Diagnosis and Supports

• When FASD goes undiagnosed, individuals may struggle with a disability that is neither acknowledged nor understood and they remain disconnected from crucial supports that can make a difference to quality of life.

Challenges to Diagnosis:

- Proper diagnosis requires a comprehensive assessment by a multidisciplinary team, and is therefore cost-, time-, and resource-intensive. This may pose a particular challenge in isolated and remote communities.
- There are no accepted screening tools for FASD or alcohol use in pregnant individuals, so identification of FASD requires a full assessment.
- The invisibility and high co-morbidity of FASD with other disorders (e.g., ADHD), means that FASD may be "masked" by other conditions.
- The difficulties associated with FASD may not fully manifest until later in life.
- Confirmation of PAE can be very challenging to obtain.
- The stigma and shame attached to the disability may prevent some individuals and families from pursuing assessment and diagnostic services.

The Diagnosis

- FASD with Sentinel Facial Features
- FASD without Sentinel Facial Features
- At-Risk for Neurodevelopmental Disorder and FASD

Misdiagnosis for Individuals with FASD

- Psychotic Disorders
- Bipolar Disorder
- Autism Spectrum Disorders
- Antisocial Personality Disorder
- Reactive Attachment Disorder
- Borderline Personality Disorder
- Attention Deficit Hyperactivity Disorder

Clinical Services-Edmonton

- Glenrose Adult FASD Clinical Services
 - Clinic Coordinator: Bernadene
 Mallon, Bernie.Mallon@albertahealthservices.ca
 - (780) 735-6167
 - There needs to be significant impairment not explained by current alcohol and drug use. There should be evidence of learning difficulties, poor adaptive functioning, and behavioral challenges with an onset in childhood. They need to confirm prenatal alcohol exposure (PAE).
 - the team has a neuropsychologist, registered nurse, speech and language pathologist, psychometrist (psych assistant), a Psychiatrist, and a Coordinator
- Glenrose Children FASD Clinical Services
 - (780) 735-8278
 - Provides multidisciplinary assessment and diagnostic services to children and youth affected by FASD. Eligible clients must be 12 months to 15 years 11 months of age, with referral from physician.

Why is Diagnosis so Important?

- Shifts focus from behavior to medical condition
- We can work differently and more effectively
- Access to needed supports.
- Helps us to understand the reality of the individual and provides increased support for families, caregivers, and the individual
- Provides invaluable information regarding the individual's learning challenges and may provide collective knowledge that can lead to educational adaptations (e.g., support in the school system)
- Identification of appropriate interventions that can help mitigate the onset and/or severity of adverse health and psychosocial outcomes
- Help eliminate many of the direct costs associated with FASD
- Assist those with FASD in accessing health, education, and vocational services tailored to meet their individual needs
- Identifying women who may struggle with problematic alcohol use and present an opportunity to offer meaningful support

- Creates a shared understanding among clinicians, as well as between clinicians, patients and caregivers.
- Helps to access programs for support and intervention.
- Validates the concerns of the individual, family and caregiver.
- Helps women at risk and people with FASD get the help needed.
- Understanding the evolving neurodevelopmental and neuropsychiatric presentations of FASD
- Critical assistance through periods of transition (i.e., entry to primary school, intermediate and high school, and when transitioning to adult life and services)
- Not only allows the challenges presented by FASD to be identified, but also the strengths and advantages associated with the disability to be recognized and promoted
- Can lead to important knowledge regarding mental health risks (e.g., comorbid conditions) or resilience of the individual
- Importance of 'having a name' for parents and caregivers

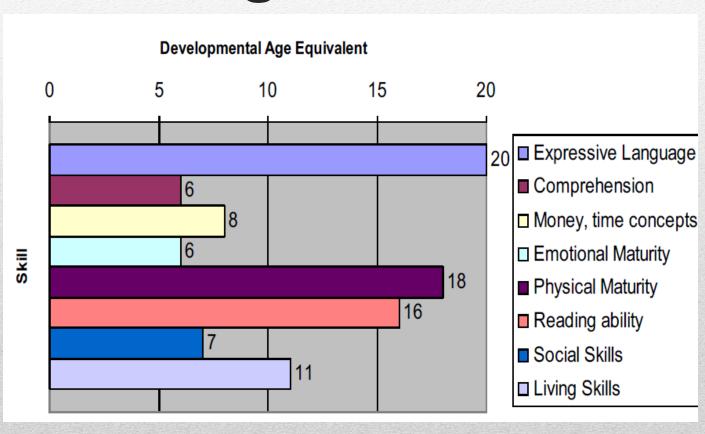
Dr. Raja Mukherjee briefly describes some of the key reasons that a diagnosis of FASD is important.

• https://www.youtube.com/watch?v=woMnzsY6Iok&feat ure=youtu.be

Strategies

- Keep it simple.
- Slow down, allow time to adjust to new activities/environments.
- Allow for lots of breaks.
- Focus on strengths.
- Connect individual with a support person.
- Try **different** (ways), not try harder.
- Communicate using concrete language and examples.
- Ask questions to check for understanding.
- Alter the environment.
- Be organized.
- Have consistent routines.
- Be clear with expectations and be consistent.
- Remember the individual's **developmental age**.

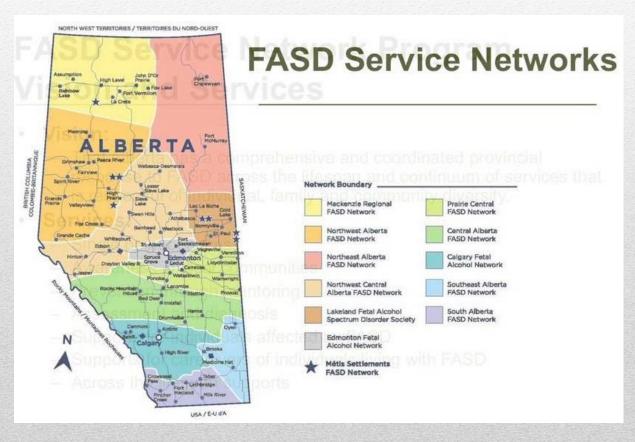
Developmental vs. Chronological



How to Support an Individual living with FASD be Successful

- Have more people understand FASD.
- Obtain an FASD assessment early.
- Provide a stable, safe, structured, sober and nurturing home/environment.
- Involve affected individuals and family in plans as abilities permit.
- Develop supportive social networks.
- Access support services for those affected by FASD.

Alberta FASD Service Networks



Call
1.877.644.9992 or
visit
fasd.alberta.ca to
link to the FASD
Service Network
in your area.

- The FASD Service Networks are groups of community and government agencies who work together to promote FASD prevention and services for families and individuals
 - What do we do?
 - Who do we help?
 - What can we provide?
 - We are:
 - Sensitive
 - Focused
 - Collaborative
 - Community based

FASD Service Networks

Calgary, Airdrie, High River

South: Claresholm, Granum and Willow Creek County, Okotoks, Nanton, Cayley

East: Vulcan, Carmangay, Arrowwood, Champion, Milo, Brant, Herronton, Kirkcaldy, Mossiegh, Lommond & Ensign, Lyalta, Langdon, Rockyford, Hussar, Chestermere, Irricana, Indus, Dalmead, Gleichen, Cluny, Beiseker

North: Didsbury, Cremona, Carstairs, Crosfield, Sundre, Cochrane, Banff, Canmore, Exshaw, Bragg Creek, Spring Bank, Elbow Valley

 Calgary Fetal Alcohol Network Suite 141, 200 Rivercrest Dr SE Calgary, AB T2C 2X5 Phone: 403-249-7215

Calgary and Area Fetal Alcohol Network

- Red Deer and area, Rocky Mountain House and area, Olds, Sundre and area, Drumheller, Three Hills, Hanna, Caster, Coronation, Consort and Stettler. Sunchild First Nation, O'Chiese First Nation, and Big Horn First Nation.
- Central Alberta FASD Network Betty Lou Benson #5, 3608-50 Avenue Red Deer, AB T4N 3Y6

Cental Alberta FASD Network

Edmonton, Fort Saskatchewan, St. Albert, Spruce Grove, Leduc, and Sherwood Park.

- Edmonton Fetal Alcohol Network
 #2 9137 Jasper Avenue
 Edmonton, AB T5H 3T2
- Lisa Rogozinsky (lisa@rogozinsky.org)

Edmonton and Area Fetal Alcohol Network

CSS FASD Programs- Edmonton

- First Steps
 - Tammi Crowley, Supervisor (780-378-2529)
 - Beth van den Elst Intakes (780-554-1819)
- Step by Step
 - Sharon Schultz, Supervisor (780-378-2539)
 - Central Intake (780-975-4893)
- Coaching Families
 - Sharon Schultz, Supervisor (780-378-2539)
 - Central Intake (780-975-4893)
- McDaniel Youth
 - Colleen Hook, Supervisor (780-378-2540)
 - Stephanie Henry, Intakes (780-378-2542)

Other Edmonton Supports:

Unlimited Potential Community Services- For adults, they have **two Open Arms programs**. One program is for men diagnosed with or suspected of having FASD, and the second program is for mothers living with FASD.

- We also have FASD-focused group care available for children.
- For more information, please contact:
- Sadie Chave, Manager Open Arms <u>Email (schave@upcs.org)</u> 780-440-0708 ext. 227

Bissell Centre

- FASD System Navigator
- Parent Child Advocacy Program, Adult Advocacy, Community Education, FASD Frontline Worker Meeting

Catherine Molyneux 780.423.2285 ext. 157 or 780-966-0041

cmolyneux@bissellcentre.org

- Lakeland Service Areas
- Smoky Lake, St. Paul, Bonnyville, Cold Lake, and Lac La Biche.
- Métis Settlements: Kikino, Elizabeth Settlement, Fishing Lake, and Buffalo Lake.
- First Nations Communities: Saddle Lake, Frog Lake, Kehewin, Cold Lake, Goodfish, Beaver Lake, and Heart Lake.
- Military Base: 4 Wing Cold Lake
- Lakeland Centre for FASD Main Office Box 479

Cold Lake, AB T9M 1P1

Phone: 780-594-9905

Toll Free: 1-877-594-5454

Fax: 780-594-9907

Lakeland FASD Network

- Mackenzie Service Areas
- High Level, Fort Vermilion, Rainbow Lake, John D'Or Prairie, La Crete, Chateh, Fox Lake, Zama City, Meander River, Garden River, Tallcree, Child Lake-Boyer, Keg River, Paddle Prairie.
- Mackenzie Regional FASD Network Box 3668 High Level, AB T0H 1Z0 Phone: 780-926-3375

Mackenzie Regional FASD Network

- Métis Service Areas
- Buffalo Lake, Gift Lake, East Prairie, Kikino, Elizabeth, Paddle Prairie, Fishing Lake, and Peavine.
- Contact Information
- Métis Settlements FASD Network Suite 101, 10335-172 Street Edmonton, AB T5S 1K9 Phone: 780-822-4078

Métis Settlements FASD Network

- Northeast Service Areas
- Fort McMurray, Fort Chipewyan, Wood Buffalo Municipal Area
- Contact Information
- Northeast FASD Service Network 600 Signal Road (Rec Centre) Fort McMurray, AB T9H 3Z7 Phone: 780-750-6678

Northeast Alberta FASD Network

- Northwest Service Areas
- Grande Prairie, High Prairie, Peace River, Fairview, Valleyview, Fox Creek, Grande Cache, Manning, Grimshaw, Spirit River, Peavine, Gift Lake, and East Prairie.
- Contact Information
- Gwen Vekved
 Northwest FASD Service Network
 Community Social Development
 PO Bag 4000
 City of Grande Prairie
 Grande Prairie, AB T8V 6V3
 Phone: 780-357-7508

Northwest Alberta FASD Network

Northwest Central Service Areas

- Jasper, Hinton, Edson, Whitecourt, Mayerthorpe, Sanguto, Onoway, Barrhead, Westlock, Swan Hills, Athabasca, Slave Lake, Lesser Slave Lake, Wabasca-Desmarais
- Contact Information
- NWC Alberta FASD Services Network Box 4455
 Barrhead, AB T7N 1A3
 Phone: 780.674.414

Northwest Central Alberta FASD Network

- Prairie Central Network Service Areas
- Prairie Central encompasses the counties of Brazeau, Wetaskiwin, Ponoka, Camrose, Beaver, Flagstaff, Lamont, Minburn, Two Hills, Vermilion River and the M.D.'s of Wainwright and Provost.
- Included in this area are 4 First Nation Communities; Samson, Ermineskin, Louis Bull and Montana.
- The major centers in the Prairie Central region would include Drayton Valley, Wetaskiwin, Ponoka, Camrose, Vegreville, Vermilion, Lloydminster, Wainwright, and Provost.
- Prairie Central FASD Service Network Stacy Graff
 3 Community Centre
 4516 54 St
 Camrose, AB T4V 4W7
 Phone: 780-385-3976

Prairie Central FASD Network

- Programs and Services Offered
- Mentoring/Coach/Advocacy for Individuals and Families (Adult Program)
- Brooks Diagnostic Assessment Coordinator
- Psychological Analysis in Diagnostic Assessment
- First Steps Program Bridges/Spec
- FASD Youth Mentor McMan For Youth (Ages 10 17)
- McMan FASD Transition Program (Ages 17-22)
- Southeast Network Service Areas
- Medicine Hat, Brooks, Oyen, and Bow Island.
- Contact Information
- Myrna Stark
 Sandfly Marketing Inc.
 # 12, 941 South Railway St. SE
 Medicine Hat, AB T1A 2W3
 Phone: 403-548-2963

Southeast Alberta FASD Network

- FASD Assessment and Diagnostic Clinic
- McMan FASD Life Span Program
- FASD Youth Justice Project
- FASD Adult Justice Project
- First Steps
- South Network Service Areas
- Lethbridge, Fort Macleod, Pincher Creek, Crowsnest Pass, Taber, Milk River, Peigan Nation (Brocket)
- Contact Information
- South Alberta FASD Service Network 217 Coachwood Point West Lethbridge, AB T1K 6A7 Phone: 403-317-0934

South Alberta FASD Network

References:

- CanFASD: Foundations in Fetal Alcohol Spectrum Disorder (FASD) Online Course
- http://fasd.alberta.ca/index.aspx
- https://edmontonfetalalcoholnetwork.org/alberta-and-fasd/fasd-service-network/

- Brittany Durant
 - 780-720-5751
 - brittany.durant@cssalberta.ca