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Photo by Hilary Gauld from
One for the Wall Photography

Message from the Chair

It is hard to believe that 2026 has arrived! I hope everyone enjoyed a safe, healthy, and joyful holiday season with family and friends, and that there was also a little time to relax before the New Year got underway.

Before we kicked off the holiday season, November was a very busy and meaningful month for WWDSS. We hosted our Fall Mini Conference, which was attended by more than 65 members. While children enjoyed daycare on site or headed out on a field trip to FunVilla, parents and caregivers had the opportunity to hear from knowledgeable experts on planning for the future, covering both legal and financial perspectives. The sessions were incredibly informative and provided families with valuable tools and insights as they think ahead and plan with confidence.

December was a wonderful way to close out 2025 for WWDSS. Over 100 members joined us at our Holiday Party at The Alpine Club, and it truly kicked off the holiday season in a memorable way. Families enjoyed games, cookie decorating, door prize draws, and singing along with the Buddy Choir, all capped off with a very special visit from Santa Claus. It was heartwarming to see so many smiling faces. A sincere thank you to Mandi Butcher and her dedicated volunteers for organizing such a fantastic event—it was a perfect way to end the year.

Earlier that week, a group of Moms and Caregivers enjoyed a fun night out at Del's Italian Kitchen in Kitchener. It was an evening filled with laughter, connection, and great conversation. Thank you to WWDSS for providing delicious appetizers, and to Janice Duncan for organizing such a lovely opportunity for parents & caregivers to connect.

Just before the holidays, our adult members from The Office and many parents gathered for a holiday dinner at Crabby Joe's. It was a fabulous evening of good food, friendship, and fun, and a reminder of how important these social connections are within our community.

Looking ahead, we have many exciting events planned for the coming months. In February, we will once again be hosting our popular Bowling Party on Sunday, February 22nd. This is always a well-attended family event, so be sure to register early as space is limited.

We are also very happy to share that Parent Connection will be starting up again in the New Year. This facilitated program is designed for families with children under the age of six and will run on Saturday mornings. Final details are being confirmed and families in this age group will receive registration information by email soon.

In March, we look forward to celebrating World Down Syndrome Day on March 21st. Our organizing committee is already hard at work planning an in-person evening celebration, along with school and public awareness activities. This year, WWDSS will also create a special World Down Syndrome Day t-shirt. Each member with Down syndrome will receive a free t-shirt if it is pre-ordered, and additional shirts are available for purchase for family and friends through our website. We encourage everyone to join us as we celebrate and raise awareness together.

In April/May, we will host our Annual General Meeting and Mini Conference and we are always eager to welcome new members to our Board of Directors. If you have ever considered getting more involved or bringing fresh ideas to the table, I encourage you to reach out to learn more about what board membership involves or to put your name forward for nomination.

As you read through this newsletter, you will also see many volunteer opportunities. WWDSS continues to grow, and our programs and events depend entirely on the support of volunteers. Please remember that volunteers do not need to be parents—friends, siblings, aunts, uncles, or grandparents are all welcome to help. Without volunteer support, many of the programs our families value would not be possible.

Finally, I am always open to suggestions for programs or events. Please feel free to email me or call me directly if you have ideas you would like to share. Thank you for your continued support of WWDSS, and I look forward to another meaningful year together.

With Gratitude,

Arisa Alexanian

Chair, Waterloo Wellington Down Syndrome Society

WWDSS Board of Directors for 2025-2026

| | | | |
|------------------------------------|---------------------------------------------|-------------------------------------------|-----------------------------------------------|
| Chair Arisa Alexanian | Treasurer Sylvia Cook | Director At Large Merita Elmazi | Director at Large Kim Murphy |
| Vice Chair TBD | Director At Large Jocelyne Bridle | Director At Large Tony Fraser | Director at Large Janine Oosterveld |
| Past Chair Lisa Buurma | Director At Large Jenn Burechails | Director at Large Tara Hart | Director at Large Janine Rorke |
| Secretary Tracey Kuepfer | Director At Large Janice Duncan | Director at Large Lori Maloney | Director at Large Roberta Thompson |

WWDSS Committee Leads for 2025-2026

| | | | |
|-------------------------------------------------------------------------|---------------------------------------------------|-----------------------------------------------------------------|---------------------------------------------------------------------------------------------|
| Newsletter Lisa Buurma | Pizza Pals Susan Powell - Older Group | WWDSS World Down Syndrome Day Celebration Lisa Buurma | Teen Hangouts TBD |
| New Parent Contact – Kitchener-Waterloo Hanika Williams | Pizza Pals Tamara Perez - Younger Group | WWDSS Family Picnic Lisa & Ross Buurma | The Office Meetups (18+) Lori Maloney Emily Pike Mary Pike |
| New Parent Contact – Cambridge Jenn Burechails | WWDSS Calendar Kate Herron | WWDSS Social Media Vanessa Richard | Independence Skills Program Jocelyne Bridle & Sylvia Cook |
| New Parent Contact – Guelph/Wellington County Vanessa Richard | Adult Programming Bursary Wendy Eichler | Volunteer Coordinator Julie Maxwell | Up Side Down Charity Golf Tournament Mike Hellyer |
| WWDSS Website Steve Nicholson | Therapy Bursaries Alison Senior | Any Which Way You Can A-Thon Janine Oosterveld | Employment Skills Program Tracey Kuepfer |
| WWDSS Store Merita Elmazi Tony Fraser | Transition Bursary Marianne Domm | WWDSS Holiday Party Mandi Butcher | Music & Speech Social Groups Mary Casagrande - Guelph Tracey Kuepfer - K-W |
| WWDSS Cooking Classes Julian Gordon | Camp Bursary Sylvia Cook | Parent's Connection Wendy Newbery | |
| | WWDSS Bowling Party Merita Elmazi | Moms' Night Out Janice Duncan | |

WWDSS Representatives

PAAC on SEAC
Marianne Domm

DSAO Representative
Lori Maloney

CDSS Representative
Amber Barens

Waterloo Region

SEAC – Catholic
Primary - Kim Murphy
Alternate - Gillian Hadden

SEAC – Public
Primary - Roberta Thompson
Alternate - Jeff Senior

Guelph/Wellington County

SEAC – Catholic
Primary - Katrina Fraser
Alternate - TBD

SEAC – Public
Primary - TBD
Alternate - TBD

Mission Statement

The Waterloo Wellington Down Syndrome Society (formerly the Waterloo Regional Down Syndrome Society) supports and informs individuals, families and the community on issues related to Down syndrome. We advocate for persons with Down syndrome to lead healthy and active lives enabling them to contribute their unique gifts to our community.



Fall Mini Conference: Planning Your Family's Future

by Lisa Buurma

We had a fabulous turnout for our Fall Mini Conference at KidsAbility in Waterloo on Saturday November 15. While members took part in engaging conference sessions, the children and adults enjoyed daycare onsite and a fun field trip to FunVilla alongside their support workers. This thoughtful balance allowed everyone to have a meaningful and enjoyable experience, making the day both productive and memorable for all involved.

The conference began with a wonderful presentation by self-advocate Emily Pike. She shared insights from her life with conference guests, and her presentation was very well done and warmly received. Following Emily's talk, the first session focused on **Planning for the Future: Wills, Trusts, and Guardianship** with guest speaker Cristina MacKenzie from SorbaraLAW.

After a delicious lunch provided by Pepi's Pizza, Patricia Benoit, Financial Advisor, gave an informative presentation on **Future Financial Planning for Families and Individuals with Down Syndrome**.

SESSION 1: Estate Planning for Families Supporting Loved Ones on ODSP

Why thoughtful planning protects both your family and your loved one's future

Estate planning is an important process for everyone—but for families who have loved ones receiving government supports such as the Ontario Disability Support Program (ODSP), proper planning becomes absolutely essential. A well-crafted plan ensures that you can provide for your child or family member after you are gone **without jeopardizing the benefits they rely on today**.

Below is an overview of key concepts and tools that can help you protect your loved one's future.

Why Every Family Needs a Will

A Will is more than a legal document—it is your voice after you're gone. It allows you to:

- Direct how your assets will be distributed
- Choose who will manage your estate
- Appoint guardians for minor or dependent children
- Protect a loved one receiving ODSP

Without a Will (a situation called intestacy), Ontario's Succession Law Reform Act dictates how your estate is divided. This may not reflect your wishes, can cause delays and legal costs, and may even result in your loved one inheriting assets directly—potentially affecting their ODSP eligibility.

The Importance of Powers of Attorney

Powers of Attorney (POAs) ensure someone you trust can make decisions on your behalf if you become incapable. Ontario recognizes two key types:

1. Continuing Power of Attorney for Property – manages financial decisions
2. Power of Attorney for Personal Care – handles health and personal decisions

Choosing these individuals is critical. Attorneys and Executors should be trustworthy, responsible, financially competent, and—when possible—live nearby. When family or friends are not appropriate choices, a professional trustee can be appointed.

Estate Planning Techniques for ODSP Considerations

1. Financial Planning

Effective planning includes understanding ODSP rules, benefit limits, and available savings options like the Registered Disability Savings Plan (RDSP). RDSPs allow long-term tax-deferred growth and may qualify for government grants and bonds. Contributions can be made by anyone, but withdrawals belong only to the beneficiary.

2. Tax Planning

Families should review available federal disability-related credits and deductions, including the Disability Tax Credit, Canada Caregiver Credit, and various medical expense credits. Maximizing tax benefits increases disposable income and helps preserve assets for future needs.

3. Henson Trusts: Protecting ODSP Eligibility

A cornerstone of planning for individuals receiving ODSP is the **Henson Trust**—a fully discretionary trust that allows you to leave an inheritance **of any size** without affecting ODSP eligibility.

Key features include:

- Assets belong to the trust, not the beneficiary
- Trustees have full discretion over payments
- The beneficiary cannot demand funds
- Often created in a Will, but can also be set up during one's lifetime

Choosing the right trustee is vital—they must understand the beneficiary's needs, manage funds responsibly, and act in the beneficiary's best interests.

Planning for Minors and Adults Who Need Support

Guardianship for Minors

Parents of minor children can use their Wills to nominate guardians, ensuring their intentions are clear and legally recognized.

Adults and Decision-Making

If an adult family member is capable, it is essential they create POAs for personal care and property. If they cannot, families may need to pursue guardianship through the court—a process that is time-consuming and intrusive.

Capacity assessments help determine whether a person can understand information relevant to a decision and appreciate the consequences. Capacity is dynamic and can vary depending on context.

Alternatives to Guardianship

Guardianship is a significant legal measure, but it is not the only option. Depending on the situation, families may consider:

- Powers of Attorney
- Supported decision-making arrangements
- Public Guardian and Trustee appointments
- Limited or temporary court orders
- Trusts
- Microboards

These tools aim to preserve autonomy while providing appropriate support.

Final Thoughts

Estate planning is not just about documents—it is about protecting your family's future. For families with loved ones on ODSP, thoughtful, well-structured planning ensures financial security, continuity of care, and peace of mind.

SESSION 2: Financial Planning for Families Supporting a Loved One with a Disability

Financial planning is about creating a roadmap that helps you meet both short-term needs and long-term goals. For families supporting a loved one with a disability, planning early is essential—both to protect financial security and to access valuable government programs.

Why Financial Planning Matters

Good financial planning helps you:

- Prepare for both expected and unexpected costs
- Take advantage of tax credits and benefits
- Understand how to structure your estate, trusts, and wills
- Reduce the tax burden on your family now and in the future

A key tip for parents: **If your child is under 18, open a joint bank account with them now.** This makes estate planning much easier and helps avoid delays later.



Important Programs & Tax Credits

Disability Tax Credit (DTC)

The DTC is a non-refundable tax credit that reduces income tax for people with impairments or their supporting family members.

It also opens the door to major benefits, including:

- RDSP eligibility
- Canada Disability Benefit
- Child Disability Benefit
- Working Income Tax Benefit supplement
- Trust tax advantages

Tip: At age 17, the person with the disability must claim the DTC first. It can then be transferred to the highest income supporting family member for life.

Permanent Disability Tax Credit

- Becomes permanent between ages 18–25 (varies by situation).
- Conditions like Down syndrome are not marked permanent before age 18, so families may need to reapply.
- Always check your CRA My Account to confirm status.

Caregiver Tax Credit

If you support a spouse, partner, or dependent with a physical or mental impairment, you may qualify.

Canada Workers Benefit

Available to people over 18 who are working part-time, including those receiving disability supports.

Important: File a tax return at age 17—even if income is \$0. This affects RDSP eligibility and other benefits.

Canada Disability Benefit (New for 2025)

This new benefit supports adults with disabilities aged 18–64 who qualify for the DTC and file a tax return.

Key points:

- Maximum of \$200 per month
- Income-tested
- Exempt as income for ODSP
- Back payments to July 2025 for those who qualify

ODSP (Ontario Disability Support Program)

ODSP provides income, health benefits, and employment supports, but also has strict income and asset limits.

Exempt Assets Include:

- \$40,000 in liquid assets (\$50,000 for couples)
- Principal residence, primary vehicle
- RDSP (unlimited value)
- Henson Trust (unlimited value)
- Up to \$100,000 combined in life-insurance cash value or inheritance trusts

Understanding these rules early can prevent accidental disqualification—especially when receiving inheritances or gifts.

RDSP - Registered Disability Savings Plan

The RDSP is a powerful long-term savings tool fully exempt from ODSP asset rules.

Benefits include:

- Up to \$70,000 in federal grants
- Up to \$20,000 in bonds
- Tax-deferred growth
- Ability to shelter inheritances
- Lifetime retirement income starting as early as age 60

Eligibility requires DTC approval and being under age 59 (or 49 for grants/bonds).

How Families Can Use This Information

- Maximize RDSP grants and bonds based on income
- Claim all available credits and benefits
- Plan for both your own financial needs and long-term support for your dependent
- Consider life insurance and trusts for future security
- Open a CRA My Account for family members aged 18+

Guest Speaker: Patricia Benoit

Email: Patricia.benoit@ipcc.org

Phone: 519-520-4992

Resources:

P4P Planning Network – www.planningnetwork.ca



WWDSS Holiday Party

by Mandi Butcher

WWDSS kicked off December and the holiday season with another fun Holiday Party.

The WWDSS store was open for business and the cookie decorating table with cookies from Blue Whisk Bakes was a hit once again. The highly anticipated door prizes table was fully stocked with toys, wellness merchandise, multiple sets of Kitchener Rangers tickets, pet supplies, chocolate, a Team Canada soccer jersey and much more. A huge thank you to all who donated. The buddy choir made an appearance to enhance the holiday spirit and their songs invited the big man in red, Santa Claus to make an appearance and hand out gifts to all of the children on the nice list. A huge thank you to Pepis pizza for supplying pizza, salad and dessert. Overall, a wonderful day was had by all who attended.

Thank you to the volunteers who helped out. Wishing you all a safe and happy 2026.



Waterloo Region District School Board SEAC Update: Strengthening Inclusion within the WRDSB Strategic Plan and Learner Profile

by Roberta Thompson

At the most recent SEAC meeting, members provided feedback on the WRDSB Strategic Plan, which was developed through extensive consultation with more than 10,000 students, families, staff, and community members, with support from Overlap Associates. Central to the plan are six Strategic Directions and a Learner Profile outlining the skills and attributes students need to succeed in school and in life, including being confident, inclusive, empathetic, and community-oriented. The full detailed plan can be viewed on the WRDSB website: www.wrdsb.ca/learning/strategic-plan/

SEAC discussion focused on how the Strategic Plan and Learner Profile are experienced by students with disabilities. Members emphasized the importance of creating a plain-language version of the Strategic Plan so it is accessible to all families, including those with disabilities and those for whom English is not a first language. Questions were raised about how learner profile attributes—such as confidence, inclusion, and relationship-building—are recognized and measured for students who are non-verbal, neurodiverse, or complex communicators, and how the Board ensures these students are truly centred, rather than marginalized, within the plan's goals.

SEAC also discussed how the Strategic Plan and Learner Profile will be communicated directly to students, so they understand how Board priorities connect to their daily learning experiences. Ensuring students can see themselves reflected in the learner profile was identified as essential to belonging, engagement, and well-being—key commitments within the Strategic Plan's directions around centring students, equitable outcomes, and student well-being.

Additional updates included positive EQAO results, particularly in literacy and math, with improvements in Grades 3, 6, and 9. The Board noted increased confidence in structured literacy, expanded learner profiles for students with disabilities and multilingual learners, and ongoing work to better capture assessment data for complex communicators. Budget updates highlighted continued investment in Educational Assistants, Child and Youth Workers, literacy and math supports, Board Certified Behavioural Analysts, technology upgrades, and an upcoming Neuroaffirmative Practices workshop, all of which align with the Strategic Plan's commitment to inclusive and equitable learning environments.

For Families: Transitions Workshop

The Waterloo Region Family Network is offering an in-person workshop to help parents and caregivers support children with exceptional needs through school transitions, including changes in routines, environments, and staffing.

Learn practical strategies to reduce stress, build predictability, and support independence.

Jan 15 | 6:30–8 PM

500 Hallmark Dr., Waterloo

Register: info@wrfn.info

SCHOOL NAVIGATION WORKSHOP SERIES



TRANSITIONS WORKSHOP

- Designed to help parents and caregivers support children with exceptional needs through daily and major school transitions—including changes in routine, environment, and staffing.
- Learn strategies for easing these shifts by creating predictable routines, encouraging independence, and helping children move from high-stress to calm.



**Thursday,
January 15**



6:30 – 8 PM



**500 Hallmark Dr,
Waterloo**

REGISTER AT INFO@WRFN.INFO

Hosted by WRFN Family Resource Coach, Lisa Cook.



Moms Night Out

On Thursday, December 4, WWDDSS moms and caregivers gathered at Del's Italian Kitchen in Kitchener for a fun and relaxing evening before the holiday rush. It was a wonderful night filled with delicious food, laughter, stories, and meaningful sharing. A heartfelt thank you to WWDDSS for providing the delicious appetizers that made the evening even more enjoyable. Thank you to Janice Duncan for planning such a fun night out.

Waterloo Catholic District School Board SEAC Report

by Kim Murphy

November 5, 2025 - WCDSB SEAC Meeting Highlights

Supporting Student Regulation: Andrea Snyder, Mental Health Lead, delivered an informative presentation on strategies and initiatives supporting student regulation within the WCDSB.

Advocacy for Special Education Funding: The committee reviewed a letter to the Hon. Paul Calandra, Minister of Education, advocating that funding for the Responsive Education Program (REP) and Summer Special Education Support be integrated into the core Special Education budget.

Sacramental Preparation Event: A Sacramental Preparation for Students in Special Education event for parents is being planned for February 4, 2026, following last year's strong participation. More details will be shared soon.

December 2025 - WCDSB SEAC Meeting

Jennifer Ritsma and Kelly Roberts presented the Board's Student Achievement Plan and Petra LeDuc presented the Math Achievement Action Plan. We discussed a series for parents of students in Grades 7 or 8 in Ontario with learning disabilities or ADHD

SEAC Meeting Minutes are available on the Board website:

[WCDSB.ca](https://www.wcdsb.ca) > Programs & Services > Special Education > Special Education Advisory Committee (SEAC) > Meeting Minutes

As your WWDDSS representatives on WCDSB SEAC, we are available as a resource for families and to ensure the concerns and needs of our children are represented.

Primary: Kim Murphy

Alternate: Gillian Hadden



Waterloo Wellington
Down Syndrome Society

Come On Out to the WWDSS Bowling Party

Sunday February 22, 2026

Victoria Bowl
280 Victoria Street South, Kitchener

3:30 to 5:30 p.m.

Please register at www.wwdss.ca

Come enjoy an afternoon of bowling with the whole family! You do not have to bowl to enjoy this event. There will be pizza and drinks for everyone to enjoy. Gluten free options are available as well.

This is open to all WWDSS members and is a no cost event. **Registration is required** for bowlers and non-bowlers so that we can plan the lanes and food.



Save the Date Events

Bowling Party

February 22

World Down Syndrome Day

March 21

Save the Date Programs

Parent Connection

TBD

by **Lori Maloney**

Over the past couple of months, The Office has had lots of fun! We had a Halloween party, and a Birthday party for all members born between July and December. We also went as a group to see Wicked for Good! In between times we met on zoom. Our big question was how would we like to be more independent? This question brought many answers including cooking, taking the bus and finding a job. A big thank you goes out to Emily Pike for continuing to lead our group and keep us organized. We look forward to a great 2026 together! We have been invited to participate in DS Collaborative with the Canadian Down Syndrome Society.



Buddy Choir

The Buddy Choir had a wonderful time performing at several events this season, including the Waterloo Region District School Board Professional Development Day for Educational Assistants, the Pioneer Park Community Centre Christmas Party, and the WWDSS Holiday Party. On December 30th, the choir was also excited to perform at the KW Titans game!

Buddy Choir continues to rehearse every Monday from 6:30 to 8:00 p.m. at Our Studio 109 Ottawa St. S Kitchener. New members are always welcome!

**A choir for the entire family
- please join us!**

For more info call Lori Maloney at 519-501-6747 or email her at lmcy50@gmail.com.