to find fitting models of service delivery for individuals with FASD who are unhoused so that they may experience opportunities to build upon their strengths, and successful achievement of their goals. Together with this community, we have developed a harmonizing housing framework that offers a more responsive, complexity-sensitive way of meeting the ever-changing needs of individuals with FASD who are unhoused, with the ultimate goal of engaging and supporting these individuals in housing tenure in ways that promote individual success and goal attainment...”

Read the full article at https://canfasd.ca/wp-content/uploads/2019/10/FASD-X-Housing-Pei-2018_Amended-March-04-2019-dl.pdf

A Feasibility Study for a Housing Trust for Adults with Intellectual Disabilities in Ottawa-Carleton

Prepared for: Citizen Advocacy Ottawa (now ABLE2), Housing Trust Research Project, Ontario Government Housing Task Force (2016)

“...This exploratory report reflects the findings of a research team tasked with exploring the feasibility of a housing trust in the Ottawa-Carleton area for adults with intellectual disabilities. The research process was grounded in the needs of adults with intellectual disabilities and their families and included stakeholder focus groups, and a thorough review of the literature...”

Read more at:

<https://www.able2.org/wp-content/uploads/2021/05/HousingTrust-Feasibility-Project-Report-Final.pdf>

More housing ideas:

1) Indwell <https://indwell.ca/>

- “Indwell is a Christian charity that creates affordable housing communities that support people seeking health, wellness and belonging.”

2) L’Arche Canada <https://www.larche.ca/>

- “Across Canada and around the world, L’Arche creates communities of friendship and belonging. In L’Arche, people with and without intellectual disabilities live, work, learn, and grow together. L’Arche demonstrates that when persons with intellectual disabilities take their place at the table, they contribute to a more just, compassionate, and vibrant world for all.”

3) Ontario Government Local Housing Programs <https://www.ontario.ca/page/find-your-local-service-manager>

- “There are 47 service managers across Ontario that can help you find housing options in your area. Use the list below to get contact information for your municipality or district.”

4) Aroha’s <https://www.uoguelph.ca/oar/entities.shtml>

- An Aroha is formed when a group of committed family members and friends join together with a person with a disability to incorporate an organization according to the laws of their province. This entity has the objects and legal powers to address the vulnerable person’s planning and support needs, to create solutions, and to manage resources in ways that are responsive and accountable. They are similar to microboards.
- The Maori word “Aroha” is the generic term for incorporated entities for personal empowerment and support and refers to the values needed in a caring circle of friends.
- The first Aroha in Ontario has been incorporated with and around a man in Guelph. This Aroha is willing to share its experience with other circles of families and friends who want to incorporate...”

5) A Mosaic of Options: A Housing Continuum for People with FASD -Whitehorse, Yukon (2020) <https://yawc.ca/files/a-mosaic-of-options-a-housing-continuum-for-people-with-fasd-2020.pdf>

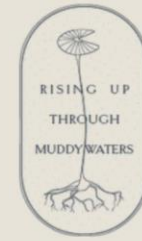
Financial & Lifetime Planning February 2022

Guest speaker:
Darlene Donnelly,
Person Directed Planning
& Lifetime Network
Facilitator



OSCAN Session Agenda and notes

Feb. 16, 2022



1. Welcome and brief overview of today's topic
2. Financial Planning and Wills
3. Social Supports - ODSP- DSO- Passport
4. Creating Circles of Care
5. Person Directed Planning
6. Wrap up and further discussion
7. Groups and activities to support caregivers
8. Next meeting date: March 20, 2022



ODSP Application forms



to register for MH and Covid
- support for caregivers



to register for mindfulness
course CAMH



Developmental
Services Ontario

Angela Geddes on FASD & Lifetime Planning



Welcome to all

- This is a tough topic
- Significant cause of worry and time spent in the 'future'...
- Acceptance is necessary, but difficult.
- How do we do this?
- Let's take a moment to pause and breathe

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Acceptance



- No matter what the diagnosis is, it is a part of us and doesn't define us
- Ignoring it doesn't make it go away.. Even though we'd certainly like to
- Excessive worry doesn't make it better either....
- Acknowledge the 'nightmare'.. Honour the fears and realities... and try not to own more than your share.
- Tools and strategies are different for each of us.. But they only work if we believe they may..

Asking for help



- We all need helpers, or at least do better with assistance..
- The people we love and support need to learn how to do this as well..
- We would not expect a blind person to see...
- People we/they trust... how do we nurture this?



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Boundaries



Ground Rules

- Not afraid to be yourself
- One voice at a time
- Trust
- Imagining the best possible future while using what we have learned from the past to guide
- Avoid being stuck and restricted by the past
- Less is more
- Visual records - review



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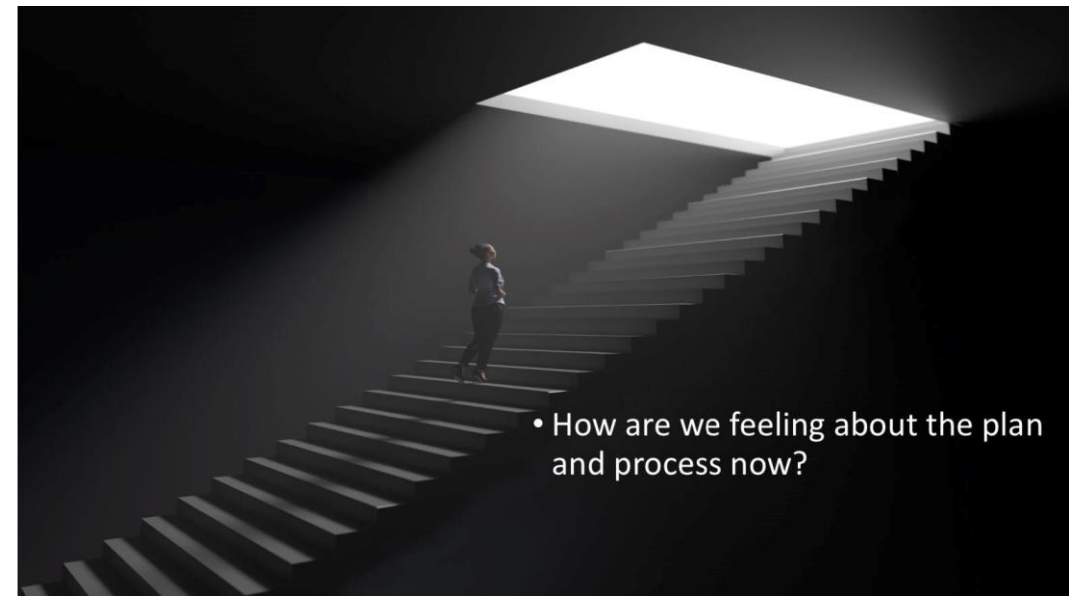
Social and Support Circles



leave you feeling

- Good about yourself
- That you belong
- No pressure..
- Supported and appreciated
- Offering support and planning 'with' them rather than 'to' them – not a topic of conversation.. But a part of the conversation.
- A 'participant' rather than a 'recipient'

Angela Geddes copyright 2022



- How are we feeling about the plan and process now?

More Resources:

Partners for Planning P4P



PLANNING NETWORK

“Who will love and protect our sons and daughters with a disability when we no longer can?”

- Created to respond to this question
- Connects network of professionals, organizations and agencies.
- Planning resource for families in Ontario.
- Directory of professionals
- Excellent FREE online webcasts, guides, tip sheets, planning tools, and personal stories

<https://www.planningnetwork.ca/>

CanFASD's Succession Planning Resource Guide

Information on:

Estate planning & trusts

Guardianship

RDSP; Disability Tax Credit

Circles of support

Provincial resources

<https://canfasd.ca/wp-content/uploads/2019/09/Succession-Planning.pdf>



PLANNED LIFETIME ADVOCACY NETWORK (PLAN)

<https://plan.ca/>

- Family-led charitable organization dedicated to building inclusive communities for all citizens.
- Founded by parents who wanted to ensure their children with disabilities could live a good lives & contribute to their communities.
- Focus on five components of a good life:
 - loving friends and family
 - a home of one's own
 - financial security
 - participating in decision making
 - the ability to contribute their unique gifts.



Lifetime Planning Tool

<https://www.planningnetwork.ca/resources/safe-and-secure>

Safe and Secure: Seven Steps on the Path to a Good Life for People with a Disability

- Free book download or order hard copy
- Free downloadable worksheets



PLAN Institute for Caring Citizenship

<https://planinstitute.ca/>

Social enterprise that provides:

- Educational training; resources
- Innovation through Community-Based Projects
- Works with stakeholders to encourage public policy reform



Why you need a Will

“Without a Will, the court will decide who manages your estate”

- Ensures you have a documented plan in place for your loved one with FASD after you're gone
- Includes a financial plan and maintenance of their government benefits
- Assigns an executor(s) and trustee(s) to manage your estate
- If it is within their ability to do so, your child with a disability should also create their own Will.

<https://canfasd.ca/wp-content/uploads/2019/09/Succession-Planning.pdf>

Guardianship / Capacity Assessments

- Guardianship issues do not apply to us legally as our children >18
- Law sees them as able to look after themselves and their property
- However, many are not developmentally able to care for themselves

Recommendations:

- Trusts, including Henson Trusts
- Circles of care

Assessing Capacity:

- To request a capacity assessment, contact an assessor directly.
- More info and links to assessors at https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/capacity_office.php#list

The Office of the Public Guardian & Trustee (Ontario):

- Administers estates when no one else available.
- Makes financial decisions for adults found “mentally incapable”.
- Provides financial, legal and / or personal services.
- “Ontario law assumes that adults are capable of making decisions until it is proven they are not capable”.
- A person is incapable “...if they do not understand the information relevant to the decision or don’t understand the consequences of making or not making it, or both...”

<https://www.ontario.ca/page/office-public-guardian-and-trustee>



Safe and Secure Worksheet 10

This worksheet will:

- Help you compile information to take to your lawyer for making a Will
- Build awareness of decisions you will need to make and help you make them.

“After completing the worksheet, you will be ready to contact a lawyer of your choice to make the Will. This worksheet does not give any legal advice. To draft a Will, you need to see a qualified lawyer.”



Henson Trusts (Absolute Discretionary Trusts)

- Important estate and financial planning tool for parents of people with disabilities
- Protects the child's assets and their right to collect government benefits / entitlements
- Usually set up with your will, in consultation with your lawyer.
- Trustee manages and invests the trust's assets.
- Maintains records; oversees tax returns for Trust.
- Maintains property owned by the Trust.
- Supports your loved one's well-being.

Resources:

<https://www.planningnetwork.ca/resources/henson-trust>

<https://pooranlaw.com/wholelifeplanning/questions/wills-trusts-estates/hensontrusts/>

How to choose Executor(s) / Trustee(s)

Think very carefully before
choosing a sibling

Consider the age of the person
and their other commitments.
Do you need more than one?

Do they understand FASD /
your wishes / your child?

Do they have basic financial
management and investment
knowledge

Where do they live? How will they
communicate with your loved
one?

The Disability Tax Credit, Registered Disability Savings Plans (RDSP), and Henson Trusts are critical elements of financial planning

Safe & Secure worksheets Assets & Debts: pages 184, 185, 185

https://cdn.agilitycms.com/partners-for-planning/SS_Worksheet_ALL_Steps.pdf

Find professionals to help across Ontario

<https://www.planningnetwork.ca/get-connected/professional-services-directory>

Future Planning Tool

<https://futureplanningtool.ca/>

Estate Planning

<https://futureplanningtool.ca/planningtopics>

Financial Planning Resources

Registered Disability Savings Plans (RDSP's)

slide 1/3

*With thanks to an OSCAN member for preparing this

- * A federal program under ESDC (Employment and Social Development Canada) and CRA (Canada Revenue Agency). It's basically a pension plan for persons with disabilities.
- * The 'Beneficiary' of the plan is the person with a disability. The 'Holder' is a person, such as a parent, who acts on behalf of the beneficiary. Any adult beneficiary able to do so can be their own 'holder.'
- * The beneficiary has to have a Social Insurance Number and a federal Disability Tax Credit Certificate, and must file tax returns, even if they have no income to report, or just Disability Income such as ODSP in Ontario.
- * The first step is to set up an RDSP account with a financial institution, such as your bank. As an example, the TD bank has an investment arm (TD Direct Investing) with a knowledgeable RDSP division. If you walk in to a local bank branch they may not be familiar with RDSPs, so it's better to make sure you're dealing with someone who knows what they are doing. This is the TD Direct Investing link:

<https://www.td.com/ca/products-services/investing/td-direct-investing/accounts/rdsp/index.jsp>

(Any of the major banks will have something similar.)

- * It is the bank/financial institution who will contact ESDC to request funds for the account, so most of your dealings will be with the bank, not the government. Unlike a regular bank account, you don't have to put any money in it when you set it up.

RDSP's 2/3

The federal government will provide two types of funding:

Savings Bond: \$1,000 per year. This is for people with a low income, and that is determined by their tax return.

Savings grant: There are two levels to the savings Grant. If the beneficiary (or anyone else on their behalf, such as a parent) contributes any amount up to \$500 per year, the government will match it in triplicate (\$1,500 for a \$500 contribution). The next \$1,000 contribution will be matched double (\$2000 for a \$1000 contribution). The end result for a contribution of \$1,500, is that the government will put in \$3,500 for a total for the year of \$5,000. Along with the 'Savings Bond' this is an annual total of \$6,000. The eligibility for these benefits is retroactive for ten years (to 2008 when the plan was established). So, that is unused grant 'room' which can be carried over and accessed whenever the person/family is able to make contributions.

This means the government will put in \$4,500 for a contribution of \$1,500.

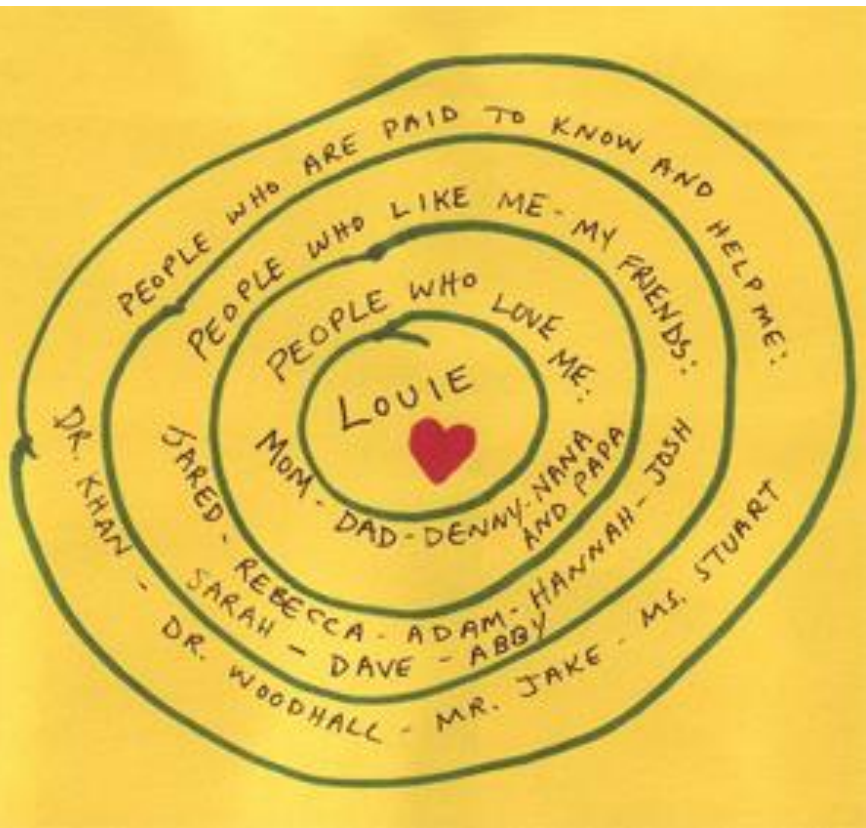
Contribution amount	Will be matched	Government contribution	Total
\$0	Bond	\$1,000	\$1,000
\$500	Grant	\$1,500	\$2,000
\$1,000	double	\$2,000	\$3,000
Total			\$6,000

RDSP 3/3

- * Once the RDSP account is set up and has some money in it, you have to provide instruction to the bank as to how it should be invested, or it will just sit there and not even earn interest. Our son, with our guidance, has put most of his funds in GICs (Guaranteed Investment Certificates) on a five year revolving maturity – very basic, very safe. Each year a GIC matures and then is rolled over into a new five year GIC along with the contributions for that year.
- * The federal government will provide this funding for twenty years (including the retroactive ten). Then, the funds have to remain untouched for another ten years. If any money is withdrawn before the thirty year period has elapsed (starting from 2008) the government will take back *all* its contributions.
- * After the thirty years has passed the funds become available through LDAPs (Lifetime Disability Assistance Payments). There is a formula for determining how much will be paid out each year. The annual payment amount is the Value of the RDSP divided by 83 minus the person's age. So if the person is 55 years old, the amount dispersed for the year will be the value of the plan divided by 28 (83-55).
- **Links for info:**
- <https://www.canada.ca/en/employment-social-development/services/disability-savings-plan.html>
- RDSP User Guide: <https://www.canada.ca/en/employment-social-development/programs/disability/savings/issuers/user-guide.html>
- The user guide link above may look a bit strange since it starts at Chapter 2. The information in chapter 2 is directed to beneficiaries/holders of RDSP accounts.
- Chapter 1 (link below) is directed at the financial institutions who will house the account.
- <https://www.canada.ca/en/employment-social-development/programs/disability/savings/issuers/user-guide.html>

Build circles
of support for
your family





Circles of Support

#1 - CIRCLE OF INTIMACY

This circle is made up of people we love - people we feel safe with, are vulnerable with - including very close family members and very close friends.

#2 - CIRCLE OF FRIENDSHIP

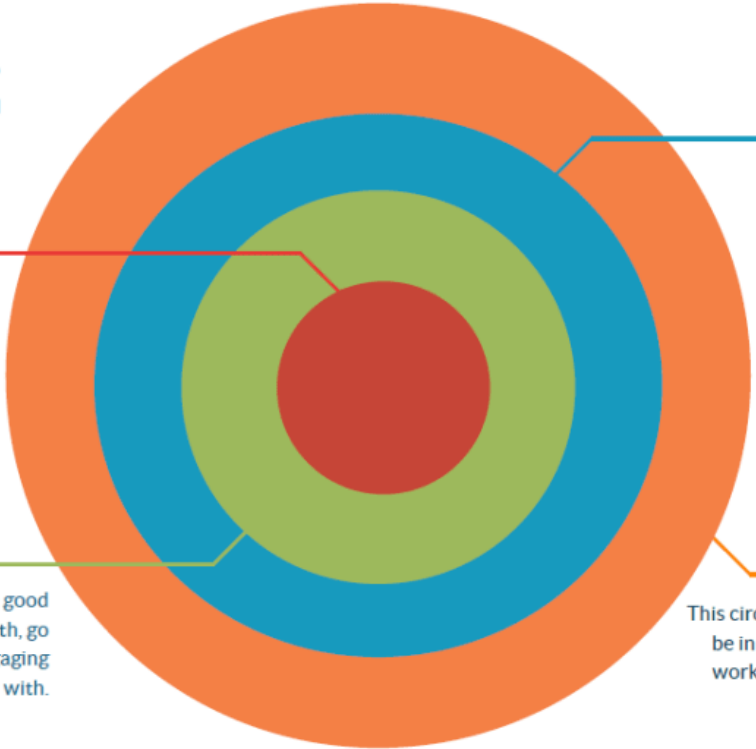
This circle includes people who are good friends - people we have coffee or tea with, go out to dinner with, spend social time engaging with.

#3. CIRCLE OF PARTICIPATION

This circle comprises acquaintances from many different areas of our lives - school, work, church, social clubs. There's an opportunity for these people to move into the friendship or intimacy circles over time.

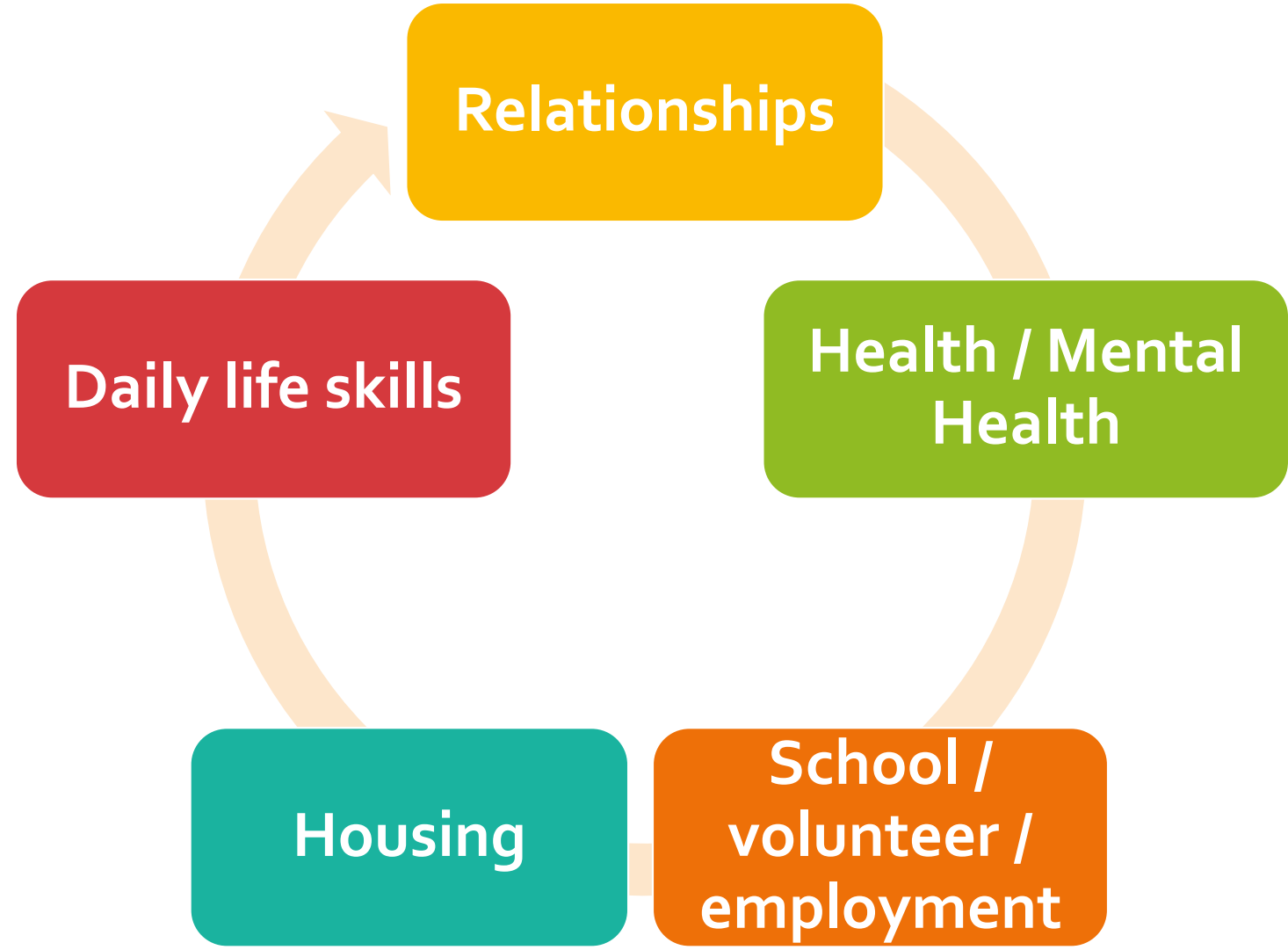
#4 - CIRCLE OF EXCHANGE

This circles includes those who are paid to be in our lives. Doctors, teachers, social workers, case managers, providers, etc. These relationships are purely transactional.



Circles of Support - Based on the work of Judith Snow, Jack Pearpoint, and Marsha Forest

Building circles of support





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Give members of
the circle
opportunities to
take over

what are other
words for
dry run?



rehearsal, trial, practice,
trial run, dummy run,
dress rehearsal, tryout,
test run, road test, war game



Thesaurus.plus

Useful Resources

Looking Forward Canada

A resource group for parents and caregivers of children with special needs, focusing on planning for the future.

<https://lookingforwardcanada.org/>

Information will be posted here weekly in Blog format. You can access various topics by clicking on the categories below, which compile all information on a specific topic on one convenient webpage. As Looking Forward continues to grow and more information is shared, this list will get longer, so keep an eye out!

- Assistance for Children with Severe Disabilities Program
- Assured Income for Severely Handicapped Program
- Disability Tax Credit
- Events
- Housing
- Ontario Disability Support Program
- Other Resources
- Provincial Support
- Registered Disability Savings Plan
- The Henson Trust
- Trusts
- Uncategorized



DANEO

<https://daneo-raipheo.ca/>



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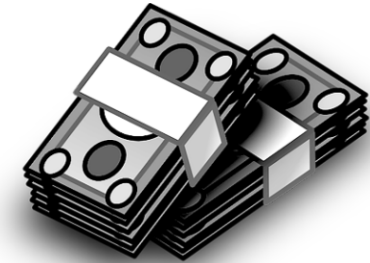
Disability Advocacy Network of Eastern Ontario

[Key Issues in Advocacy](#)

[Resources](#)

[Upcoming Events](#)

Key Issues in Advocacy





NEW Ontario Support and Education Group for Older Parents & Caregivers of Adults with FASD

Are you aged 50+ and the parent/caregiver, kin, or customary caregiver to an adult aged 18+ who has or may have FASD? Adopt4Life is launching a monthly support and education group where members will address many of the unique issues often experienced by this age group.

This group is free of charge and open to members of the Adopt4Life community. Meetings are held on the 2nd Wednesday of each month from noon until 1:00 p.m. and runs from May 2022 to March 2023. (There is no meeting in July 2022)

REGISTER:

<https://www.adopt4life.com/support-groups>

“Adopt4Life—Ontario’s Association for kin, customary care, and adoptive parents and caregivers, is a community of people with lived experience that strengthens and empowers parents and caregivers to achieve permanency for children so that they reach their full potential.” Adopt4Life welcomes carers of all ages and stages on their journey. Join their community to access Parent2Parent support, resources, webinars, and events. They are launching a support group for older caregivers of adults with FASD in May 2022.

<https://www.adopt4life.com/>



Join Our Community!

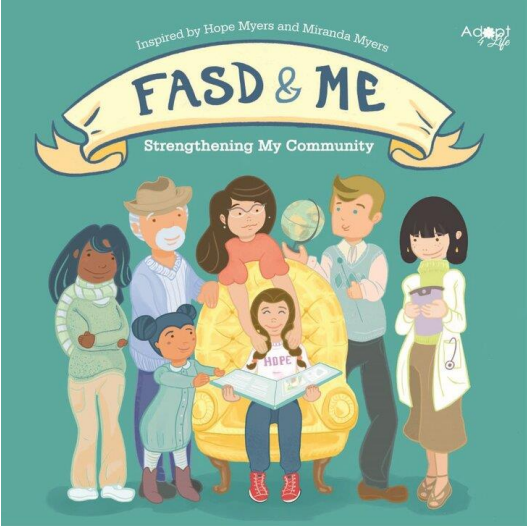
Awaiting parents, newly matched parents, existing adoptive parents, kin and customary caregivers, all benefit from the free resources of the Parent2Parent Support Network

The journey to adoption can be complex, but families don't have to walk it alone. There's a whole community who understands.

#StrongerTogether

Visit: adopt4life.com/join-our-community


 Adopt4Life



Inspired by Hope Myers and Miranda Myers

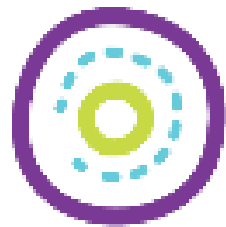
FASD & ME

Strengthening My Community



- **Health Nexus provides:**

- Bilingual provincial website with accurate, up-to-date FASD information and links to resources <https://fasdinfotsaf.ca/>
- Free FASD Service Provider Training: a course for service providers from all sectors
https://training.fasdinfotsaf.ca/?_ga=2.66424492.342200040.1643648424-2083348561.1615390678
- FASD Family / Caregiver Support Group Project with funded groups across Ontario <https://fasdinfotsaf.ca/gethelp/>
- Webinars, podcasts and events




FASD / TSAF
ontario

Community Legal Education Ontario (CLEO) & Steps to Justice

<https://www.cleo.on.ca/>


COVID-19: Get updates on the law and legal services on Steps to Justice

CHANGE FONT SIZE: Aa a- A+ f t v i @ Français


 CLEO | Community Legal Education Ontario
Éducation juridique communautaire Ontario

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 Steps to Justice
Your guide to law in Ontario

Visit stepstojustice.ca for legal information

Subscribe to CLEO's email list 

What's New

On the Radar
COVID-19 benefits that are still available

[Read more](#)

Eviction Solution Explorer
This pathway will help you if your landlord is trying to evict you because of unpaid rent. Unpaid rent is called "arrears."
This pathway can produce various documents, such as:

- a tip sheet with notes from this pathway, which explains what you can do next
- letters to send to your landlord
- speaking notes for you to use at an eviction hearing
- a form for a payment plan of arrears

[Continue](#)

1 Information about your situation


Introduction

Is your landlord trying to evict you because of unpaid rent?

CLEO's new **Eviction Solution Explorer** offers a tip sheet with possible defences, speaking notes to use at your hearing, letters to send to your landlord, and a form to make a payment plan.

[Read more](#) ▶

CLEO Resources and Publications

Legal Resources Catalogue 

Planned Parenthood

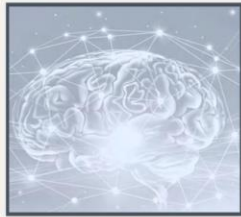
- Sexual health
- Counselling
- Birth control
- STI's
- Relationships
- Parenting, adoption, abortion



Purchase at

AngelaGeddes.ca

A Complicated & BEAUTIFUL BRAIN



A guide to understanding the effects of prenatal exposure to alcohol (PAE) and what Fetal Alcohol Spectrum Disorder (FASD) looks like across the lifespan

Angela Geddes
INTEGRATIVE SUPPORT & WELLNESS

A Complicated & Beautiful Brain

GET A STEP CLOSER TO UNDERSTANDING THE IMPACT OF PRENATAL EXPOSURE TO ALCOHOL AND FASD WITH THIS COMPREHENSIVE E-BOOK



SHOP

Here's what people are saying:

"It is a game changer for us 100%. I wish I had read it before I started the process of assessment... It's exactly what we need as a family to better understand all this..."

Mother of adult children with confirmed PAE

"Angela's depth of knowledge and warm, strength-based approach bring years of training and experience into a respectful space for people to grow and learn. This book will help caregivers and service providers create supportive environments for improving work and lives, leading to more positive outcomes"

Tracy Grant, Founding member of FASD ELMO network

Loving your book... Such an honest, well researched and concise look at how FASD diagnosis impact those affected, their families, and those who provide service and support. Thank you!

Amarilis MacEachern Drouillard, RSSW

Purchase now at

AngelaGeddes.ca

Now it's your turn...

Do you have resources and ideas to share?

Have you come up with an "out-of-the-box" idea for supporting your loved one with FASD?

OSCAN-FASD wants to hear from you. This is a working document and we will be adding to it over time.

Please send ideas and resources to nlockwood44@gmail.com.



Please note, this guide is the intellectual property of OSCAN-FASD.

Feel free to share this pdf within your networks.

Inquiries can be directed to Nancy Lockwood
nlockwood44@gmail.com

