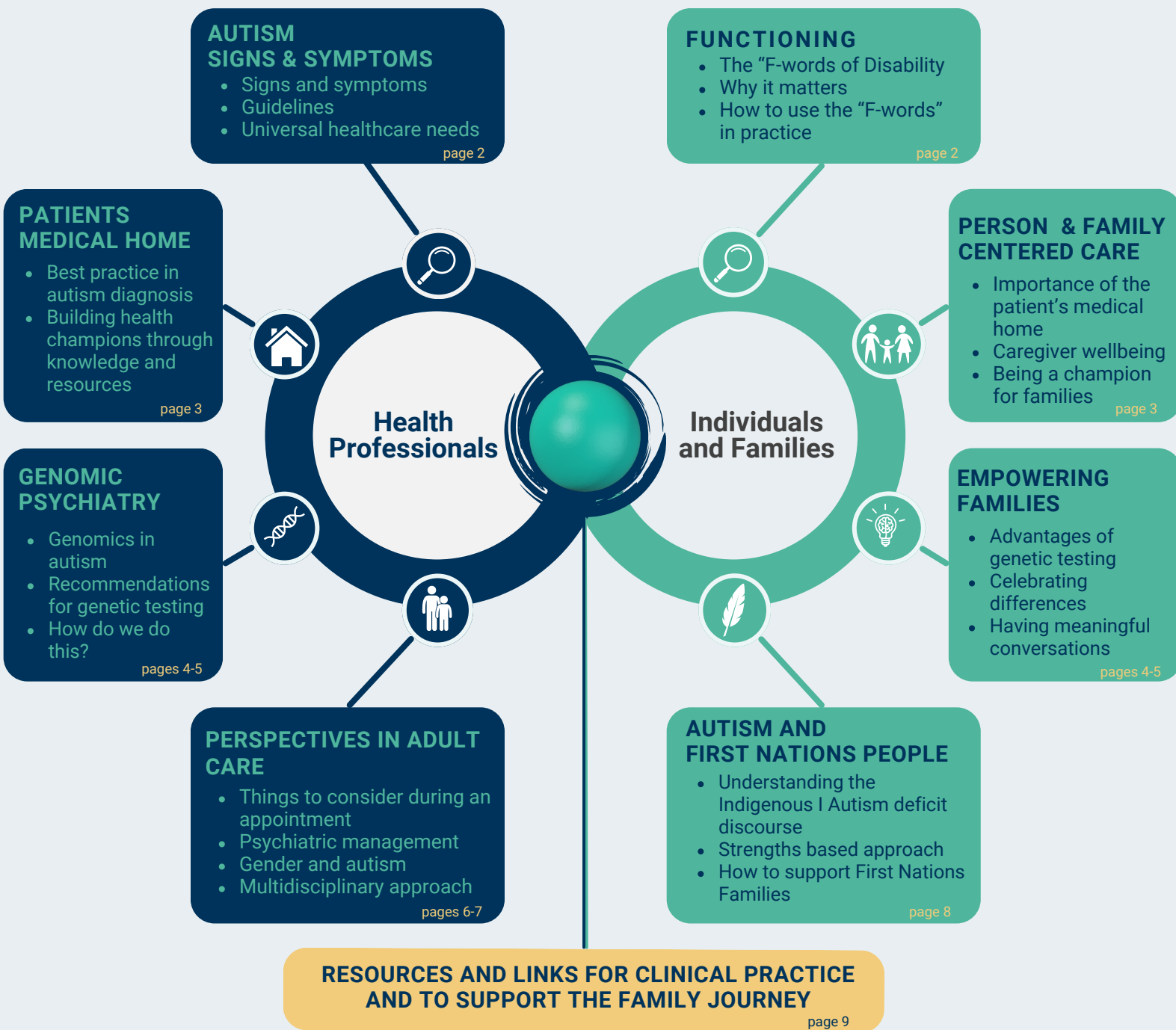


Following the spark:

Actionable strategies to untangle the complexities of neurodevelopmental disorders

I Pearls for practice



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Dr. Lonnie Zwaigenbaum and Karen Kelm

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SESSION 1

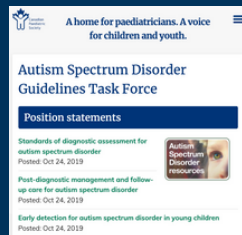
AUTISM SIGNS & SYMPTOMS

Signs of autism in the first 18 months

Zwaigenbaum et al., 2020

- May not respond when their name is called
- Quieter, may not babble back and forth in a reciprocal way
- Reduced eye contact in infancy and toddlerhood
- Insistence on particular object
- Difficulty transitioning between activities
- Intense sensory interests, exploration of the environment by visually inspecting things, through tactile senses, more attune to the environment

Autism Spectrum Disorder Guidelines Task Force



Standards of diagnostic assessment for autism spectrum disorder

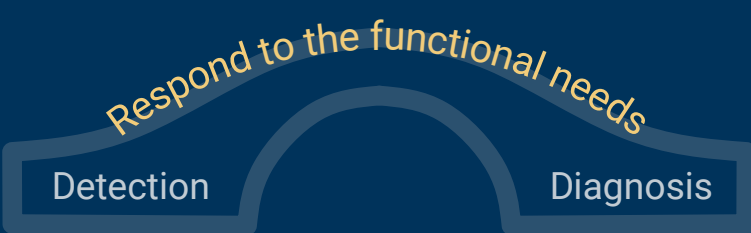
Post-diagnostic management and follow-up care for autism spectrum disorder

Early detection for autism spectrum disorder in young children

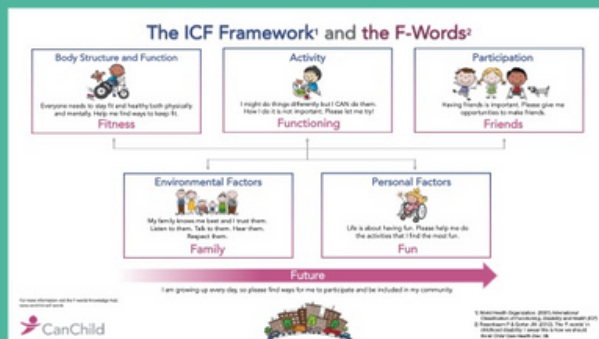
Click here: [Canadian Paediatric Society](#)

Universal healthcare needs

We need a system that responds to the functional needs of individuals across the lifespan.



FUNCTIONING



The "F-words of Disability"

A framework introduced by the International Classification of Functioning, Disability, and Health (ICF) to shift the focus from a traditional medical model of disability to a more holistic and inclusive approach

Why does this matter?

- empowering narrative around disability
- challenging stereotypes
- highlighting the multifaceted nature of individuals' lives
- fostering a more inclusive and supportive environment
- promote participation and contribution to society.

Click here: [F-Words: Tools Resources and Practice](#)

How can we use the "F-words" in practice?

Follow the spark, identify the interests and strengths of individuals and their family.

Create a sense of purpose and belonging by:

- Engaging in meaningful conversations
- Identifying supports based on interests, not deficits
- Acknowledging challenges, but draw upon strengths

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SESSION 1

PATIENTS MEDICAL HOME

PERSON AND FAMILY CENTRED CARE



Support roles as individual clinicians

- Compassion, respectful, culturally safe
- Focus on strengths and hope
- Patient and family-centred approach: addressing questions, concerns and priorities to help people achieve their goals
- Welcoming office environment
- Continuity of care
- Advocate for and participate in system change

Best practice in autism diagnosis

Zwaigenbaum & Penner, BMJ, 2019

- Determine definitive behavioural diagnosis
- Explore co-occurring conditions (which may overlap with autism)
- Determine adaptive function; strengths, challenges, interests
- Practical information about accessing supports and services

Building health champions through knowledge and resources:

ECHO Autism Communities

Extension for **C**ommunity **H**ealth **O**utcomes

Online platform of support: Moving knowledge not people
“Unites professionals and advocates globally around key concepts to ignite important conversations and take action together. Learn from leading experts as we engage in empowering ourselves and each other through knowledge, practice, and advocacy” Dr. Kristin Sohl
<https://echoautism.org/symposium-2024/>

Autism Speaks Toolbox

[Click Here](#) for a listing of the online library of resources

Ask parents, with purpose and intention...

How are you doing?

Parents carry a heavy load:

- Navigating complex systems
- Translating new knowledge and between complex systems
- Implementing strategies

Striving for meaningful and active participation in life for their child and family. They often forget about their health.

How can you be a champion for families?

Remove some of the load, parents can then focus on building a strong relationship with their child

- Connect them with local supports and services
- Assist them in filling out forms and reports
- Care planning / coordination
- Long-term relationship building



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SESSION 2

GENOMIC PSYCHIATRY

There are multiple factors that contribute to the cause of autism:

environmental factors | common genetic factors | **rare genetic factors**

Why is this relevant for autism

- Autism has a high genetic basis
- Individually rare but collectively common
 - o no **individual rare** genetic factor accounts for more than 1-2%
 - o **collectively common**, 40% of autism diagnosis have a specific genetic cause
- Heterogeneity & Overlap - **All for one and one for all**
 - o clinical presentation
 - o genetic etiologies
- Pleiotropy - individually rare genetic causes
 - o often affect multiple organ systems

What are the recommendations for genetic testing?

- Canadian Paediatric Society
- American Academy of Child and Adolescent Psychiatry
- American Academy of Pediatrics
- American Society of Human Genetics
- International Society of Psychiatric Genetics

Genetic testing is first line recommendation from multiple professional societies after autism diagnosis

EMPOWERING FAMILIES

Public Health Impact

**6,000
PEOPLE
→ IN EDMONTON ←
WITH AUTISM
FROM
A GENETIC
CAUSE**

Empower families with all the information they need so that they can make the best decision that aligns with their priorities and values by:

- Offering genetic testing
- Have genetic testing discussions in the clinic

What are the advantages of genetic testing?

- Etiological explanation, ends diagnostic odyssey
- Recurrence estimates and family planning
- Connecting with other families with the same genetic variant
- Alert about potential medical co-occurring conditions

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SESSION 2

GENOMIC PSYCHIATRY

EMPOWERING FAMILIES

Attitudes, perceptions, results of autism genetic testing

- Families have a high interest in genetic testing
- Families are familiar with basic genetic concepts
- Majority of families are not being offered genetic testing

91%
acceptance
of genetic testing

**Families are very supportive of genetic testing
Families will elect not to move forward based
on their own values and priorities**



This is possible now, how do we do this?

Modify treatment algorithms to include clinically actionable interventions

- Assessment of current clinical management guidelines to identify decision points where genetic information could alter clinical management
- susceptibility to specific medication side effects
- pharmacological treatment based on underlying biology
- Prophylaxis of co-occurring conditions
- Many more!

Sharing information

Like this video aimed at kids on the autism spectrum and their families, explaining in a clear and engaging way key concepts like autism, genetics and genetic testing. Watch the video, where you'll meet Bo, DiNA, and the rest of their friends!

To learn more about the PRISMA LIBRARY OF LIFE [Click HERE](#)

Whats your thing? Follow the spark!

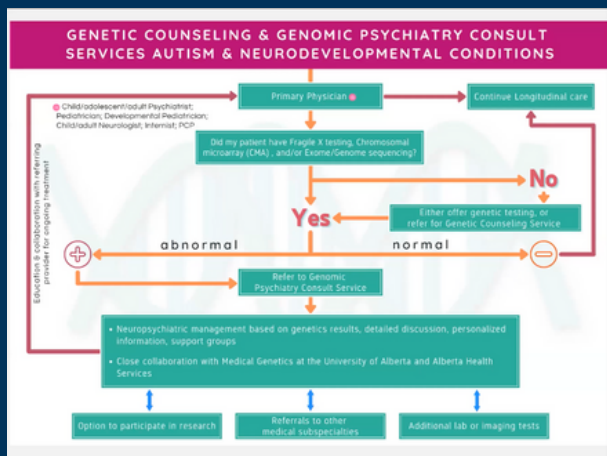
Celebrating difference:

- Empower the community and individuals to be the best version of themselves
- Acknowledge challenges
- Draw upon strengths

Having meaningful conversations

How to be a Champion

- Person centred care
- Shared decision-making & coordination with families
- Advocacy for continued research & support
- Mental health and emotional support
- Provide feedback
- Long-term relationship building
- Acknowledge expertise



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SESSION 3

PERSPECTIVES IN ADULT CARE



Adopting a lifespan perspective in autism care is crucial

Early diagnosis and intervention are key factors for success for autistic people as well as for their caregivers

Considerations during an appointment

- Any prior assessments available?
- What is the individual's level of functioning (is there an intellectual disability)?
- What supports and services are currently being utilised, have dropped off, or are needed?
- Does the patient require medication change or review?

Psychiatric Management

Medication:

Use with caution, primarily to address co-occurring conditions such as anxiety, depression, and ADHD. Monitor for unusual responses due to sensory sensitivities and communication differences

Psychological Treatments:

Adapt therapeutic techniques to accommodate communication styles, sensory sensitivities, and cognitive processing differences. Include cognitive-behavioral therapy (CBT) tailored for ASD, focusing on managing anxiety, improving social skills, and dealing with rigid behaviors.

Gender and Autism

- Females are genetically protected from autism, linked to X-chromosome gene expression
- Diagnostic bias - 4:1 male-to-female diagnosis, overlooking females
- Females with autism often develop adaptable skills to mask their autism traits, influenced by societal expectations.
- Higher rates of anxiety and depression are reported among females with autism, often due to unrecognized and undiagnosed symptoms.

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PERSPECTIVES IN ADULT CARE



Multidisciplinary Approach

Psychology:

Address mental health issues, improve coping strategies, and enhance understanding of social cues.

Speech Therapy:

Assist with communication difficulties, focusing on both verbal and non-verbal skills, and pragmatic language use.

Occupational Therapy:

Help manage sensory sensitivities, improve motor coordination, and teach daily living skills to promote independence.

Examples of multidisciplinary teams include:

COAST: Community Outreach Assessment Support Team

<https://www.albertahealthservices.ca/findhealth/Service.aspx?id=1084126&serviceAtFacilityID=1133471>

BARRIERS

to supports and services

70 IQ

LIMITED

SPECIALIZED PROGRAMS

**GEOGRAPHIC
DISPARITIES**

STIGMA

W
a
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Supports and Services

Education and Training:

Provide specialized programs to enhance life skills, social interaction, and vocational abilities. Emphasize the development of routines that accommodate the individual's needs and preferences.

Social Support/Care:

Engage community resources and social services to offer supportive environments, social groups, and activities that cater to individuals with ASD, promoting social integration and participation.

Autism Edmonton

[Click HERE to view supports and services which include:](#)

Support, advocacy, employment, housing workshops

Gateway Association of Edmonton

[Click HERE to view supports and services which include:](#)

Employment, family resources, resource centre

Collaboration and Inclusion

Family and Carers:

Involve families and carers in the treatment and support plan, providing education and resources to understand ASD better and support their loved ones effectively.

Integrative Services:

Foster collaboration among healthcare providers, educational institutions, employment services, and voluntary organizations to create a cohesive support network.

Autonomy and Self-Advocacy:

Encourage self-advocacy and participation in decision-making processes, respecting the preferences and autonomy of individuals with ASD.

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SESSION 3

INSIGHTS INTO AUTISM AND FIRST NATIONS PEOPLE: PERSPECTIVES FROM A PARENT, COMMUNITY MEMBER, AND RESEARCHER

Critical need for research that addresses autism in Indigenous communities within Canada and shows the importance of having research done in full partnership with, or led by, Indigenous people

Indigenous Autism in Canada: A Scoping Review Bruno et al. 2023

Indigenous | Autism deficit discourse

- Contributes to stigmatization when problematic health issues are repeatedly characterized in the context of a specific population.
- Risk of stereotyping
- Perpetuates negative characterization

DSM-5

Abnormal social approach and failure of back and forth conversations

Deficits in non verbal communicative behaviours used for social interaction

Strengths-Based

Tendency to talk passionately about certain topics and not engage in small talk

Differences in nonverbal communication, including stimming while talking, looking elsewhere, or being bored



Strengths-based approach

See each person for who they are

- supporting autistic people
- capture and share stories of success, resilience, and positive experiences
- capacity building within individuals and communities, aiming to enhance their abilities, skills, and resources

The Gift of Being Different

View **HERE**: https://youtu.be/Rw_aleWg5Ac?si=OPnh_jgVv965Jj8o

Acahk Pimâtsiwin
"A spiritual way of life"

How to support First Nations Families

- It is all about relationships / connections (wahkotôwin)
- Become trauma informed / post traumatic growth
- Lean into discomfort / uncomfortable conversations
- Look upstream for solutions
- Meet families where they are at
- Ongoing reflexivity
- Become aware of the -ism's ableism/racism
- Be flexible and patient
- Get familiar with the Truth and Reconciliation Commission calls to action

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RESOURCES - SUPPORTING FAMILIES ACROSS A LIFESPAN



UNDERSTANDING FUNDING SUPPORTS



CONTRIBUTION TO FAMILY CARE



MEANINGFUL CONVERSATIONS WITH FAMILIES

DTC Disability Tax Credit <https://www.canada.ca/en/revenue-agency/services/forms-publications/forms/t2201.html>

Provides a tax credit for people with impairments, or their supporting family member, that lowers the amount of income tax they may owe when they do their taxes every year. Eligible individuals can claim up to \$9,428, with an additional \$5,500 for those under 18. You need to apply for the DTC and once approved, you can claim it when doing your taxes.

A medical practitioner certifies that you have a severe and prolonged impairment in 1 of the categories, significant limitations in 2 or more categories, or receive therapy to support a vital function:

walking, mental functions, dressing, feeding, eliminating (bowel or bladder functions), hearing, speaking, vision, life-sustaining therapy

Ask families that qualify if they have applied for DTC
Understand that DTC reduces the amount of income tax you may have to pay by offsetting some of the extra costs related to the extraordinary care needs.

Help with and sign the application form. Some approved DTC applications expire after a certain number of years and you will have to re-apply. DTC eligibility may help you access other federal, provincial, or territorial programs.

FSCD Family Support for Children with Disabilities <https://www.alberta.ca/fscd-how-to-apply>

The program aims to enhance the quality of life for children with disabilities and their families by providing funding for various supports and services tailored to the individual needs of each child.

- Family Support Workers
- Therapies and Interventions
- Respite and Community Aide funding
- Extraordinary costs of care

Confirmation the child has a disability or is awaiting a diagnosis.

The diagnosis for a disability or health condition must: be chronic, be a developmental, physical, sensory, mental or neurological condition or impairment, health condition that impacts their daily living activities such as eating, grooming, walking, interacting with others, playing and problem solving

FSCD supports help to build a strong relationships within the family and community environments.

Help families recognize that respite is not a babysitting service but an opportunity to take a break from their caregiving responsibilities and provide socialization opportunities, a break from daily routine at home, exposure to other environments.

There is quite a lot of responsibility placed on the care provider to manage contracts and find care providers. However these opportunities do help to increase the capacity of parents.

PDD Persons with Developmental Disabilities <https://www.alberta.ca/pdd-how-to-apply>

The adult program aims to enhance the quality of life, independence, and inclusion of individuals with developmental disabilities by providing a range of services and supports tailored to their specific needs.

- Community Supports
- Respite Services
- Supported Living Services

General criteria for eligibility for PDD supports and services include:

Diagnosis of Developmental Disability: Specifically, a diagnosed developmental disability that significantly impairs their intellectual or adaptive functioning. This must impact the individual's ability to perform daily living activities, communicate, learn, and/or participate in social interactions or community life.

It is important to understand that PDD assesses eligibility and support needs on a case-by-case basis.

An IQ score of 70 is often a significant factor in determining eligibility and support needs in addition to adaptive functioning. The process to access PDD and other adult services takes quite some time. Individuals are encouraged to start applications around 16 years of age.

AISH

Assured Income for the Severely Handicapped
<https://www.alberta.ca/aish>

This program in Alberta is designed to provide financial and health-related assistance to eligible individuals with disabilities who have a severe and permanent impairment that prevents them from earning a living.

Trusteeship

<https://www.alberta.ca/trusteeship>

Guardians can only make personal decisions, they cannot make financial decisions. Consequently trusteeship may be considered.

Alternatives to trusteeship include:

- informal trusteeship
- enduring power of attorney

Guardianship

<https://www.alberta.ca/adult-guardianship>

Where an individual seeks legal authority to make decisions on behalf of someone who is incapable of making those decisions for them. Individuals considering applying for guardianship should seek legal advice to understand their rights and responsibilities and navigate the application process effectively.

Alternatives to guardianship include:

- supported decision-making
- specific decision-making
- a personal directive
- co-decision-making