

Understanding Down Syndrome: Key Facts, Strengths, and Supports



First Nations Technical Services
Advisory Group



edmonton
down syndrome
society

Land Acknowledgement

EDSS respectfully acknowledges that we are gathered on Treaty 6 territory, the traditional lands of the Cree, Dene, Blackfoot, Saulteaux, Nakota Sioux, and Inuit peoples. We recognize the enduring relationships Indigenous Peoples have with this land and honour their histories, cultures, and contributions. As an organization that works alongside families and communities, we commit to listening, learning, and building respectful relationships in our shared work.



Director of Community and Family Services



I have been with the Edmonton Down Syndrome Society for 10 years and have over 26 years of experience in Human Services.

In my role, I provide personalized support and guidance to individuals with Down syndrome and their families as they navigate a variety of systems and services. This includes helping families access government supports such as Guardianship, PDD, FSCD, Jordans Principle and AISH, as well as advocating for appropriate accommodations in schools, childcare, and workplaces.

I am committed to empowering families and individuals with the knowledge, tools, and confidence they need to successfully navigate the complexities of life with a disability.





Edmonton Down Syndrome Society

- The Edmonton Down Syndrome Family Support Group was founded in 1988 by four families.
- Parents shared information about services, things they had read and practical suggestions on child raising. They talked about how to motivate their kids to move and learn.
- The group grew larger, and they wanted to do more for their kids and families. So, they organized a volunteer board of directors, made up of community members and parents.
- In 1995 they incorporated as a charitable organization as the Edmonton Down Syndrome Society.
- In 2008, in partnership with Capital Health, EDSS funded a pilot project to develop a Pediatric Down Syndrome Medical Clinic at the Stollery Children's Hospital after 2 years the project received full funding through Capital Health. The Clinic's caseload now exceeds 600 children a year.



Mission-Vision-Values



Our Mission - is to empower individuals with Down syndrome and their families by fostering a strong inclusive community, delivering transformative support and services across all life stages, and driving systems change through advocacy, innovation and partnership.

Our Vision - is of a society where inclusion of people born with Down syndrome in our communities not only enriches their lives and gives them the confidence necessary to achieve their full potential but also creates awareness, knowledge, compassion and inspiration for all of society.

Our Values - will be guided by our beliefs and commitment to Inclusiveness, Quality, Transparency and Participation.

What is Down syndrome?

Down syndrome happens when chromosome 21 has 3 copies instead of 2. Typical people have 46 chromosomes, people with Ds have 47. When babies are growing, the extra chromosome changes how their body and brain develop. This can cause both physical and mental challenges.

Down syndrome is not a disease or illness; you can't catch it like a cold or a flu. It is a genetic make up like you having blonde or brown hair.

- There is no cure for Down syndrome
- Down syndrome is not a spectrum disorder
- Down syndrome is the most common genetic disorder in Canada and worldwide.
- Down syndrome is not caused by something parents did
- There is no correlation between the number of Ds characteristic a baby has and the person's cognitive ability.



There are 3 types of Down syndrome

- **Trisomy 21**



- **Translocation**



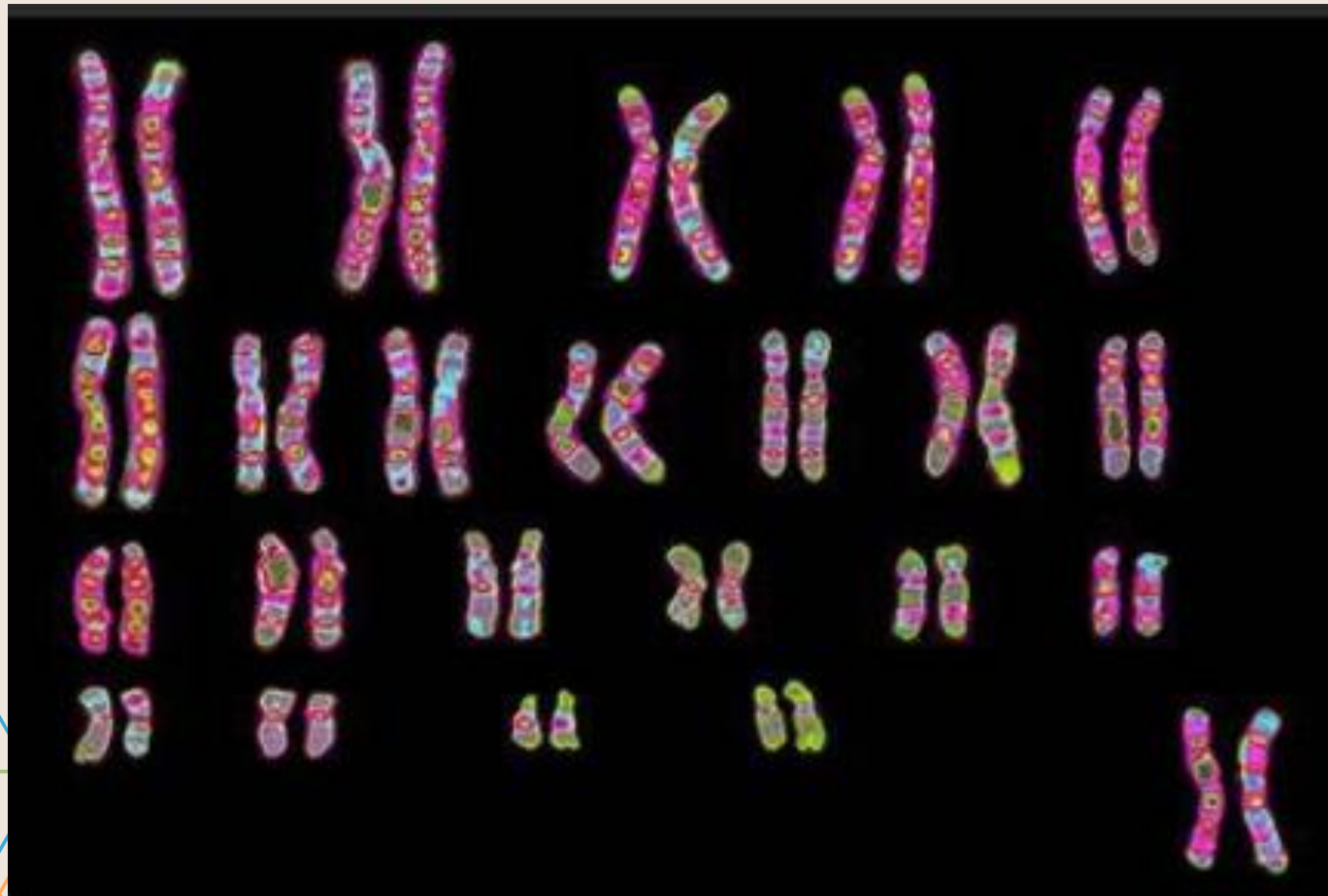
- **Mosaic**



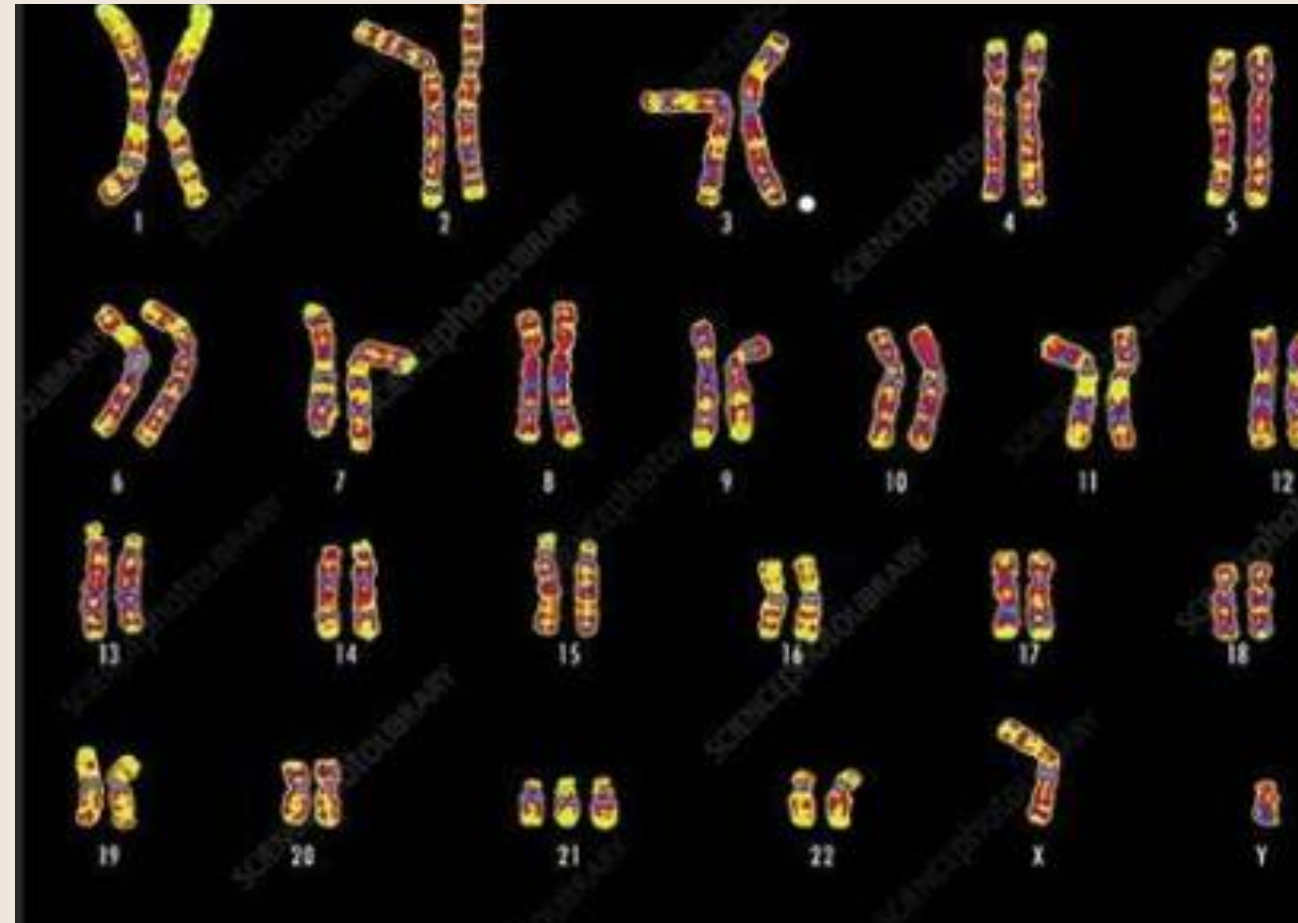
Typical person Vs Trisomy 21

Down syndrome Karyotype

TYPICAL



TRISOMY 21



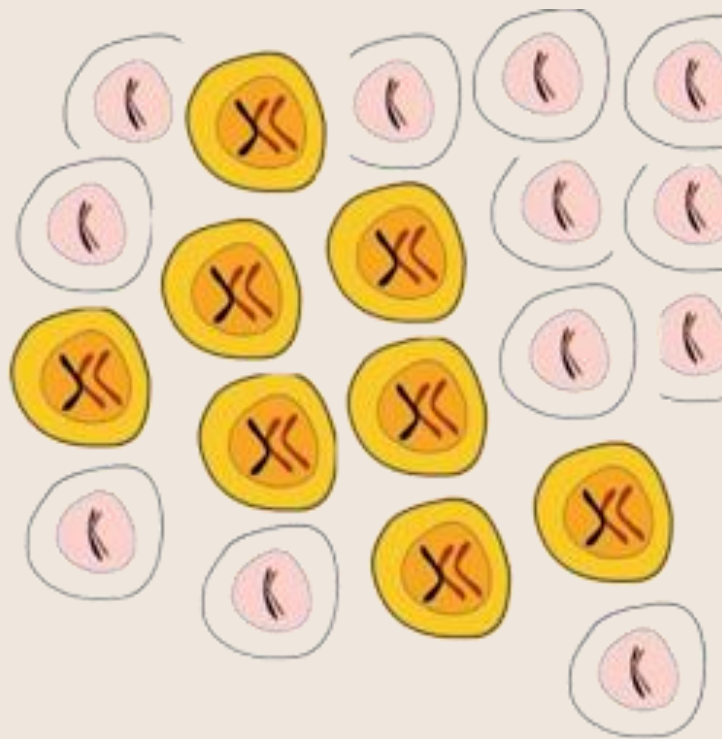
Mosaic Vs Translocation

Down syndrome Karyotype

MOSAICISM

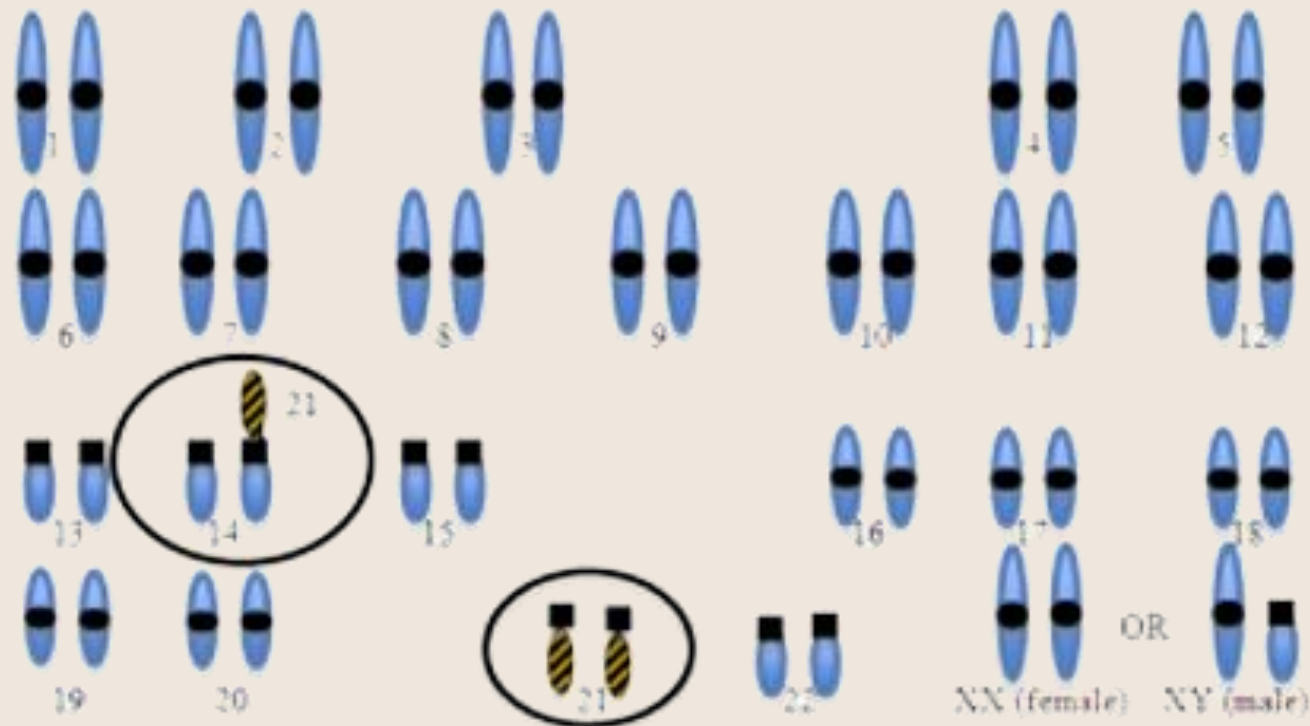
**Mosaic
Down
Syndrome**

Mosaicism



People with mosaic Down syndrome have a mixture of cells.

TRANSLOCATION



An extra copy of chromosome 21 is attached to another chromosome.

Can anyone be born with Down syndrome?

YES, It doesn't matter

...if you are a boy or girl.
...what your nationality is.
...where you were born.
...if you are rich or poor.
...who your parents are.



Down syndrome just happens, like winning the lottery.

Language to use when referring to a person with Down syndrome

- The correct terminology is Down syndrome. There is no apostrophe and there is no capital "s" in syndrome.
- A shorter way of writing Down syndrome is Ds.
- The syndrome is named after the physician, Dr. John Langdon Down, who identified the common characteristics as a syndrome in 1866.
- People with Down syndrome should always be referred to as people first. Instead of a "Down syndrome child," it should be "a child with Down syndrome."



Myths and Facts about Down syndrome

Myth 1: People with Down syndrome have a short lifespan. **Fact:** With modern medical care and early support, individuals with Down syndrome can live well into their 60's and beyond.

Myth 3: Down syndrome is hereditary and runs in families. **Truth:** Only 1% of all cases are hereditary. In 99% of cases, Down syndrome occurs randomly. The only type with a hereditary link is Translocation.

Myth 4: Most children with Down syndrome are born to older women. **Truth:** While risk increases with age, most children with Down syndrome are born to women under 35, simply because younger women have more children.

Myth 5: A child with Down syndrome will negatively impact siblings. **Truth:** Studies show no negative effects. Siblings often develop greater empathy, tolerance, and compassion.

Myth 6: People with Down syndrome cannot have Children. **Truth:** Some can, Women more easily than men, though fertility rates are lower overall. About 35–50% of children born to mothers with Down syndrome are also born with Down syndrome.

Common Physical Characteristics

- Distinct facial features such as a flat bridge of the nose
- Palmer crease on the palms
- Short stature
- Small hands and feet
- Extra space between the big toe and adjacent toe
- An extra fold of skin around the eyes
- Widely spaced and upward-slanting eyes
- Structural differences in the mouth and ears



WIDELY SEPERATED
FIRST AND
SECOND TOES AND
INCREASED SKIN CREASES

TYPICAL PALM



PALMER CREASE



Common Developmental Concerns

- Neurological and cognitive differences – Thinking, memory and attention, processing information and problem solving.
- Mild to moderate intellectual delays – take longer to learn new things and understand ideas.
- Behavioural issues, which we will get too soon
- Speech deficits -may have trouble talking clearly or getting their words out the way they want. They might speak slower, use fewer words and have difficulty pronouncing some sounds.
- Memory impairment -may have trouble remembering things, like instructions, names, or steps in a task. They might need reminders, visual cues, or extra practice to help them remember important information.
- Higher prevalence of autism spectrum disorder (16 to 18%)



Common Health Concerns

- Congenital heart defects - 50% are born with this
- Vision and hearing impairment- higher incidence of hearing and vision loss.
- Thyroid problems – increased risk of hypothyroidism
- Respiratory issues – increased infections and respiratory problems
- Sleep disorders – Obstructive Sleep Apnea
- Mental health issues – 50% - anxiety, OCD, oppositional behaviours, tics and depression.
- Childhood leukemia – about 3%
- Early-onset Alzheimer's and dementia – 50%

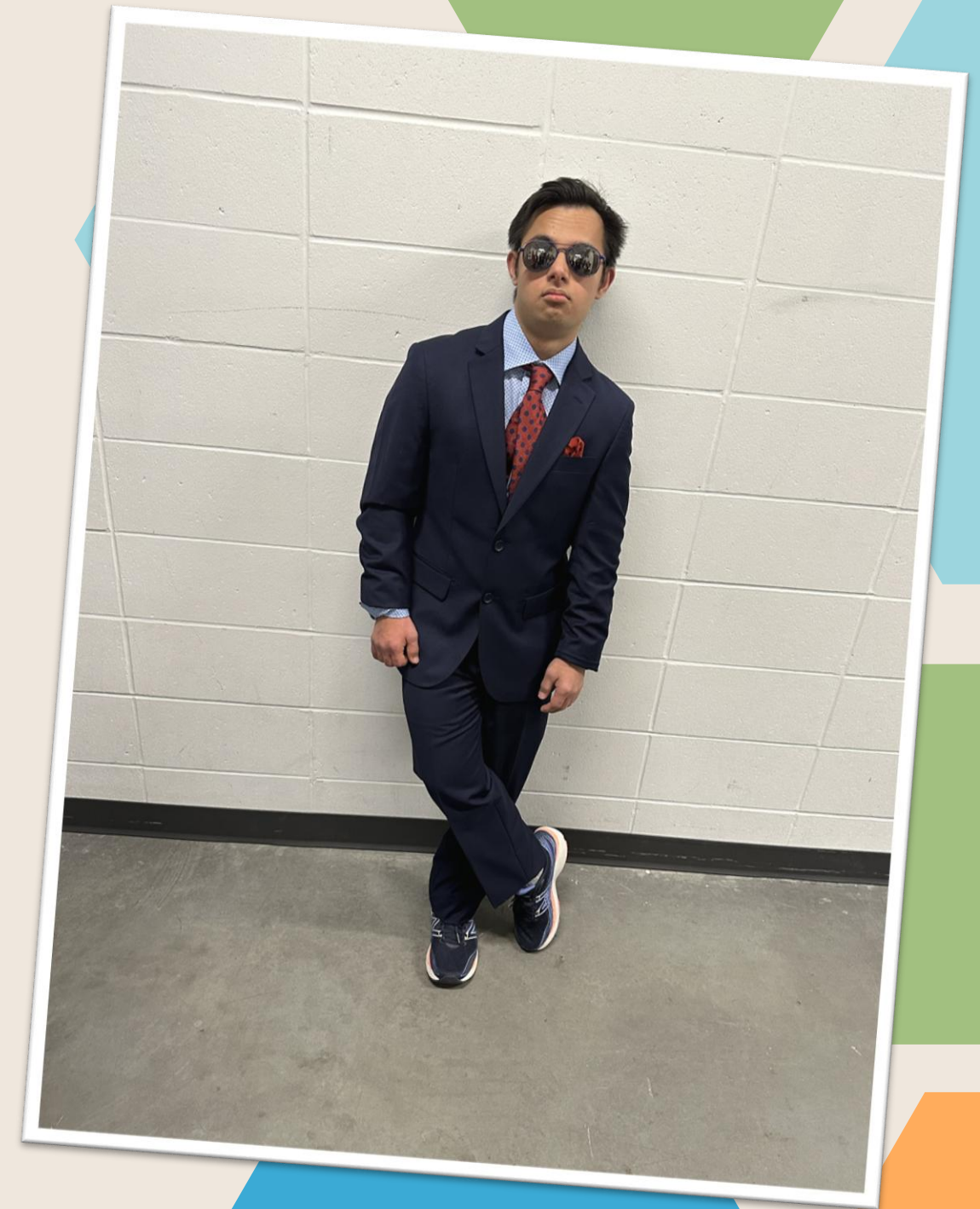


Understanding Challenging Behaviour

People with Down syndrome may be more likely to show behaviours that can be challenging at home, school, or in community.

Examples of Challenging Behaviours:

- Noncompliance (refusing tasks or directions)
- Attention-seeking actions
- Self-injury or aggression
- Repetitive or compulsive behaviours (e.g., arranging, repeating actions)
- Withdrawal or avoidance



Why These Behaviours Occur

Common Contributing Factors:

- **Communication challenges** — difficulty expressing needs
- **Sleep difficulties** — poor rest affects regulation and mood
- **Medical issues** — frequent illness or pain
- **Environmental responses** — how adults react can reinforce behaviours

Tip:

When we understand the *why*, we can prevent rather than react.



What is Behaviour?

What is Behaviour:

Behaviour is anything a person says or does (breathing, talking, smiling, crying, hitting)

Behaviour is always learned and serves a purpose

Can be subjectively positive or negative



Fun activities to build listening skills

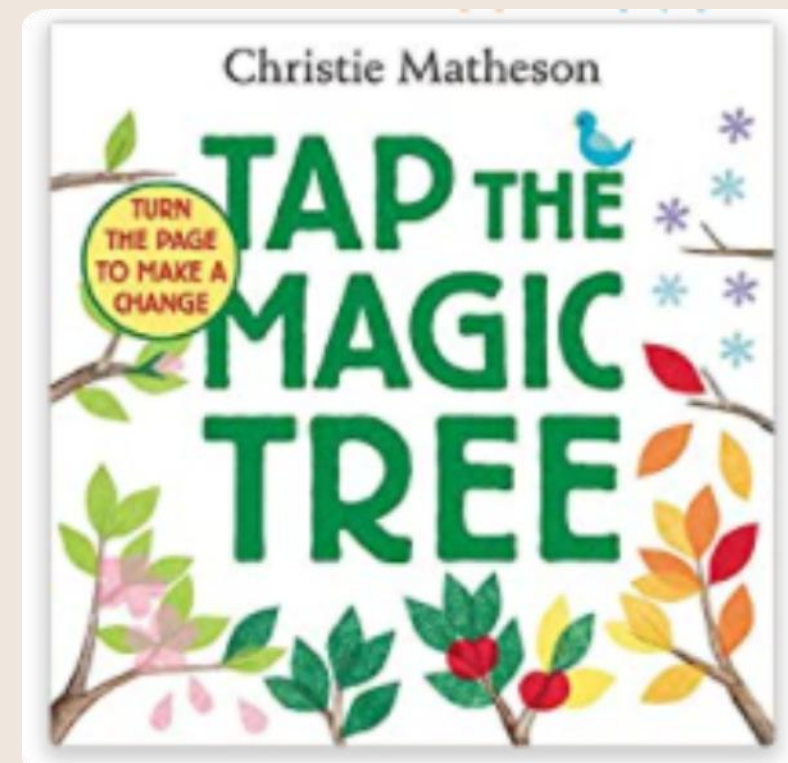
Red light, green light

Simon says

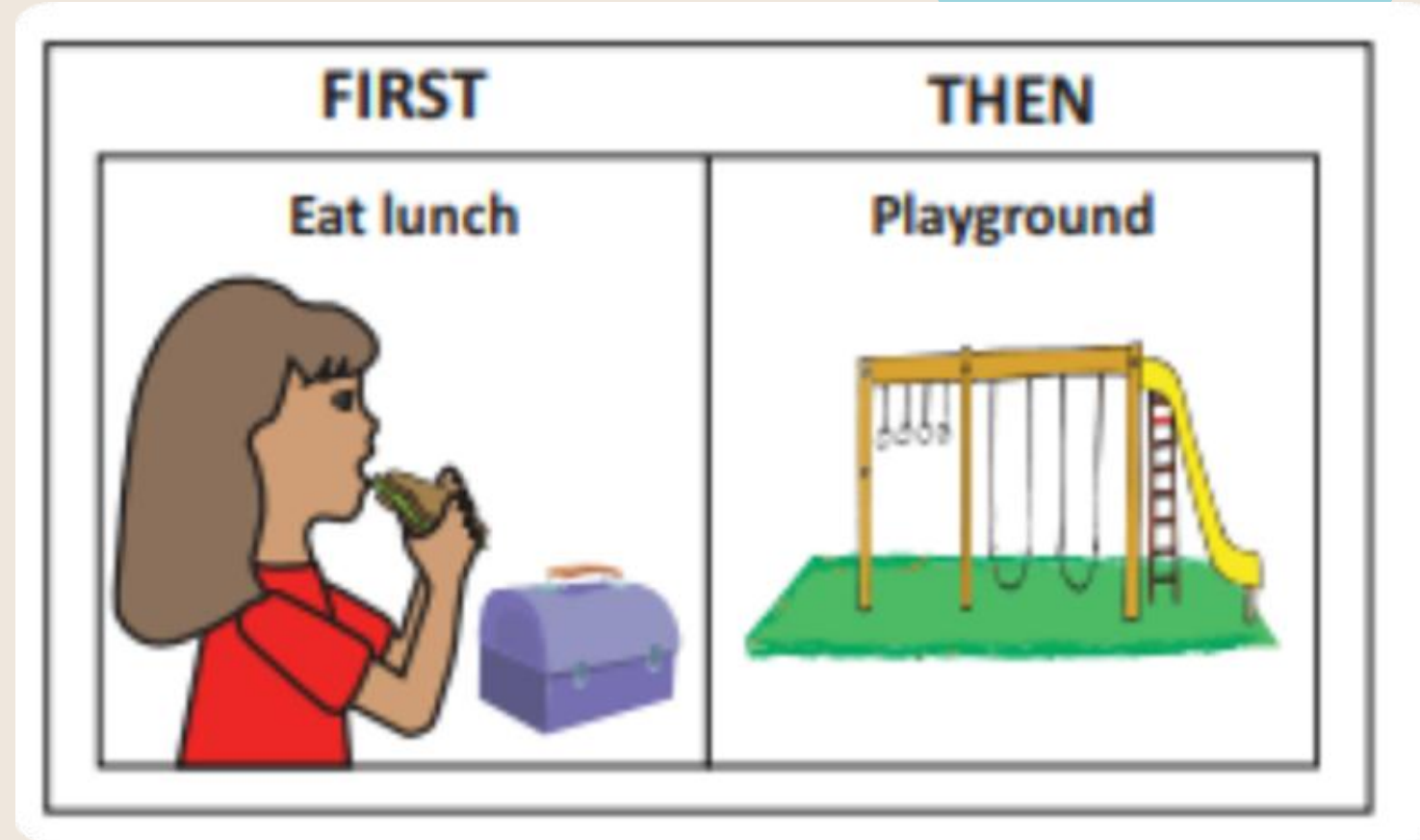
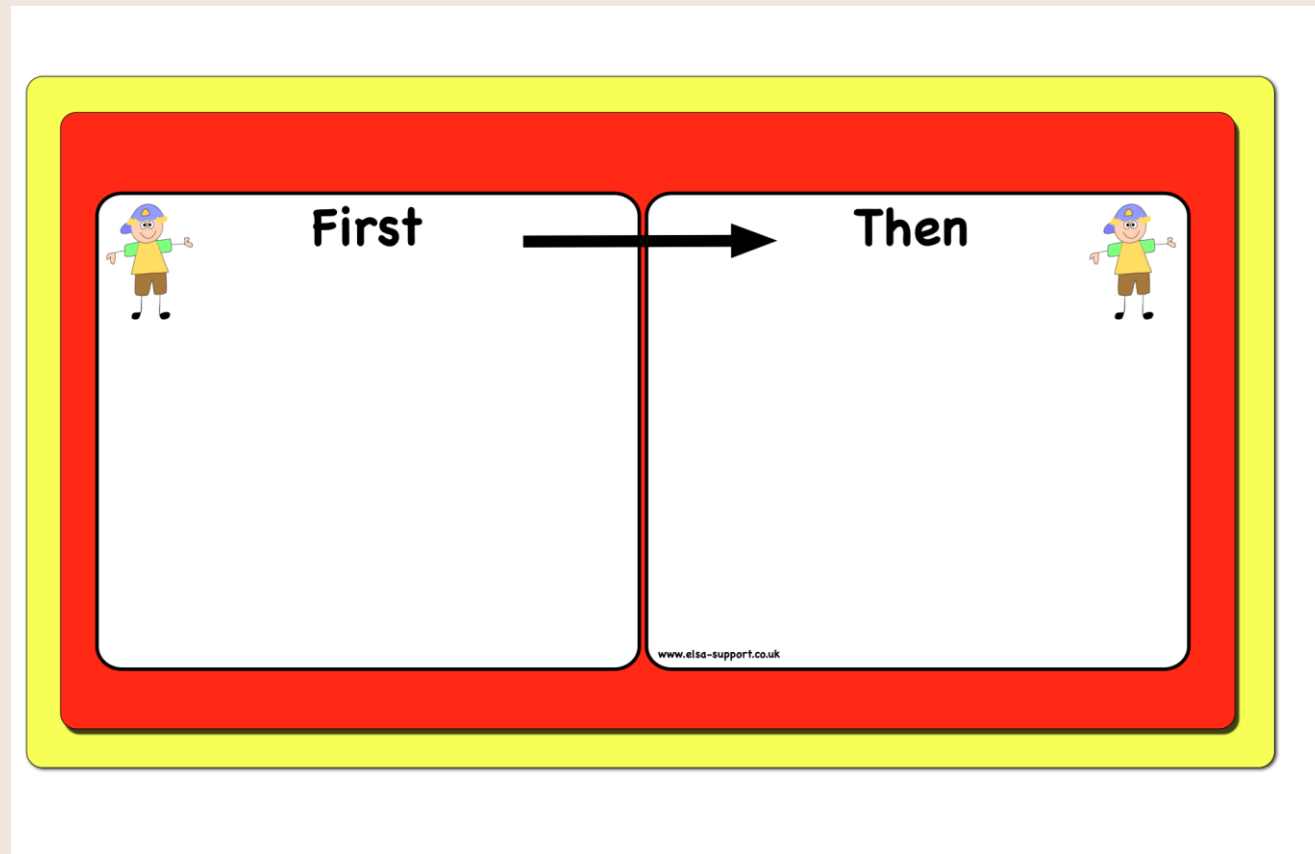
Tap the magic tree

Telephone

Freeze dance



Visuals –how do they help?

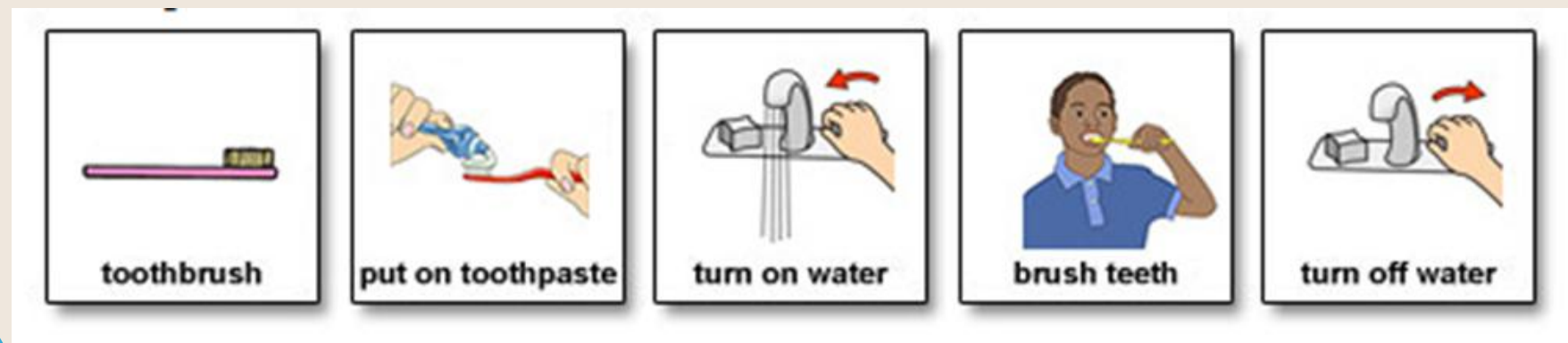


First - child follows through with an expectation or demand from an adult

Then - they get a reward by doing something they like

Visual Schedules

- Start by pointing to each activity and labelling it enthusiastically, ex. Breakfast, play time, snack
- Give transition warnings before end of an activity (Bonus hint: use timers if transitions are difficult)
- Show the schedule again when activity ends and then point to and label the next activity while beginning to move toward the area
- Reference throughout the day, not only during transitions
- Children do not need to know the symbols or words before you start; when you consistently pair them with the activity, they begin to learn that is what they mean
- Portable schedules help with quicker transitions
- Try to make them as clear and accurate as possible
- Praise, praise, praise!!!



Routines – Are they important?



Here's Why?

- **Provide stability and security** – to feel calm and safe
- **Promote independence** by helping children learn what to expect and do on their own.
- **Build positive habits** that support learning and daily life.
- **Reduce anxiety** by making the day more predictable and easier to understand.
- Routines aid in **cognitive development and social skills**, making them a vital part of their daily lives. i.e.: time and sequencing.

Kids At Home DAILY SCHEDULE

Early
Morning

Mid
Morning

Lunch

Early
Afternoon

Late
Afternoon

Evening

 superhealthykids

Supporting People with Down Syndrome

What can you do?

- **Provide autonomy and choice in daily life and learning:**

What is perceived as “stubbornness” often happens when individuals are not given choices or decision-making opportunities.

- **Ensure access to safe healthcare:**

People with Down syndrome are living longer, healthier lives, but access to healthcare can be unequal across regions, including in Indigenous communities.

- **Support emotional well-being and social connection:**

Individuals with Down syndrome experience the full range of emotions, including grief, loneliness, and friendship challenges. These experiences are often underrecognized.

- **Share successful strategies across communities:**

Edmonton Down Syndrome Society identify strategies that are effective in one context and with support from the community can adapt them for other communities. This ensures that supports for people with Down syndrome are evidence-based, scalable, and respectful of cultural and community differences.





Supporting Indigenous People with Down Syndrome in Community



At EDSS, we understand that every family and community is unique, and there's no single way to support someone with Down syndrome. We work with you to build supports that respect your strengths, values, and ways of caring.

We know accessing services can be challenging, Geographic distance, limited resources, and past experiences with systems can make it harder for families to seek or trust support.

Collaboration is at the heart of what we do. We work with families, community leaders, and organizations to create supports that are meaningful and lasting.

We take a strengths-based approach, focusing on inclusion, communication, and participation to help people with Down syndrome build independence, confidence, and a sense of belonging.

We are here to listen, show up consistently, and hopefully work in partnership with you—honouring both your needs and your community's strengths.”



Quick Tools & Resources

Visual & Behaviour Tools:

- Visual schedule templates
- Emotion regulation visuals (e.g., *Zones of Regulation*)
- Positive reinforcement charts
- First/Then boards
- Social stories templates
- Choice boards
- Behaviour tracking sheets
- Visual timers and countdown tools
- Calm-down kits / sensory boxes

CONTACT ME FOR ANY OF THESE

Websites & Organizations:

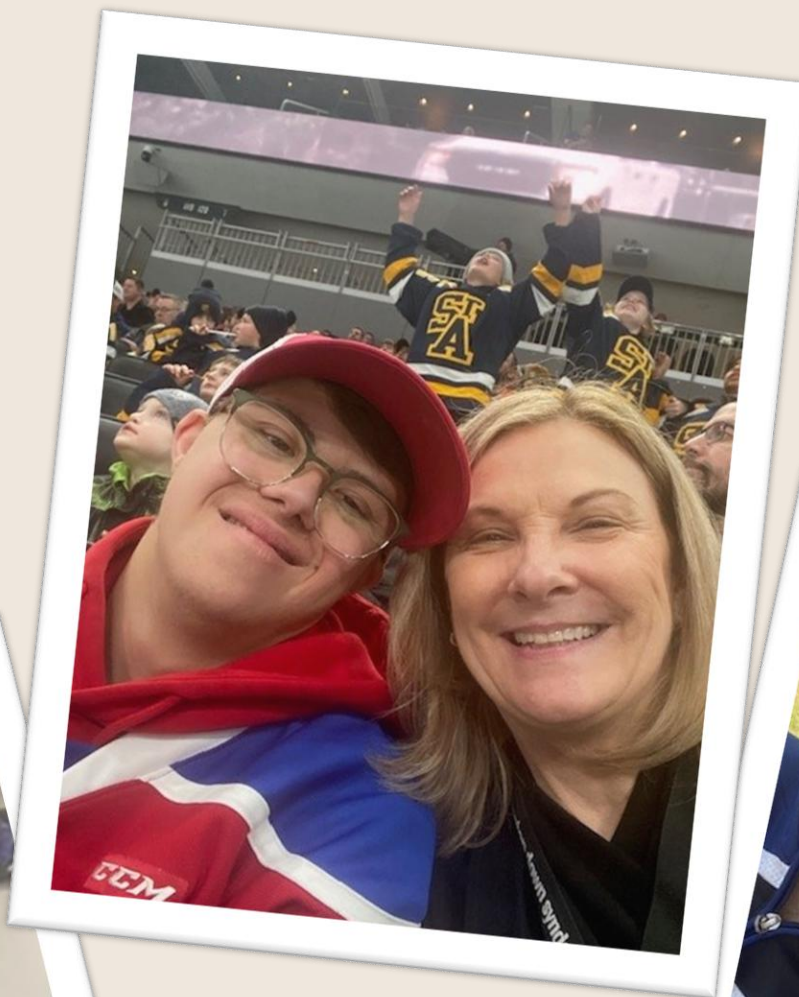
- Jordans Principle - [Jordan's Principle](#)
- First Nation Health Consortium - [First Nations Health Consortium – Community Links Resources](#)
- Otipemisiwak Métis Government - [Who We Are - Otipemisiwak Métis Government](#)
- Down Syndrome Resource Foundation (DSRF) – [dsrf.ca](#)
- The Hanen Centre – [hanen.org](#)
- Positive Behaviour Support (PBS) Canada – [pbs-canada.ca](#)
- Canadian Down Syndrome Society (CDSS) – [cdss.ca](#)
- National Down Syndrome Society (NDSS, US) – [ndss.org](#)
- Autism & Behaviour Support Resources (Autism Speaks, free strategies) – [autismspeaks.org](#)



Books you can learn more about Ds



QUESTIONS





Thank you for listening!

Feel free to send in any questions to
Julie@edss.ca.

Director of Community and Family Services



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