



PARENT & PARTICIPANT HANDBOOK

Edmonton Down Syndrome Society
9139 39 AVE NW Edmonton, AB T6E 5Y2

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Part 1: Welcome to EDSS

1.1 Welcome Letter

Welcome to the Edmonton Down Syndrome Society (EDSS). We are truly delighted to partner with you and your family to bring you programs and services that are designed to support you and your family on your journey.

This handbook has been designed to provide you with important information about our programs, services, policies, processes and expectations. Our goal is to ensure a safe, inclusive, and collaborative experience for all participants and their families.

We recognize that every family's journey is unique, and we are honored to be a part of yours. If you have any questions, feedback, or need additional support, please do not hesitate to reach out to our team—we are here for you.

We look forward to building a strong and positive relationship with you and your family. I encourage you to please let us know how we are doing to meet your family's needs, and how we can improve to better support you.

Janet Tryhuba
Executive Director, EDSS

1.2 About EDSS

The Edmonton Down Syndrome Society (EDSS) is a community-based organization dedicated to supporting individuals with Down syndrome and their families through resources, programs, and advocacy. While our primary focus is on Down syndrome, we welcome individuals with other disabilities to participate in our programs, fostering an inclusive and supportive community for all. We strive to create meaningful opportunities for growth, connection, and community engagement.

Mission, Vision and Core Values

Mission: To support individuals with Down syndrome and their families by providing inclusive programs, resources, and advocacy that promote growth, independence, and community involvement.

Vision: A world where individuals with Down syndrome are valued, empowered, and fully included in all aspects of society.

Core Values: Respect and dignity; inclusion and accessibility; Empowerment and independence; Collaboration and community; Safety, integrity, and transparency.

1.3 Who We Serve

Edmonton Down Syndrome Society (EDSS) was established to support individuals with Down syndrome, and many of our programs and services are specifically designed to meet the needs of individuals with Down syndrome and their families.

Some EDSS programs and services may also welcome individuals who do not have Down syndrome when the program is appropriate to their needs and they meet the established eligibility and participation requirements.

Participation is based on the individual's ability to safely and meaningfully participate within the program's structure, staffing model, and available supports. EDSS considers each individual's strengths, needs, goals, and support requirements when determining whether a program or service is an appropriate fit.

Eligibility and participation requirements may vary between programs and services and may be affected by available space, staffing, funding requirements, and the nature of the program or service.

Regular attendance supports participation, relationships and continuity of programming. Families are asked to notify EDSS as soon as possible when a participant will be absent. Program-specific attendance requirements may apply.

1.4 Inclusion, Diversity and Belonging

EDSS is committed to creating welcoming, respectful, and inclusive environments where individuals and families feel valued and supported.

EDSS does not discriminate against individuals based on disability or other protected characteristics. We recognize that individuals have different strengths, experiences, preferences, and support needs and strive to provide meaningful opportunities for participation while supporting the safety, dignity, and well-being of everyone involved.

1.5 Our Team and Leadership

At the Edmonton Down Syndrome Society (EDSS), our team is made up of dedicated professionals who are committed to providing high-quality, inclusive, and supportive programs and services for individuals and families.

Our team brings together a range of roles and areas of expertise, with staff, volunteers, and contracted professionals working collaboratively to support the needs of individuals and families across EDSS programs and services.

- **The Leadership Team** provides organizational direction, program oversight, and ensures the quality and safety of all services.
- **Program Staff and Volunteers** facilitate day-to-day programming, support participant engagement, and create a positive and inclusive environment.
- **Day Program Staff** offer consistent, hands-on support tailored to individual needs, focusing on skill development, independence, and community involvement.

- **Contracted Professionals** include specialists such as Speech-Language Pathologists, Occupational Therapists, and Behaviour Therapists who provide targeted, individualized support within their areas of expertise.

1.6 Key Contacts

We encourage you to contact the staff member most closely connected to your question or concern.

Executive Director

Responsible for overall leadership, organizational direction, and strategic planning.

Name: Janet Tryhuba

Email: janet@edss.ca

Phone: 780-944-4224 ext. 103; 780-887-8155 cell

Director of Community and Family Services

Leads family navigation at EDSS and helps families access government funding, disability supports, financial resources, advocacy, professional services, learning opportunities, and community supports.

Name: Julie Boucher

Email: julie@edss.ca

Phone: 780-944-4224 ext. 102; 780-221-4862 cell

Program Manager

Manages program operations, including scheduling, staff training, and participant support.

Name: Meghan Schritt

Email: meghan@edss.ca

Phone: 780 944 4224 ext. 105; 587-785-5556 cell

Office Manager

Oversees the day-to-day operations of the EDSS office, including administration, scheduling, memberships, communications, and general office support.

Name: Michelle Hill

Email: michelle@edss.ca

Phone: 780-944-4224 ext. 104;

Community Services Coordinator

Assists in all areas of EDSS, working primarily in Family Services.

Name: Janna Sibal

Email: janna@edss.ca

Phone: 780-944-4224 ext. 101

General Inquiries

Email: contact@edss.ca

Phone: 780-944-4224

If you are unsure who to contact, please contact General Inquiries and we will direct you to the appropriate team member.

Part 2: EDSS General Information, and Expectations

This handbook provides general information about EDSS programs, services, policies, processes, and participant and family expectations. Program- and service-specific requirements may apply in addition to the information outlined in this handbook.

Where a detailed EDSS policy or procedure is referenced, families may request a copy or access the policy through the provided link.

2.1 Membership

- Memberships of EDSS are offered to all families with a person born with Down syndrome who are participating in EDSS programs, attending events, accessing resources, scholarships, and staying connected with news, advocacy initiatives and research in the Ds community.
- All membership run from January to December of each year. An active membership is required for participation in any EDSS programs or services and some events as determined by EDSS.
- **Family Membership** – The Annual fee is \$40 dollars.
- For a family with a newborn baby their first year of membership is free.
- **Community Memberships** are also available for the same fee for those individuals or organizations who do not have a family member with Ds and who are in support of the organization's purpose and values;
- **Voting Memberships** are an optional \$10 add-on to any of the Membership categories and provides an invitation to the AGM to vote.
- The voting membership annual deadline for registration and fee payment is March 31st. You must have your membership and voting add-on paid in full to be invited to vote at the AGM. Any voting membership add-ons purchased after March 31st will qualify for the AGM taking place the following year.

Membership Benefits

- Membership supports the society's operations and allows participants access to programs, professional services, and family events at a reduced/cost shared fee.
- Access to the Resource Lending Library materials
- Exclusive access to a private member's only Facebook page
- Exclusive Members only special events, learning sessions, and "first year" Wonder Years workshop.
- Membership renewal - Each December you will receive an invoice to renew your membership for the following year.

2.2 Registration and Access to EDSS Programs and Services

EDSS offers a variety of programs and services, and the process for accessing them may differ depending on the program or service.

Intake Forms at Registration

Families are responsible for providing accurate and complete information about their child's medical, behavioural, and support needs on the **Intake Form** at the time of registration. This information allows EDSS to determine appropriate supports and whether the participant's needs can be safely accommodated within the available staffing model.

Program-specific registration or intake requirements will be identified in the applicable program or service information. Families are responsible for completing any additional requirements before participation begins.

For more information, please see Addendum: EDSS Intake and Registration Procedure

Programs

Some EDSS programs require a formal registration process, while others may be accessed by contacting the appropriate EDSS staff member.

Depending on the program, registration may be completed through:

- an EDSS registration form;
- an online registration process; or direct contact with the Program Manager, Director of Community and Family Services, or the designated staff member.

Families should follow the registration instructions provided for the specific program or service.

Regardless of how a participant registers, EDSS will provide an electronic confirmation once their spot or session has been reserved. The electronic confirmation confirms the participant's registration and provides any relevant program or service information.

Families should review their confirmation carefully and contact EDSS if any information is incorrect or if they have questions about the program or service.

Services

EDSS services do not require a general program registration form.

Families wishing to access an EDSS service should contact the Director of Community and Family Services to discuss their needs and determine the appropriate next steps.

Depending on the service and the participant's identified goals, families may be asked to complete service-specific documentation or provide additional information to support service planning and delivery.

Where appropriate and with the required consent or authorization, EDSS professionals may communicate or collaborate with other members of the participant's support network, such as teachers, therapists, healthcare professionals, or other service providers. Additional documentation or consent may be required to support this collaboration.

Keeping Information Current

Information collected through EDSS registration, intake, or service documentation must be kept current.

Families are responsible for notifying EDSS when information changes that may affect a participant's program or service.

Specific information requirements will be identified within the applicable registration, intake, or service documentation.

Waitlist Management

The Edmonton Down Syndrome Society (EDSS) maintains waitlists when demand for a program or service exceeds available spaces, staffing, resources, or service capacity.

The purpose of this policy is to ensure that waitlists are managed in a consistent, fair, transparent, and respectful manner, while considering the needs of participants, program requirements, available resources, and the capacity of EDSS to safely provide the program or service.

For more information, please see Addendum: EDSS Waitlist Procedure

2.3 Participant Rights, Responsibilities and Code of Conduct

Participant and Family Code of Conduct

EDSS expects participants, parents/guardians, support persons, caregivers, visitors, and others participating in or attending EDSS programs, services, activities, or events to conduct themselves in a respectful and appropriate manner.

The following conduct is not acceptable:

- abusive, threatening, or disrespectful language or behaviour toward staff, volunteers, contractors, participants, families, or others;
- harassment, bullying, intimidation, or violence toward any person;
- conduct that may endanger the health, safety, or well-being of another person;
- taking unfair advantage of, exploiting, or intentionally harming another participant; or
- behaviour that significantly disrupts the safe operation of an EDSS program, service, activity, or event.

Depending on the circumstances, EDSS may take appropriate action to protect the safety and well-being of participants, staff, volunteers, and others, including reviewing participation arrangements or removing an individual from a program or activity where necessary.

Where concerns arise, EDSS may work with the participant, family, guardian, support person, or other appropriate supports to identify strategies that promote safety and successful participation.

For more information, please see Addendum: Participant Rights and Responsibilities.

2.4 Participant Dignity, Inclusion, and Accessibility

EDSS is committed to ensuring that all participants are treated with dignity, respect, and fairness and have opportunities to participate in a safe, supportive, and inclusive environment. Participants have the right to privacy and to receive support that recognizes their individual strengths, needs, preferences, and abilities.

EDSS will work with participants and families to identify reasonable accommodations and accessibility supports that may assist with meaningful participation in programs and services. Accommodations and supports will be considered based on the individual's needs, the nature of the program or service, and the supports available.

Participants, families, and support persons are expected to contribute to a respectful and inclusive environment by respecting the rights, privacy, safety, and personal space of others.

For more information, please see Addendum: Participant Dignity, Inclusion, and Accessibility

2.5 Behaviour Management

EDSS is committed to supporting participants in a respectful, person-centred, and positive manner. Behaviour is understood as a form of communication, and staff focus on understanding the needs and circumstances that may contribute to behaviour.

Staff use proactive strategies, positive supports, respectful communication, and individualized approaches to promote safety, participation, and successful engagement in programs and services.

EDSS does not use punishment, humiliation, or practices that compromise the dignity or safety of participants. Staff are expected to respond to behaviour in a calm, respectful, and supportive manner and to seek additional support when needed.

Where concerns arise regarding a participant's behaviour or support needs, EDSS will work with the participant, family, guardian, behaviour consultant, or other appropriate supports, where applicable, to identify strategies that promote successful participation and safety.

Where behaviour presents a risk to the safety or well-being of the participant or others or significantly affects the ability of a program or activity to operate safely, EDSS will work with the participant and their family or support team to identify appropriate strategies and supports. In some circumstances, EDSS may need to modify participation arrangements or take other steps to maintain safety and support successful participation.

Detailed expectations, procedures, and prohibited practices are outlined in the **Behaviour Management Policy and Procedure**.

For more information, please see Addendum: EDSS Behaviour Management Policy and Procedure

2.6 Participant Complaints and Concerns

EDSS values the feedback and experiences of participants and is committed to ensuring that participants feel safe, respected, heard, and supported.

Participants have the right to raise a concern, make a complaint, ask questions, or provide feedback about an EDSS program, service, staff member, volunteer, or experience. Participants may communicate their concerns directly or with the assistance of a family member, guardian, advocate, support person, or staff member.

EDSS will listen to concerns respectfully and make reasonable efforts to respond, address concerns, and identify appropriate solutions.

Concerns raised in good faith will not result in retaliation, reprisal, or negative treatment, or prevent a participant from accessing EDSS services.

Concerns will be handled as confidentially as reasonably possible, recognizing that some situations may require information to be shared to ensure safety or meet legal requirements.

The detailed process for submitting, reviewing, and responding to complaints is outlined in the Participant Complaints Resolution Policy.

For more information, please see Addendum: EDSS Participant Complaints Resolution Policy and Procedure.

2.7 Health and Wellness

EDSS is committed to supporting the health, safety, and well-being of all participants. Families are asked to keep participants home when they are unwell or unable to safely participate in programming.

If a participant becomes ill while attending an EDSS program or activity, staff will take appropriate steps to support the participant and may contact the family or emergency contact to arrange pick-up when necessary.

EDSS considers weather and environmental conditions when planning activities and may modify, relocate, or cancel activities when conditions may affect participant safety.

Families are responsible for providing EDSS with current emergency contact and health information through the intake process and for notifying EDSS of significant changes to a participant's health, medications, allergies, or support needs that may affect participation or safety.

For more information, please see Addendum: Participant Health & Safety Policy

2.8 Medication Administration

EDSS may assist participants with medication administration when the required documentation, authorization, and procedures have been completed. Families are responsible for providing accurate and current medication information and notifying EDSS of any changes.

Medication administration is provided in accordance with the **EDSS Medication Administration Policy and Procedures** and the participant's documented needs.

For more information, please see Addendum: EDSS Medication Administration Policy

2.9 Safety and Emergency Procedures

All EDSS staff are required to follow HR-3-02 – Emergency Response Plan when responding to an emergency involving any participant. This includes, but is not limited to:

- Emergency response
- Bomb threat
- Fire or smoke evacuation
- Lockdown
- Missing person
- Chemical, Biological, or Radiological
- Natural Disaster or Severe weather
- Structural Failure

Staff, contractors, and volunteers will follow the procedures outlined in HR-3-02, including emergency notification, evacuation or shelter procedures, participant support, communication, documentation, and follow-up as applicable. EDSS may document incidents, injuries, safety concerns, or near misses and may follow up with the participant, family, guardian, or support person as appropriate.

For more information, please see Addendum: HR-3-02 – Emergency Response Plan

2.10 Drop-Off, Pick-Up and Transportation

EDSS is committed to ensuring that participant drop-off, pick-up, and transportation arrangements are safe, clear, and appropriate to the program or service being provided.

Families are responsible for ensuring that participants arrive at the designated location and are picked up at the scheduled time. EDSS must be informed of any changes to a participant's usual drop-off or pick-up arrangements, including when someone other than an authorized person will be picking up a participant.

Staff will only release a participant to an individual who is authorized by the family or designated through the appropriate EDSS process.

Transportation arrangements vary by program. Families are responsible for understanding the transportation arrangements that apply to the specific program or activity their participant is attending. Where EDSS provides or coordinates transportation, participants are expected to follow applicable safety expectations and staff instructions.

If a participant is not picked up as scheduled or an unexpected transportation issue occurs, EDSS will follow appropriate procedures to ensure the participant's safety and contact the family or designated emergency contact as required.

Families are responsible for ensuring EDSS has current authorized pick-up information.

For more information, please see Addendum: EDSS Drop-Off and Pick-Up and Transportation Policy

2.11 Cold Weather Policy

EDSS is committed to maintaining the safety and well-being of participants, families, volunteers, and staff during periods of severe cold weather.

EDSS may modify, relocate, or cancel programming when weather conditions may create a safety concern. Weather conditions will be monitored using information from Environment Canada.

Cold Weather Guidelines

- **-20°C with wind chill:** Outdoor outings will be modified to an indoor activity when possible.
- **-30°C with wind chill or below:** Programs may be cancelled when temperatures reach -30°C or below, based on Environment Canada information and an assessment of safety conditions.
- **Extreme Weather Alerts:** Programs may be modified, relocated, or cancelled when Environment Canada issues an extreme weather warning or alert that may affect the safety of participants, families, volunteers, or staff.

Programs operating during regular office hours at the EDSS facility may continue when the building is open and appropriate staffing is available.

The Adult Day Program will generally continue when staff are present at the EDSS facility. Changes may be made when severe weather conditions create a safety concern for participants or staff travelling to or from the program.

Families will be notified as soon as reasonably possible when programming is modified, relocated, or cancelled due to severe weather.

2.12 Privacy and Confidentiality

EDSS is committed to protecting the privacy and confidentiality of participants, families, guardians, and others who access EDSS programs and services. Personal information is collected, used, stored, and shared respectfully and only as necessary to provide programs and services, support safety and well-being, and meet legal, funding, or organizational requirements.

EDSS takes reasonable steps to protect personal information from unauthorized access, use, disclosure, loss, or misuse. Information will only be shared with appropriate individuals or organizations when authorized, necessary to provide support, required by law, or necessary to address a safety or emergency concern.

Participants and families are expected to respect the privacy and confidentiality of others involved with EDSS and not share personal information about other participants or families.

For more information, please see Addendum: Privacy and Confidentiality Procedure

2.13 Communication with Families

EDSS is committed to maintaining respectful, timely, clear, and accessible communication with individuals and families who access EDSS programs and services. Effective communication supports positive relationships, helps families stay informed, and promotes the safety and well-being of participants.

How EDSS Communicates

EDSS may communicate with families through:

- Email
- Telephone
- Newsletters and program updates
- Scheduling and registration platforms
- Other communication methods appropriate to the program or service

Communication Expectations

Families are expected to keep their contact information current and to respond to communications when a response is required. EDSS will make reasonable efforts to provide important program and service information in a timely manner.

EDSS staff will communicate respectfully and professionally. Communication outside regular business hours may not receive an immediate response, except where an urgent or emergency response process applies.

Communication Boundaries

EDSS maintains appropriate professional boundaries in communication with participants and families. Program-specific communication expectations, response times, and communication procedures may vary depending on the program or service.

For more information, please see Addendum: Communication with Families – Procedure

2. 14 Changes to Programs and Services

EDSS may make reasonable changes to program schedules, locations, activities, staffing arrangements, or service availability based on operational needs, participant needs, staffing, funding, facility availability, or other circumstances. Families will be notified of significant changes as soon as reasonably possible.

2.15 Fees, Payments and Refunds

EDSS program and service fees vary depending on the program, service, and funding source.

Families will be provided with information about applicable fees and payment requirements at the time of registration or before services begin.

- Program and Service fees
- Payment timelines
- FSCD payments
- DocuSign
- Private payment
- Refunds
- Overpayments
- Non-refundable fees

For more information, please see Addendum: EDSS Program Fees and Refund Policy

2.16 General Cancellation and No-Show Information

EDSS understands that circumstances may change and that participants or families may occasionally need to cancel or miss a scheduled program, service, appointment, or activity.

Families are asked to notify EDSS as soon as possible when a participant will not be attending or when a scheduled service or activity needs to be cancelled. This allows EDSS to adjust staffing, scheduling, and program planning as needed.

Specific cancellation, attendance, and no-show requirements may vary depending on the program or service. Families will be provided with any program-specific information that applies to their participation.

Repeated no-shows or cancellations may be reviewed with the family to determine whether adjustments to scheduling, supports, or participation is appropriate.

Families should always review the cancellation policy specific to the program or service they are registered for.

For more information, please see Addendum: EDSS Service Cancellation and No-Show Policy

2.17 Photography, Video and Media

Photographs and videos may be taken during EDSS programs, events, and activities for program documentation, promotional materials, social media, newsletters, and other organizational purposes.

Participation in photography and media use is voluntary. Members and participants may indicate their consent or refusal through the EDSS membership registration process. EDSS will respect the media preferences recorded by the member or their authorized representative.

Privacy and Photography at EDSS

To protect the privacy of all participants:

- Participants, families, and visitors must not photograph, video, or otherwise record another participant without permission from the participant or their parent, guardian, or authorized representative, as applicable.
- Photographs or videos of other participants must not be shared on social media or other public platforms without appropriate consent.
- EDSS will not provide photographs or videos of other participants to families or other individuals.
- Identifying information about participants must not be shared without appropriate authorization.

Families and participants are asked to respect the privacy and media preferences of others when taking or sharing photographs or videos at EDSS programs, events, and activities.

2.18 Personal Belongings

- Participants should bring only items that are necessary for their participation in EDSS programs, services, activities, or outings. All personal belongings should be clearly labelled.
- EDSS is not responsible for lost, damaged, or misplaced personal belongings.
- Some activities or outings may provide opportunities for participants to purchase food, beverages, souvenirs, or other personal items. Families will be informed in advance if spending money is recommended or if additional items are required.
- Participants are encouraged to manage their own spending money independently whenever possible, with support from staff when appropriate. Participants are responsible for their own spending decisions and money.

Service Changes or Discontinuation

Programs and services may be discontinued or changed when circumstances, participant needs, funding, availability, safety, or program requirements change. EDSS will communicate with families regarding significant changes and, where appropriate, discuss available options or transition supports.

For more information, please see Addendum: Service Termination/Discontinuation Procedure

2.19 Community Participation

EDSS encourages participants to be active and engaged members of their communities. Community activities provide opportunities to develop independence, build relationships, learn new skills, and participate in meaningful experiences.

Part 3: EDSS Programs

3.1 Adult Day Program

Unless otherwise stated, all **General Program Policies and Procedures** outlined in this handbook apply to participants enrolled in the **Adult Day Program**.

Purpose

The Adult Day Program provides adults (16+) with disabilities opportunities to build independence, develop life skills, foster meaningful relationships, and participate in their community.

Through person-centred programming, participants are supported in pursuing individual goals, developing skills, exploring interests, and making meaningful choices in a safe, inclusive, and welcoming environment.

Attendance

- Adult Day Program attendance may be arranged for one or more days per week, including up to five days per week, based on program availability, participant needs, and the arrangement established with EDSS.
- Regular attendance is encouraged to support skill development, establish routines, build relationships, and promote consistent participation.
- Families should notify EDSS as soon as possible if a participant will be absent.

PDD and FSCD Funding

- Families who have an approved PDD Family Managed Supports (FMS) agreement may be able to use their approved FMS funding to pay for participation in the Adult Day Program.
- For participants who are 16 or 17 years old and have an FSCD FMS agreement, approved FSCD funding may also be used toward the Adult Day Program under Respite or Extraordinary Childcare in their agreement.
- Families are responsible for confirming with EDSS that they would like to use their approved FMS funding to fund the participant's participation in the program. EDSS can provide families with the information and documentation required to support the use of approved funding.
- *EDSS does not determine eligibility for government programs or make funding decisions on behalf of government agencies.*

Participation

Participants are encouraged to participate in daily programming based on their interests, preferences, and support needs.

Activities may include:

- Life skills development

- Recreation and leisure
- Creative arts
- Health and wellness activities
- Community outings
- Social activities
- Volunteer and community experiences
- Skill-building and learning opportunities

Staff will provide reasonable supports and adaptations to promote meaningful participation while encouraging participants to make choices, explore interests, and build confidence.

Individual Support Plans (ISP)

The Adult Day Program uses a person-centred approach that recognizes each participant's strengths, abilities, interests, preferences, and goals.

Participants who attend the Adult Day Program four or more times per month will have an Individual Support Plan (ISP) developed to help guide programming and support meaningful participation. Participants who attend less frequently may not require an ISP; however, EDSS will consider individual support needs and circumstances when determining whether an ISP is appropriate.

The ISP may identify:

- Personal goals and aspirations
- Strengths, skills, and interests
- Areas where support may be beneficial
- Preferred activities and learning styles
- Opportunities to increase independence and community participation

Participants will be supported to participate in the development, review, and evaluation of their ISP in a manner appropriate to their communication, preferences, and abilities. Families are an important part of the ISP process and will be included in the development, review, and evaluation of the plan. Where appropriate, other members of the participant's support network may also be involved with the participant's and family's consent.

ISPs are reviewed regularly to recognize progress, celebrate successes, adjust goals, and ensure programming continues to reflect the participant's current interests, goals, and support needs.

The ISP helps guide programming and support, but the Adult Day Program remains a group-based program. Activities and supports may be adapted to promote participation; however, EDSS does not provide dedicated one-to-one staffing unless specifically arranged through another funding or support agreement.

Community Participation

Community inclusion is an important part of the Adult Day Program.

- Participants may regularly take part in community-based activities and outings that promote:
 - Independence
 - Social engagement
 - Life skills
 - Community awareness
 - Confidence
 - Meaningful participation
- Participants are expected to follow staff directions and remain with the group while participating in the community.

Meals

- Participants are responsible for bringing a nutritious lunch, snacks, and beverages unless otherwise communicated by EDSS.
- Families are responsible for providing information regarding allergies, dietary restrictions, or other dietary needs through the appropriate EDSS intake and registration processes.

Volunteer and Community Experiences

- Where appropriate, participants may have opportunities to participate in volunteer or other community-based experiences.
- These opportunities are intended to support skill development, confidence, social connection, and meaningful community involvement.
- Participation will be based on the individual's interests, abilities, goals, support needs, and available opportunities.

3.2 Centre Stage Musical Theatre

Program Description

Centre Stage is an inclusive musical theatre program that provides participants with opportunities to develop confidence, creativity, communication skills, teamwork, and friendships through singing, dancing, and acting. The program works toward a fully scripted musical theatre production and concludes with a **final public performance** for family, friends, and the community. Performance details, including the date, time, location, and arrival requirements, will be provided to families in advance.

Rehearsal Information

Regular attendance is encouraged, as rehearsals build progressively toward the final production and participants learn music, choreography, stage direction, and other elements of the performance.

Costumes

Families may be asked to provide basic clothing, footwear, or other items required for the performance. EDSS will provide information about costume requirements in advance. Any costumes, props, or other items supplied by EDSS remain the property of EDSS and should be returned following the performance unless otherwise advised.

Performance Information

Families will receive information about performance schedules, rehearsal requirements, costumes, arrival times, and other performance-related details in advance. Participation in the final performance is encouraged, but EDSS recognizes that circumstances may arise that prevent a participant from performing.

3.3 Sports Programs

EDSS Sports Programs provide participants with opportunities to develop physical literacy, teamwork, confidence, and healthy lifestyles through recreational sport in a safe, inclusive, and supportive environment.

EDSS Sports Programs include:

- Junior Basketball
- Senior Basketball
- Floor Hockey
- Hip Hop Dance

Unless otherwise stated, the **General Program Policies and Procedures** outlined in this handbook apply to all EDSS Sports Programs.

Purpose

Sports Programs focus on skill development, participation, teamwork, sportsmanship, and enjoyment. Activities are designed to encourage physical activity, social connection, confidence, and participation at each individual's ability level.

Attendance

Regular attendance is encouraged to support skill development, team participation, and relationship building.

Families should notify EDSS as soon as possible if a participant is unable to attend a scheduled practice, game, or other sports activity.

Participation

Participants are encouraged to participate based on their interests, preferences, comfort level, and support needs.

Coaches, staff, and volunteers will make reasonable adaptations, when possible, to support participation and promote a positive experience for all athletes.

Clothing and Equipment

Participants should arrive prepared for physical activity and wear:

- Comfortable athletic clothing appropriate for the activity.
- Clean, non-marking indoor athletic shoes.
- Any required sport-specific equipment identified by EDSS.

Families will be informed in advance of any additional equipment or clothing requirements.

Sportsmanship

Participants are encouraged to demonstrate good sportsmanship and treat teammates, coaches, volunteers, officials, opponents, and other participants with respect.

Participants are encouraged to:

- Demonstrate good sportsmanship.
- Respect teammates, coaches, volunteers, officials and opponents.
- Follow directions and safety instructions.
- Encourage and support teammates.
- Respect the rules, and decisions of officials.
- Play fairly and safely.

Families and spectators are expected to model respectful and supportive participation.

3.4 Club 21

EDSS offers Club 21 as social and recreational programs designed to provide participants ages 10 years old to 17 years old with opportunities to build friendships, develop independence, and participate in meaningful activities in a safe, inclusive, and supportive environment.

Purpose

Club 21 provide opportunities for participants to develop social connections, confidence, independence, and community participation through age-appropriate recreational and social activities. The programs also provide families and caregivers with planned respite while participants engage in meaningful social experiences.

FSCD Respite Funding

Club 21 may qualify as a respite service for families receiving FSCD funding, where the service is included and approved in the family's FSCD agreement.

Families are responsible for confirming their available respite funding and eligibility with their FSCD worker. EDSS can provide families with the information and documentation required to support the use of approved FSCD respite funding for the program.

Group Placement

Participants are grouped based on age and other relevant considerations to support meaningful participation and positive peer interactions.

EDSS may adjust group placement when appropriate to support participant engagement, group dynamics, safety, and the overall success of the program.

Program Activities

Activities may include:

- Games and recreational activities
- Arts and crafts
- Cooking
- Group challenges
- Social activities
- Seasonal celebrations
- Community outings
- Other activities based on participant interests and program planning

Activities may vary between Club 21 based on the age, interests, and needs of the participants.

Participants are encouraged to participate based on their interests, preferences, comfort level, and support needs.

Sign-In and Sign-Out

For the safety of participants, a parent, guardian, or authorized caregiver is required to sign participants in and out of the program unless an alternative arrangement has been approved by EDSS in advance.

Participants will only be released to individuals authorized by the family and identified through the required registration or emergency information.

Snacks

Snacks may be provided during Club 21.

Families may be asked to provide an alternative snack when required to meet a participant's specific dietary needs.

Community Activities

Some Club 21 sessions may take place in the community. Families will be informed when a program session includes a community activity and of any additional information participants may need to bring or prepare for the activity.

Participants are expected to remain with the group and follow staff directions while participating in community activities.

3.5 Adult Outings

Unless otherwise stated, all **General Program Policies and Procedures** outlined in this handbook apply to participants enrolled in the **Adult Outings Program**.

Purpose

The Adult Outings Program provides adults with Down syndrome opportunities to build friendships, develop independence, and participate in meaningful community experiences.

Outings are designed to encourage social connection, confidence, independence, and participation in the community through recreational, cultural, social, and other activities.

Attendance

Regular attendance is encouraged to support relationship building and participation in planned activities.

Families should notify EDSS as soon as possible if a participant will be unable to attend a scheduled outing.

Meeting Locations

Families will be provided with information about the meeting location, departure time, and expected return or pick-up time for each outing.

Participants are expected to arrive at the designated meeting location on time so the group can depart as scheduled.

Outing Information

Information about each outing will be provided to families in advance and may include:

- Date and time
- Meeting and pick-up locations
- Activity or destination
- What participants should bring
- Appropriate clothing or footwear
- Transportation information
- Any other information specific to the outing

Outings may include restaurants, sporting events, community festivals, cultural attractions, recreational activities, shopping, and other community experiences. Outing locations and activities may vary based on participant interests, community opportunities, availability, and program planning.

Transportation

Transportation arrangements are the responsibility of participants and their families unless otherwise communicated by EDSS.

When transportation is provided or arranged by EDSS for a specific outing, families will be provided with the relevant transportation details in advance.

Participants are expected to follow staff directions and any applicable transportation safety requirements while travelling as part of an EDSS outing.

Community Expectations

Participants are expected to follow staff directions, remain with the group unless an alternative arrangement has been approved, and follow the rules and safety requirements of the community setting.

3.6 Summer Camp

EDSS Summer Camp provides children and youth with Down syndrome, other disabilities, and their siblings with opportunities to participate in fun, inclusive, and engaging recreational experiences during the summer. Camp promotes social connection, independence, confidence, skill development, and community participation.

Themes

Each camp week has a different theme, with activities planned around the theme.

Eligibility

Participants must meet the age and eligibility requirements for the specific camp program. EDSS also considers whether a participant's support needs can be safely accommodated within the camp's staffing model.

Reduced-Hour Arrangements

Families requesting reduced camp hours must indicate this at registration. A minimum daily charge applies to reduced-hour arrangements.

Camp Staffing Model

Summer Camp generally operates using a **1 staff to 3 participants ratio**. Staff provide active supervision and support throughout the day.

One-to-One Support Arrangements

EDSS may provide dedicated one-to-one staffing for individual campers. Families must disclose significant support needs during registration so EDSS can determine whether those needs can be safely supported within the available staffing model. Where additional individualized support is required beyond the camp's staffing model, EDSS will work with the family to determine whether an appropriate support arrangement can be established.

Camp Activities

Camp activities may include recreation, arts and crafts, games, music, creative activities, life and independence skills, educational activities, community outings, and special events. Activities may be modified or adapted to support different abilities and support needs.

Swimming/Water Activities

When swimming or water activities are included, families will be informed of any specific clothing, equipment, or safety expectations.

Food and Allergies

Families are responsible for providing required lunches, snacks, and beverages unless otherwise communicated. Allergies and dietary restrictions must be identified during registration.

Sunscreen/Bug Spray

Families are responsible for applying sunscreen before camp and providing sunscreen and bug spray as needed for outdoor activities.

Camp-Specific Program Fit

EDSS strives to provide an inclusive camp experience. If a participant's needs cannot be safely accommodated within the available staffing, supports, and resources, EDSS will work with the family to identify reasonable accommodations or alternative supports.

Part 4: EDSS Services

4.1 Professional Services

EDSS offers access to professional services to support participants in their development, communication, independence, participation, and overall well-being. Services are provided by qualified professionals and are individualized based on the participant's needs, strengths, goals, and areas of development.

Professional services available through EDSS for current members may include:

- Speech-Language Pathology (SLP)
- Speech-Language Pathology Assistant (SLPA)
- Behaviour Services
- Physiotherapy (PT)
- Occupational Therapy (OT)

Unless otherwise stated, the following procedures apply to all professional services.

Registration and Intake

All general registration and intake requirements outlined in Part 2 apply to Professional Services unless otherwise stated.

All professional service intakes are completed by the Director of Community and Family Services before services begin. The intake process helps EDSS understand the participant's needs and the type of service being requested.

Assessment

An assessment is completed by the professional providing the service. The assessment allows the professional to learn more about the participant's history, strengths, needs, current abilities, and goals.

The information gathered through the assessment is used by the professional to develop an individualized approach to service delivery and establish goals that are specific to the participant. The assessment also helps guide the professional in determining appropriate strategies, supports, and activities based on the participant's needs and goals.

Ongoing Services

Following the intake and assessment, the participant and family will work with the professional service provider to identify goals and determine the type of service and support that best meets the participant's needs.

Once the participant has been seen by the professional, the family and professional will work together to establish an ongoing service schedule that works for both parties and supports the participant's goals.

Goals and service approaches may be reviewed and adjusted over time as the participant's needs, progress, and goals change.

Fees

Professional services are subject to the current EDSS fee schedule. Families are informed of the applicable fee before services begin.

Where approved FSCD funding is being used to pay for a professional service, EDSS will process the service in accordance with the applicable funding agreement and provide the family with the information and documentation required to support the use of their approved funding.

If a family does not have approved FSCD funding for the service, or chooses to pay privately, the family is responsible for the applicable fee. Private-pay services are paid following each session unless otherwise arranged with EDSS.

Fees, payments, refunds, and other financial requirements are outlined in **Part 2 — EDSS General Information, Policies and Expectations, Section 2.15 Fees, Payments and Refunds** and the **Addendum - EDSS Program Fees and Refund Policy**.

Booking

All new professional service appointments are booked through the Director of Community and Family Services. An intake must be completed before professional services begin.

Following the initial appointment and assessment, ongoing appointments may be booked by either the professional service provider or the Director of Community and Family Services, depending on the service and scheduling arrangements.

Families will receive a confirmation email with the appointment details and are responsible for notifying EDSS of any changes or scheduling concerns.

Payment and Funding

Professional services may be paid through approved government funding, including FSCD where applicable, or through private payment.

Where approved funding is being used, EDSS will work with the family to support the use of the approved funding and provide the information and documentation required.

Families who are paying privately are responsible for payment of the applicable service fees.

Payment requirements, private-pay procedures, refunds, and other applicable financial information are outlined in the **EDSS Program Fees and Refund Policy**. Families are encouraged to review this policy before beginning professional services.

Cancellation

Families are expected to provide notice when they are unable to attend a scheduled appointment. Cancellation and missed-appointment requirements are outlined in the applicable **EDSS cancellation policy**.

4.2 Service Descriptions

Speech-Language Pathology

EDSS offers Speech-Language Pathology services through qualified Speech-Language Pathologists. Services may support speech, language, communication, social communication, functional communication, augmentative and alternative communication (AAC), and other communication-related goals.

Matching Participants with an SLP

Each Speech-Language Pathologist may have different areas of experience, training, and professional expertise. For example, an SLP may have additional training or experience with approaches such as Hanen or PROMPT, or with specific areas of speech, language, or communication.

When an SLP service is requested, the Director of Community and Family Services will review the participant's identified needs and goals and will make every reasonable effort to match the participant with an SLP whose experience and areas of practice are closely aligned with the service being requested.

Speech-Language Pathology Assistant

Speech-Language Pathology Assistant services may support the implementation of goals and strategies developed by the Speech-Language Pathologist. Services are provided under the direction and supervision of a Speech-Language Pathologist, as applicable.

Behaviour Services

Behaviour services may support participants with skill development, communication, emotional regulation, positive behaviour supports, and strategies that promote participation and independence.

Physiotherapy

Physiotherapy services may support movement, mobility, strength, balance, coordination, physical function, and participation in daily activities.

Occupational Therapy

Occupational Therapy services may support functional skills, independence, sensory processing, self-care, such as toileting, fine motor skills, participation in daily activities, and environmental or activity adaptations.

4.3 Family Services and Navigation

Family Services and Navigation is provided by the Director of Community and Family Services.

The Director leads family navigation at EDSS and helps individuals and families access and navigate government funding, disability supports, financial resources, advocacy, professional services, learning opportunities, and community supports. Support is individualized based on the needs, goals, and circumstances of each individual and family.

Navigation

The Director of Community and Family Services supports individuals and families in navigating educational and childcare options from early childhood through high school.

Support may include:

- Providing information about childcare and daycare options
- Helping families understand and explore **PUF (Program Unit Funding)** and other educational supports
- Providing information about preschool and early learning programs
- Helping families explore elementary, junior high, and high school options
- Providing information about inclusive education and available school-based supports
- Helping families prepare for meetings with schools, teachers, and other education professionals, including ISP meetings.
- Supporting families in understanding their options and identifying questions to ask when making educational decisions
- Providing information about community programs and resources that may complement a participant's education

EDSS provides information, navigation, and advocacy support to help families make informed decisions. Families make the final decisions regarding childcare, school placement, and educational programming. EDSS does not determine school placement or eligibility for educational programs or funding.

Advocacy

The Director supports individuals and families in advocating for their needs, rights, goals, and access to appropriate supports. This may include helping families prepare for meetings, understand their options, communicate their needs, and work through concerns with service systems.

Family Support

EDSS provides information, guidance, and support to families as they navigate the various systems and services that may be part of their lives. Support may be provided to participants, parents, caregivers, and other members of the participant's support network.

Downright Lucky Team

The Downright Lucky Team (DLT) provides peer support to new parents who have recently welcomed a baby with Down syndrome. The team offers families an opportunity to connect with other parents who have lived experience and can provide reassurance, shared experiences, information, and guidance during the early stages of their journey.

The Canadian Down Syndrome Society (CDSS) developed and provided specialized training for the Downright Lucky Team peer-support model. The Director of Community and Family Services and the DLT Coordinators use this training and their experience to support and orient new DLT team members and to help prepare them to provide peer support to new families.

The DLT is led by the Director of Community and Family Services, with support from the DLT Coordinators. Team members provide a safe and supportive space for families to ask questions, share experiences, and connect with another parent who understands.

New families may be referred to the Downright Lucky Team by hospitals and other professionals in the community, or families may self-refer to EDSS.

All Downright Lucky Team members have signed a confidentiality agreement.

Peer-to-Peer Family Support

EDSS also provides peer-to-peer support for parents and families of older children and youth with Down syndrome. This support provides opportunities for families to connect with others who have similar experiences, share information and resources, and provide encouragement and practical support.

Peer support may be helpful as families navigate different stages of their child's development and may include topics such as education, social opportunities, community participation, transitions, and other family experiences.

EDSS works to connect families with other parents and families based on their needs, experiences, and interests.

Referrals

The Director may provide referrals or connections to appropriate community organizations, professionals, programs, services, and other resources based on the participant's or family's identified needs.

Transition Support

The Director can support individuals and families through transitions and changes in services, education, employment, living arrangements, and other stages of life. Transition support may include planning, identifying available options, connecting with resources, and helping families prepare for changes.

Funding and Navigation Assistance

The Director provides information and navigation assistance related to government funding and disability supports, including FSCD, PDD, AISH, DTC, RDSPs and other applicable benefits and resources.

Support may include helping families understand funding programs, identify potential supports, understand processes, and navigate available options. EDSS does not determine eligibility for government programs or make funding decisions on behalf of government agencies.

Education and Community Awareness

The Director of Community and Family Services provides professional presentations and education about Down syndrome, disability supports, inclusion, and related topics to schools, daycares, community organizations, service providers, workplaces, and other groups.

Presentations may be tailored to the audience and may include information about Down syndrome, communication and learning, inclusion, supporting individuals with Down syndrome, available resources and services, and creating welcoming and inclusive environments.

EDSS may also provide education and information to organizations and professionals who support individuals with Down syndrome and their families.

If you need help with...	Contact
Program Registration	Program Manager
Program Concerns	Program Manager
Family Navigation/Funding Support	Director of Community and Family Services
Professional Services	Director of Community and Family Services
Billing/Payment/Donations	EDSS Office
Donations	Executive Director
General Questions	EDSS Office
Complaints/Formal Concerns	Executive Director/Director of Community and Family Services/Program Manager

Thank You

Thank you for taking the time to read the Edmonton Down Syndrome Society Parent & Participant Handbook.

We hope this handbook provides helpful information about EDSS programs, services, policies, and the supports available to individuals and families.

Our goal is to ensure that every participant and family feels welcomed, respected, informed, and supported. We value the opportunity to work alongside you and look forward to being part of your journey with EDSS.

If you have questions or need assistance navigating a program, service, or support, please reach out to the EDSS team. We are here to help.

Part 5: Addendum – Policies and Procedures

The Addendum contains the policies and procedures referenced throughout this Handbook. Parents/guardians and participants are asked to read each section carefully to ensure they understand the guidelines, expectations, and practices of the Edmonton Down Syndrome Society (EDSS).

EDSS Intake and Registration Procedure

Step 1 — Registration

The family completes the applicable registration and intake forms.

Step 2 — Review

The designated EDSS staff member reviews the information provided and identifies any missing, unclear, or concerning information.

Step 3 — Follow-Up

If additional information is required, EDSS contacts the family to obtain clarification or additional documentation.

Step 4 — Program/Service Fit

EDSS determines whether the participant's identified needs can be appropriately and safely supported within the program or service's available structure and staffing model.

Step 5 — Additional Supports

Where appropriate, EDSS discusses reasonable accommodations, support strategies, or other options with the family.

Step 6 — Confirmation

Once required information and documentation are complete and the program or service is determined to be an appropriate fit, participation may proceed.

Step 7 — Ongoing Updates

Staff and families communicate changes in participant needs and update information when necessary.

EDSS Waitlist Procedure

Procedure for Waitlist Management

Step 1 — Program or Service Reaches Capacity

When a program or service reaches its available capacity, EDSS staff will determine whether a waitlist should be established.

Step 2 — Confirm Eligibility and Information

Before adding an individual to the waitlist, staff will confirm the applicable registration, intake, eligibility, or service requirements.

Step 3 — Add Individual to Waitlist

The individual will be added to the appropriate waitlist, and the following information will be recorded:

- Participant name;
- Family/contact information;
- Program or service requested;
- Date added;
- Relevant preferences or scheduling information;
- Applicable support information; and
- Any other information necessary to manage the waitlist.

Step 4 — Review Available Spaces

When a space becomes available, the responsible staff member will review the waitlist and identify individuals who may be appropriate for the available space.

Step 5 — Contact the Family

The selected family will be contacted and provided with information about the available space.

The date and method of contact will be documented.

Step 6 — Family Response

The family may:

Accept the space:

EDSS will complete any outstanding registration, intake, funding, or documentation requirements and confirm participation.

Decline the space but remain on the waitlist:

EDSS will document the decision and retain the individual on the waitlist.

Decline the space and leave the waitlist:

EDSS will update the individual's status and remove them from the waitlist.

Step 7 — No Response

If the family does not respond, EDSS will make reasonable follow-up attempts.

If the family does not respond after the established number of attempts, EDSS may remove the individual from the waitlist and document the reason.

Step 8 — Ongoing Review

EDSS will periodically review waitlists to ensure that:

- Contact information is current;
- Families remain interested;
- Participant needs have not significantly changed;
- Program fit remains appropriate; and
- The waitlist accurately reflects current demand.

Participant Rights and Responsibilities

EDSS is committed to ensuring that all participants are treated with dignity, respect, fairness, and compassion. Participants have the right to be involved in decisions that affect them and to receive services in a safe, inclusive, and supportive environment.

Participant Rights

Participants have the right to:

Be treated with dignity, respect, and kindness.

Participate in EDSS programs and services in a safe, welcoming, and inclusive environment.

Be supported to communicate their preferences, needs, choices, and concerns.

Be involved in decisions about their programs, services, and supports to the greatest extent possible.

Receive information about EDSS programs and services in a way that is understandable and accessible to them.

Have their privacy and personal information respected and protected.

Be free from discrimination, abuse, neglect, harassment, intimidation, or inappropriate treatment.

Raise concerns, provide feedback, or make a complaint without fear of retaliation.

Request reasonable accommodations or supports when needed to participate.

Have their individual strengths, abilities, culture, preferences, and goals respected.

Choose, where appropriate, to have a parent, guardian, support person, or advocate involved in discussions about their services.

Be supported to develop greater independence, self-advocacy, and participation in their community.

Participant Responsibilities

Participants are expected to:

Treat EDSS staff, volunteers, other participants, families, and community members with respect.

Participate in programs and services to the best of their ability.

Follow reasonable program or service guidelines and safety expectations.

Communicate their needs, concerns, or requests for support when they are able to do so.

Respect the personal space, privacy, belongings, and rights of others.

Use EDSS facilities, equipment, and resources appropriately.

Follow reasonable instructions related to health, safety, and emergency procedures.

Work with EDSS staff and their support network to address concerns that may affect participation.

EDSS recognizes that participants may require different levels of support to understand and meet these responsibilities.

Parent/Guardian Responsibilities

Parents and guardians are expected to:

Provide EDSS with accurate and current information that is relevant to the participant's participation in programs or services.

Inform EDSS of changes that may affect the participant's safety, support needs, communication, or ability to participate.

Ensure that required forms, consents, and emergency contact information are kept up to date.

Support the participant to understand their rights and responsibilities and to express their preferences and choices.

Communicate respectfully with EDSS staff, volunteers, and other participants and families.

Ensure appropriate transportation, drop-off, and pick-up arrangements are in place.

Follow EDSS policies and procedures that apply to the participant's program or service.

Work collaboratively with EDSS staff when concerns arise regarding the participant's participation, safety, or support needs.

Where the participant is an adult, EDSS will support the individual's right to participate in decisions about their own services to the greatest extent possible, while recognizing the legal role of a guardian or other authorized decision-maker where applicable.

Support Person/Advocate Responsibilities

A support person or advocate may assist a participant in communicating, understanding information, making choices, or expressing concerns.

Support persons and advocates are expected to:

Respect the participant's choices, preferences, privacy, and dignity.

Support the participant to speak for themselves whenever possible.

Avoid speaking or making decisions on behalf of the participant when the participant is able to communicate their own wishes.

Work collaboratively and respectfully with EDSS staff.

Maintain appropriate confidentiality regarding the participant and other individuals involved in EDSS programs or services.

Follow EDSS safety requirements and applicable program guidelines.

Raise concerns or request additional support when they believe the participant's needs are not being met.

The role of a support person or advocate is to support the participant's voice and participation, not to replace the participant's voice where the participant is able to express their wishes.

Respectful Participation

EDSS is committed to creating an environment where everyone feels safe, respected, and included.

Participants, parents, guardians, support persons, advocates, staff, volunteers, and visitors are expected to communicate and interact respectfully.

EDSS recognizes that individuals may communicate distress, frustration, or unmet needs in different ways. Staff will respond using appropriate supports and strategies whenever possible. However, behaviour that threatens the safety or well-being of another person, including violence, harassment, intimidation, or significant property damage, may require EDSS to take steps to ensure everyone's safety.

When concerns arise, EDSS will seek to understand the circumstances, work with the participant and their support network to identify appropriate solutions and use the least restrictive and most supportive response possible.

EDSS may review or modify a participant's participation in a program or service when ongoing behaviour or circumstances create significant safety concerns or prevent EDSS from safely meeting the needs of the participant or others.

Participant Dignity, Inclusion, and Accessibility

EDSS is committed to creating an environment where every participant is treated with dignity, respect, fairness, and compassion. We recognize and value the individual strengths, identities, experiences, abilities, preferences, and support needs of the people and families we serve.

Dignity and Respect

Every participant has the right to be treated with dignity and respect.

EDSS staff, volunteers, participants, families, caregivers, and support persons are expected to interact with one another in a respectful and considerate manner.

Participants will be supported to express their opinions, preferences, choices, and concerns and to participate in decisions that affect them to the greatest extent possible.

Inclusion

EDSS is committed to creating inclusive programs and services where participants feel welcomed, valued, and able to participate.

We strive to remove barriers to participation and encourage meaningful involvement in programs, services, activities, learning opportunities, and community experiences.

Where additional support is needed, EDSS will work with the participant and their support network to identify reasonable ways to support participation.

Equity, Diversity and Belonging

EDSS recognizes that every individual and family has their own experiences, backgrounds, perspectives, strengths, and needs.

We are committed to promoting equity, diversity, and belonging and to creating an environment where individuals feel accepted and respected.

EDSS strives to ensure that differences are respected and that participants and families have equitable opportunities to access and benefit from our programs and services.

Accessibility and Accommodations

EDSS recognizes that participants may require different types or levels of support to participate fully in programs and services.

EDSS will work with participants, parents/guardians, and support persons to identify reasonable accommodations and supports where possible.

Accommodations may relate to communication, mobility, sensory needs, learning, behaviour, scheduling, or other individual circumstances.

Families are encouraged to communicate relevant support needs with EDSS so that appropriate planning can occur.

While EDSS will make reasonable efforts to accommodate individual needs, some accommodations may require additional resources, specialized supports, or advance planning.

Individual Differences and Support Needs

EDSS recognizes that individuals with Down syndrome have diverse strengths, abilities, preferences, communication styles, and support needs.

There is no single approach that works for every participant.

EDSS works with participants and their families or support networks to understand individual needs and, where possible, adapt our approach to support meaningful participation and success.

Information about a participant's support needs should be shared with EDSS (in the EDSS Intake Form) when it is relevant to their safety, participation, or ability to benefit from a program or service.

Non-Discrimination

EDSS does not tolerate discrimination, harassment, or exclusion based on characteristics protected under applicable human rights legislation.

Participants, families, caregivers, support persons, staff, volunteers, and visitors are expected to contribute to an environment free from discrimination, harassment, intimidation, and disrespectful treatment.

Concerns related to discrimination or harassment can be brought forward to EDSS staff or management. Concerns will be taken seriously and addressed in accordance with EDSS policies and procedures.

Our Commitment

EDSS is committed to continually improving accessibility, inclusion, and the experience of participants and families.

We welcome feedback from participants and their families about barriers they experience and ways EDSS can improve our programs, services, and practices.

Our goal is to ensure that every person who interacts with EDSS feels welcomed, respected, valued, and included.

EDSS Behaviour Management Policy and Procedure

1. Purpose

The Edmonton Down Syndrome Society (EDSS) is committed to providing a safe, respectful, welcoming, and inclusive environment for participants, families, employees, volunteers, and community members.

The purpose of this policy is to provide EDSS staff and volunteers with a consistent approach for responding to situations where a participant displays behaviour that is disruptive, escalated, aggressive, inappropriate, or creates a potential safety concern.

EDSS recognizes that behaviour is often a form of communication and may be influenced by a participant's communication abilities, environment, sensory needs, emotions, physical well-being, frustration, anxiety, changes in routine, or other circumstances.

The goal of behaviour management at EDSS is to:

- maintain the safety and dignity of the participant and others.
- respond respectfully and appropriately.
- prevent situations from escalating whenever possible.
- support the participant to regain regulation and return to participation when appropriate.
- provide staff and volunteers with clear direction and support; and
- ensure that significant or recurring concerns are appropriately addressed.

EDSS is a community-based organization and does not provide intensive behavioural intervention or operate residential services. Staff and volunteers are expected to respond within the scope of their training and responsibilities and to seek assistance when a situation exceeds their ability to safely manage it.

2. Scope

This policy applies to all EDSS employees, contractors, volunteers, students, and other individuals acting on behalf of EDSS.

It applies to behaviour occurring during:

- EDSS programs and services.
- camps.
- workshops and educational sessions.
- social and recreational activities.
- community activities.

- events.
- activities involving EDSS staff or volunteers; and
- other activities where an individual is participating under the direction or supervision of EDSS.

3. Guiding Principles

3.1 Respect and Dignity

Participants will be treated respectfully regardless of the behaviour they are displaying.

3.2 Person-Centred Approach

Staff and volunteers will consider the individual's communication style, abilities, preferences, and circumstances when responding to behaviour.

3.3 Behaviour as Communication

EDSS recognizes that behaviour may communicate frustration, anxiety, discomfort, pain, sensory overload, confusion, a need for assistance, difficulty communicating, or another unmet need.

Staff should consider what the behaviour may be communicating rather than assuming that the individual is intentionally being difficult or disruptive.

3.4 Prevention and De-escalation

Whenever possible, staff will use proactive strategies and de-escalation techniques to prevent situations from becoming more serious.

3.5 Least Restrictive Response

Staff will use the least intrusive response necessary to maintain safety.

3.6 Safety

The safety of participants, staff, volunteers, and others is the priority when a situation becomes unsafe.

3.7 Consistency

Staff and volunteers should respond consistently and follow EDSS procedures rather than reacting emotionally or creating their own consequences or disciplinary approaches.

4. Behaviour Covered by This Policy

Behaviour that may require staff intervention includes, but is not limited to:

- yelling or significant verbal escalation.
- threatening behaviour.

- physical aggression toward another person.
- hitting, kicking, pushing, biting, or grabbing.
- throwing objects.
- damaging property.
- inappropriate sexual behaviour.
- persistent disruption that significantly affects a program.
- leaving a supervised area when doing so creates a safety concern.
- self-injurious behaviour.
- refusal to follow a reasonable safety direction; or
- other behaviour that creates a significant concern for the safety or well-being of the individual or others.

A participant should not be considered to be displaying problematic behaviour simply because they communicate, move, respond, or behave differently from others.

5. Staff and Volunteer Responsibilities

Staff and volunteers are responsible for:

- remaining calm and professional.
- recognizing early signs of escalation.
- using appropriate de-escalation strategies.
- maintaining the dignity of the participant.
- protecting other participants from unnecessary exposure to the situation.
- seeking assistance when required.
- following EDSS procedures.
- documenting significant incidents; and
- reporting concerns to their supervisor, program lead, or EDSS management.

Staff and volunteers must not use punishment, humiliation, threats, intimidation, or unnecessary physical intervention.

Staff and volunteers should not attempt to manage a situation beyond their training or ability to safely respond.

6. Preventative Strategies

Whenever possible, staff and volunteers should attempt to prevent escalation by:

- providing clear and simple instructions.
- allowing additional processing time.
- offering appropriate choices.
- providing breaks.
- reducing unnecessary noise or stimulation.
- identifying when a participant may be becoming frustrated or overwhelmed.
- adjusting an activity where reasonably possible.
- using the participant's preferred communication method.
- maintaining predictable routines; and
- addressing concerns early rather than waiting until behaviour escalates.

Staff should consider whether the environment, activity, communication, or expectations can be adjusted to support successful participation.

7. Responding to Behaviour

When behaviour begins to escalate, staff should follow these steps.

Step 1 – Remain Calm

Staff should maintain a calm voice, neutral body language, and professional manner.

Staff should avoid arguing, yelling, threatening, or attempting to reason with a participant who is highly escalated.

Step 2 – Assess the Situation

Determine:

- Is anyone in immediate danger?
- Is the participant in distress?
- Are other participants at risk?
- Does the environment need to be changed?
- Is additional staff support required?

Step 3 – Reduce Stimulation

Where possible:

- reduce noise.
- reduce the number of people involved.
- provide physical space.
- remove unnecessary demands.
- move other participants away; and
- provide an opportunity for the participant to take a break.

Step 4 – Communicate Clearly

Use short, simple statements and avoid giving multiple instructions at once.

Allow the participant time to process what has been said.

Step 5 – Offer Choices

When appropriate, provide reasonable choices such as:

- taking a break.
- moving to another area.
- continuing the activity later; or
- choosing an alternative activity.

Step 6 – Seek Assistance

If the behaviour continues to escalate or staff are unsure how to proceed, staff should contact their supervisor, program lead, or another appropriate EDSS staff member.

Staff should not attempt to manage a situation alone when doing so may compromise safety.

8. Immediate Safety Concerns

If a participant's behaviour creates an immediate risk of serious injury to themselves or another person, staff must prioritize safety.

Depending on the circumstances, staff may:

- move other participants away from the immediate area.
- remove objects that may create a safety risk, where it is safe to do so.
- create additional physical space.
- request assistance from other trained staff.

- contact the participant's parent/guardian or designated support person where appropriate; and
- contact emergency services when there is an immediate risk of serious harm or a medical emergency.

Staff should never place themselves or another participant at unnecessary risk.

9. Physical Intervention

EDSS does not use physical restraint as a routine behaviour management strategy.

Staff and volunteers must not use physical intervention as punishment or to force compliance.

Physical intervention should only occur where it is necessary to prevent imminent harm and where the individual is appropriately trained and permitted to do so.

Any physical intervention must be reported immediately to EDSS management and documented as an incident.

10. When a Participant Needs to Leave a Program or Activity

There may be circumstances where a participant's behaviour cannot be safely managed within an EDSS program or activity.

Where appropriate, EDSS management may determine that:

- the participant requires a temporary break from the activity.
- a parent/guardian or designated support person needs to attend.
- the participant needs to leave the activity for the remainder of the session; or
- additional supports need to be identified before the participant returns.

Staff should not make decisions about permanent exclusion from an EDSS program without consultation with EDSS management.

Any decision to significantly restrict participation should be reasonable, documented, and based on safety and EDSS's ability to provide appropriate support.

11. Parent/Guardian Communication

Where appropriate, EDSS may contact a participant's parent, guardian, or designated support person when:

- behaviour creates a significant safety concern.
- the participant cannot safely continue participating.
- an incident results in injury.

- repeated incidents are occurring.
- staff require additional information or support; or
- management determines follow-up is necessary.

Communication should be factual, respectful, and focused on the incident, the participant's well-being, and any next steps.

12. Behaviour Specialist Consultation

EDSS has access to a Behaviour Specialist who may be consulted to support staff, volunteers, participants, and families when behavioural concerns arise.

The Behaviour Specialist provides guidance, consultation, education, and practical strategies to help understand and respond appropriately to behaviours of concern.

Consultation may be requested when:

- staff or volunteers are unsure how to respond to a behavioural situation.
- a participant is experiencing recurring behaviours that are affecting participation.
- staff would benefit from additional strategies or guidance.
- a family is seeking support or information related to behaviour.
- a participant's behaviour appears to be communicating an unmet need.
- a program or environment may be contributing to the behaviour.
- staff require assistance with de-escalation strategies; or
- EDSS management determines that additional behavioural consultation would be beneficial.

The Behaviour Specialist may:

- consult with staff or volunteers.
- meet with a participant and/or family when appropriate.
- observe a situation or program when appropriate and with appropriate consent.
- help identify possible triggers or contributing factors.
- provide suggestions for proactive and preventative strategies.
- provide strategies for responding to escalation.
- provide education and resources to families, staff, and volunteers.
- assist staff in understanding behaviour as a form of communication.

- recommend additional community or professional supports when appropriate; and
- work collaboratively with EDSS staff and families to support successful participation.

The Behaviour Specialist does not replace medical, psychological, psychiatric, or other clinical services. Where behaviour may be related to an underlying health, mental health, or other professional concern, the participant or family may be encouraged to seek appropriate external assessment or support.

Accessing the Behaviour Specialist

Staff and volunteers should speak with their supervisor or program lead when they believe consultation would be helpful.

Families may request consultation directly through EDSS or may be referred to the Behaviour Specialist by an EDSS staff member.

Consultation is a supportive resource and should not be viewed as disciplinary action for the participant, family, staff member, or volunteer.

13. Incident Documentation

Significant behavioural incidents must be documented according to EDSS's Incident Reporting Procedure.

Documentation should include:

- date, time, and location.
- individuals involved.
- what occurred before the behaviour.
- an objective description of the behaviour.
- staff response.
- any de-escalation strategies used.
- whether anyone was injured.
- whether emergency services were contacted.
- who was notified; and
- any follow-up required

14. Management Follow-Up

EDSS management will review significant or repeated behavioural incidents to determine whether:

- additional information is required.

- staff require additional training or support.
- program or environmental changes could prevent future incidents.
- the participant or family requires additional support or referral.
- consultation with the Behaviour Specialist would be beneficial.
- additional safety measures are necessary; or
- the participant's ability to safely participate in the program needs to be reviewed.

The purpose of the review is to improve safety and support successful participation, not to punish the participant.

15. Repeated Behavioural Concerns

If a participant demonstrates repeated behaviours that significantly affect their own safety, the safety of others, or the ability of a program to operate safely, EDSS management will determine appropriate next steps.

Depending on the circumstances, this may include:

- meeting with the participant and/or family.
- consulting with the Behaviour Specialist.
- identifying strategies that may support participation.
- modifying the participant's participation or supports.
- consulting with an appropriate professional or service provider.
- providing additional guidance or training to staff or volunteers.
- developing specific safety strategies for an activity; or
- determining whether EDSS can safely continue to provide the particular service.

Any decision regarding significant restrictions on participation should be made by EDSS management and should be reasonable, documented, and based on safety and the organization's ability to provide appropriate support.

16. Staff and Volunteer Training

EDSS will provide staff and volunteers with appropriate training related to behaviour management and de-escalation based on their roles and responsibilities.

Training may include:

- positive behaviour support.

- de-escalation techniques.
- communication strategies.
- recognizing signs of escalation.
- crisis response.
- person-centred approaches.
- disability awareness.
- Non-Violent Crisis Intervention; and
- other training determined appropriate by EDSS management.

Staff and volunteers will only use intervention techniques for which they have received appropriate training.

17. Confidentiality

Information regarding behavioural incidents is confidential and will only be shared with individuals who require the information to perform their responsibilities or provide appropriate support.

Staff and volunteers must not discuss behavioural incidents with other participants, families, volunteers, or community members who are not directly involved.

18. Policy Review

This policy will be reviewed at least every three years or sooner if there are changes to legislation, organizational practices, accreditation requirements, or EDSS services.

PROCEDURE

Behaviour Management – Quick Reference for Staff and Volunteers

When a participant displays behaviour requiring intervention:

STOP → STAY CALM → ASSESS SAFETY → DE-ESCALATE → GET HELP

1. Stay Calm

Do not argue, threaten, shame, punish, or raise your voice.

2. Assess Safety

Ask yourself: Is anyone in immediate danger? Does anyone need to be moved away?

3. Give Space

Reduce noise, stimulation, demands, and the number of people involved where possible.

4. Communicate Simply

Use short, clear, respectful statements. Allow the participant time to process.

5. Offer Choices or a Break

When appropriate, offer reasonable choices, a change of activity, or an opportunity to take a break.

6. Get Help

Contact your supervisor, program lead, or another EDSS staff member if the situation is escalating or you are unsure what to do.

7. Consult the Behaviour Specialist

The EDSS Behaviour Specialist is available to provide consultation and strategies for staff, volunteers, participants, and families when additional behavioural support or guidance is needed.

8. Prioritize Safety

If there is an immediate risk of serious harm, follow emergency procedures and contact emergency services when necessary.

9. Document

Complete an incident report for significant behavioural incidents.

10. Follow Up

Notify the appropriate EDSS manager. Management will determine whether family communication, Behaviour Specialist consultation, staff follow-up, additional supports, or other action is required.

EDSS Participant Complaints Resolution Policy and Procedure

1. Purpose

The Edmonton Down Syndrome Society (EDSS) is committed to providing safe, respectful, inclusive, and high-quality programs and services.

EDSS recognizes that participants may have concerns or complaints about their experiences with an EDSS program, service, staff member, volunteer, or the way a service is provided.

The purpose of this policy is to provide participants with a clear, accessible, and fair process for raising concerns and making complaints about EDSS programs and services.

EDSS will make every reasonable effort to resolve concerns promptly, respectfully, and at the earliest appropriate level.

2. Scope

This policy applies to **participants receiving programs or services from EDSS**.

It applies to concerns or complaints related to:

- EDSS programs;
- services provided by EDSS;
- participant experiences within an EDSS program or service;
- EDSS staff or volunteers providing a program or service;
- communication regarding a program or service;
- decisions affecting a participant's participation in an EDSS program or service; and
- the quality, accessibility, or delivery of an EDSS program or service.

A participant may make a complaint independently or may choose to have a parent, guardian, family member, advocate, or other support person assist them.

3. Guiding Principles

EDSS is committed to:

Respect and Dignity

Treating every participant with dignity, respect, and fairness.

Accessibility

Making the complaint process understandable and accessible to participants.

Participants may receive assistance to communicate or document a concern when needed.

Participant Voice

Supporting participants to express their concerns and have their views heard.

Early Resolution

Whenever appropriate, attempting to resolve concerns as early as possible through discussion and problem-solving.

Fairness

Ensuring complaints are reviewed fairly and objectively.

Confidentiality

Handling complaints as confidentially as possible and only sharing information with individuals who need it to address the concern.

Non-Retaliation

Ensuring a participant can raise a concern or make a complaint without fear of retaliation or being treated unfairly as a result.

4. Definitions**Concern**

A question, problem, or dissatisfaction that a participant would like EDSS to address.

Informal Resolution

An attempt to resolve a concern through discussion, clarification, or problem-solving with the appropriate EDSS staff member or program/service lead.

Formal Complaint

A complaint that requires a documented review by EDSS management because the concern has not been resolved informally or because of the nature or seriousness of the concern.

Participant

An individual who is receiving or participating in an EDSS program or service.

5. Informal Concern Process

Whenever appropriate, participants are encouraged to raise concerns as soon as possible so that EDSS can work toward a resolution.

A participant is encouraged to speak with their parent, guardian, or other designated support person about their concern. Their guardian or support person may assist the participant in understanding the concern, communicating with EDSS, and determining the best way to address it.

A participant may also raise a concern directly with EDSS. A participant does not need to obtain permission from a parent or guardian before bringing a concern forward.

Step 1 – Speak with Your Guardian or Support Person

Where appropriate, the participant should speak with their parent, guardian, or designated support person about the concern.

The guardian or support person may:

- listen to the participant's concerns;
- help the participant communicate their concerns;
- assist the participant in determining whether the concern can be resolved informally;
- attend meetings or discussions with EDSS; and
- support the participant throughout the complaint process.

EDSS recognizes that participants have different levels of independence and decision-making ability. The participant's views and wishes should be respected and supported throughout the process.

Step 2 – Speak with the EDSS Staff Member Involved

Where the participant is comfortable doing so, the participant and/or their guardian or support person may discuss the concern with the EDSS staff member directly involved in the program or service.

The staff member will listen to the concern and attempt to resolve the matter where appropriate.

Step 3 – Speak with the Program or Service Lead

If the concern cannot be resolved, or the participant does not feel comfortable speaking with the staff member involved, the participant, guardian, or support person may speak with the appropriate EDSS Director.

Program concerns:

Meghan Schritt, Program Director

Service concerns, including therapy, navigation, and family support:

Julie Boucher, Director of Community and Family Services

The Director will review the concern and attempt to resolve it when possible.

Participant Choice and Guardian Involvement

EDSS encourages participants to involve their parent, guardian, or designated support person in the complaint process whenever appropriate.

A participant may choose to raise a concern directly with EDSS, particularly when they are able and comfortable doing so.

Where a participant has a legal guardian, EDSS will involve the guardian as appropriate and in accordance with the participant's legal and decision-making arrangements.

EDSS will make reasonable efforts to ensure that the participant's own perspective, wishes, and experience remain central to the complaint process.

6. Formal Complaint Process

A participant may make a formal complaint when:

- the concern has not been resolved through the informal process;
- the participant does not feel comfortable addressing the concern informally; or
- the nature of the concern requires a formal review.

Formal complaints should be submitted in writing whenever possible.

However, EDSS recognizes that some participants may have difficulty expressing themselves in writing. A participant may communicate a formal complaint verbally, with assistance from a parent, guardian, advocate, support person, or EDSS staff member.

A formal complaint should include, where possible:

- what happened;
- when or where it happened;
- who was involved;
- what steps have already been taken; and
- what the participant would like to see happen.

7. Formal Complaint Review

The appropriate EDSS Director will review the complaint.

The review may include:

- speaking with the participant;
- speaking with the staff or volunteer involved;
- speaking with other individuals who may have relevant information;
- reviewing relevant records or documentation; and
- identifying appropriate steps to address the concern.

Where possible, the participant will be kept informed about the status of the complaint.

The person reviewing the complaint should not be directly responsible for the issue being complained about where this would create a conflict of interest.

8. Serious or Sensitive Complaints

Some concerns should proceed directly to formal review and do not need to go through the informal process.

These may include concerns involving:

- abuse or neglect;
- discrimination;
- harassment;
- serious safety concerns;
- threats or violence;
- exploitation;
- serious misconduct; or
- other matters that EDSS management determines require immediate attention.

Such concerns should be reported to EDSS management as soon as possible.

Where required, EDSS will follow applicable legislation, reporting obligations, and organizational policies.

9. Final Review

If the participant is not satisfied with the outcome of the formal complaint review, they may request a final review by:

Janet Tryhuba, Executive Director

The Executive Director will review the available information and determine whether additional action is required.

The Executive Director will communicate the decision to the participant or their designated support person in writing whenever possible.

The Executive Director's decision is considered final within EDSS.

10. Timelines

EDSS aims to:

- acknowledge a formal complaint within five (5) business days;
- begin the review promptly; and
- provide a response within fifteen (15) business days, whenever possible.

Some complaints may require additional time.

When additional time is required, EDSS will advise the participant and provide an update whenever possible.

11. Confidentiality

EDSS will handle participant complaints as confidentially as possible.

Information will only be shared with individuals who need the information to review, investigate, respond to, or otherwise appropriately address the complaint.

Participants and their support persons will be encouraged to respect the confidentiality of the complaint process.

12. Non-Retaliation

A participant will not be denied or unfairly restricted from accessing EDSS programs or services because they have made a complaint in good faith.

EDSS will not tolerate retaliation against a participant for raising a concern or participating in a complaint process.

13. Participant Support

A participant may choose to have a parent, guardian, advocate, family member, or other support person assist them throughout the complaint process.

EDSS will make reasonable efforts to support participants in communicating their concerns in a manner that is accessible to them.

The participant's voice and wishes will be considered throughout the process to the greatest extent possible.

14. Complaint Records

Formal complaints and related documentation will be maintained in accordance with EDSS privacy and records management requirements.

Records may include:

- the complaint;
- relevant correspondence;

- notes from conversations or meetings;
- information gathered during the review;
- actions taken; and
- the final response.

15. Continuous Improvement

EDSS recognizes that participant complaints and concerns provide valuable opportunities to improve programs and services.

Where appropriate, EDSS may use information from complaints to identify improvements to:

- programs;
- services;
- communication;
- accessibility;
- staff training; and
- organizational practices.

PROCEDURE

Participant Complaints – Quick Reference

CONCERN → TALK → RESOLVE → FORMAL COMPLAINT → FINAL REVIEW

1. Speak Up

A participant can raise a concern with:

The EDSS staff member involved, or
the appropriate program/service lead.

A participant does not have to speak with a parent or guardian first.

A participant can have a parent, guardian, advocate, or support person help them.

2. Try to Resolve the Concern

EDSS will try to resolve the concern through respectful discussion and problem-solving whenever appropriate.

3. If the Concern Is Not Resolved

Program concern:

Contact Meghan Schritt, Program Director

Service concern:

Contact Julie Boucher, Director of Community and Family Services

4. Make a Formal Complaint

A participant may make a formal complaint verbally or in writing.

Include, when possible:

- What happened?
- When did it happen?
- Who was involved?
- What would you like EDSS to do?

5. Formal Review

The appropriate EDSS Director will review the complaint and gather information as necessary.

EDSS aims to acknowledge the complaint within 5 business days and provide a response within 15 business days, whenever possible.

6. Final Review

If the participant is not satisfied with the outcome, they may request a final review by:

Janet Tryhuba, Executive Director

The Executive Director's decision is final within EDSS.

Important

Concerns involving abuse, neglect, discrimination, harassment, serious safety issues, threats, violence, exploitation, or serious misconduct should be reported directly to EDSS management and do not need to go through the informal process first.

Participant Health & Safety Policy

Intent

Edmonton Down Syndrome Society (EDSS) is committed to providing a safe, healthy, respectful, and supportive environment for all participants who access EDSS programs and services. EDSS takes reasonable steps to identify and reduce health and safety risks and to support participants in participating safely and meaningfully in programs and activities. EDSS recognizes that participants may have individual health, communication, mobility, sensory, or support needs. Relevant information provided through the intake and registration process will be considered when planning and delivering programs and services.

Guidelines

Communication

EDSS encourages participants, families, guardians, caregivers, and support persons to communicate health and safety concerns to EDSS staff.

Health and safety concerns may be communicated verbally or in writing to a staff member, Program Lead, Manager, Director, or Executive Director.

EDSS will review and respond to health and safety concerns in a timely and appropriate manner. Participants and families will not be discouraged from raising a health or safety concern.

Participant Responsibilities

- Participants, parents, guardians, caregivers, and support persons are expected to:
- Provide accurate and current health, emergency contact, medication, and support information.
- Inform EDSS of significant changes that may affect participation or safety.
- Follow reasonable safety instructions provided by EDSS staff.
- Use required safety equipment or supports when applicable.
- Communicate health or safety concerns to staff whenever possible.
- Treat staff, volunteers, other participants, and community members with respect.
- Follow applicable EDSS program policies and procedures.

EDSS Responsibilities

EDSS will:

- Take reasonable steps to provide a safe and supportive environment.
- Identify and address foreseeable health and safety risks.
- Consider participant-specific health, communication, accessibility, and support needs.
- Ensure staff and volunteers receive appropriate information and training related to participant safety.
- Maintain current emergency contact and relevant health information.
- Respond appropriately to health and safety concerns and incidents.
- Document significant incidents and follow-up as required.
- Communicate with families, guardians, or emergency contacts when appropriate.

- Review and update health and safety practices as needed.

Health and Safety Concerns

When a health or safety concern is identified, EDSS will assess the situation and take reasonable steps to protect the participant and others.

- Depending on the circumstances, this may include:
- Providing immediate support;
- Modifying an activity;
- Contacting a parent, guardian, caregiver, or emergency contact;
- Seeking emergency medical assistance;
- Temporarily removing a participant from an activity; or
- Reviewing whether additional supports or accommodations are required.

Incidents and Emergencies

All staff, contractors, and volunteers are required to follow HR-3-02 – Emergency Response Plan when responding to an emergency involving a participant.

This includes procedures related to emergency response, fire or smoke evacuation, lockdown, missing persons, severe weather, and other emergency situations.

Emergency response will be based on the circumstances and severity of the incident. EDSS will communicate with the participant's parent, guardian, caregiver, or emergency contact as appropriate.

For immediate medical or life-threatening emergencies, 911 will be contacted.

Documentation and Follow-Up

Significant health and safety incidents will be documented in accordance with EDSS procedures and privacy requirements.

EDSS will complete appropriate follow-up after an incident to determine whether additional supports, accommodations, communication, or changes to program practices are required.

EDSS Medication Administration Policy

1.0 Purpose

To provide guidelines for the safe, consistent, and legally compliant administration of medication during EDSS programs and services. Medication administration is considered a critical intervention, not part of standard duties unless pre-approved.

2.0 Scope

This policy applies to all EDSS staff and volunteers who support individuals with medication administration across all EDSS activities and environments.

3.0 Definitions

- **Medication Administration:** Providing a prescribed or authorized medication to a participant.
- **Adverse Reaction:** An unexpected or harmful response to a medication, such as rash, difficulty breathing, or swelling.
- **Life-Saving Medication:** A medication administered to prevent serious harm or death.
- **Medication Error:** A preventable mistake that occurs during the medication administration process.
- **Eight Rights of Medication Administration:**
 - Right Person
 - Right Medication
 - Right Dose
 - Right Time
 - Right Route (oral, topical, injection)
 - Right Reason
 - Right of Refusal
 - Right of Documentation

4.0 Policy Details

a) Annual Certification

- Staff must complete Medication Administration Training **every 3 years**.

b) Safety Checks

- Follow triple-check process with prescriber order and medication label:
 - When retrieving
 - When preparing
 - When administering

c) Conditions for Administration

- Medication can only be administered with:

- A **prescriber order** with clear instructions
- A **Medication Administration Authorization Form**
- A current **Medication Care Plan** prepared by a health professional or parent

d) Life-Saving Medications

- Must be administered **immediately** when needed.
- Staff will be trained via Seizure First Aid sessions.

e) Documentation

- Use EDSS **Medication Administration Record (MAR)** form. Must include:
 - Client name
 - Date/time
 - Medication name/dosage
 - Picture of Medication
 - Method of administration
 - Staff initials and signature
 - Observations/incidents

f) Storage

- Medications must be:
 - In original, pharmacy-labeled containers
 - Stored according to labeled requirements (e.g., **“Store at room temperature.”** or **“Refrigerate. Do not freeze.”**)
 - In a **locked, secure location**
 - Carried by staff/participant only if lifesaving

g) Medication Label Requirements

- Medications must be labeled with:
 - Participant’s full name
 - Name of medication
 - Dosage and route of administration
 - Frequency and time(s) of administration
 - Prescribing physician’s name
 - Expiry date
 - Storage instructions (if applicable, as indicated by the pharmacy or packaging)

h) Medication Refusal, Adverse Reaction or Medication Error

In the event of a participant’s refusal, an adverse reaction, or a medication error, the following steps must be taken:

- Follow Emergency Protocol
- Call 911 if required
- Notify parent/guardian
- Complete an Incident Report

i) Limitations

EDSS staff may **not**:

- Alter medication (e.g., crush pills) unless authorized.
- Judge effectiveness.
- Administer PRN ("as needed") medications without specific direction.

5.0 Consent

- Written parental/guardian consent is **required before** administering any medication.
- Consent must be renewed **annually** or upon medication changes.

6.0 Policy Review

This policy will be reviewed annually or earlier if legislation or best practices change.

HR-3-02-Emergency Response Plan

Intent

Edmonton Down Syndrome Society is committed to protecting the health and safety of its employees and visitors to the premises. In pursuit of this, the company has established an emergency response plan to address potential and foreseeable types of emergencies affecting the company. This plan outlines the processes and procedures for appropriate responses to emergencies.

Guidelines

Employees must report an emergency event immediately to a member of management or other appropriate authority. For the purposes of this plan, an emergency is an instance or combination of instances of unsafe conditions that pose a threat to people or property, and include instances of fire or smoke; natural disaster or severe weather; chemical, biological, or radiological incidents; structural failures; and missing persons.

Not all emergencies require the same level of response. Appropriate responses are dictated by the severity of the event and its effect on the health and safety of employees, visitors, and property.

Emergency Response Lead

The Edmonton Down Syndrome Society Executive Director will ascertain emergency situations and be the first to respond to an incident. The ED is responsible for assessing the severity of the emergency and communicating appropriate actions immediately with assigned groups as appropriate. Response teams include at least one person per department to coordinate and instruct co-workers. Responsibilities in an emergency are delegated among various response team members who coordinate emergency or evacuation efforts within their areas of responsibility.

Employee and Visitor Evacuation Procedure

- If Edmonton Down Syndrome Society declares that an evacuation of the premises is necessary, employees and visitors must follow these steps:
- Stop working and shut down any equipment.
- Proceed to the closest emergency exit, following posted evacuation routes.
- Touch doorknobs and door handles carefully to check for heat and if hot, proceed to the next closest evacuation route; and
- Proceed to the designated meeting area at the Muster Point on the west side of the parking lot or Beacon House Early Learning Academy & OSC office as an alternate location unless otherwise instructed.

Bomb Threats

In the unlikely event of a bomb threat, it is impossible to discern valid threats from hoaxes. Therefore, all threats will be treated as real in order to protect lives and property, and the premises will be evacuated immediately. In the event of a bomb threat, immediately call 911.

Fire or Smoke

The primary purpose of the fire procedure is to provide a course of action for all personnel to follow in the event of a fire or smoke emergency. Any blaze (fire) of combustible materials causing danger of burns from fire or suffocation or choking from smoke inhalation can initiate the fire or smoke response procedure. This plan can also be implemented for fires nearby where there is a clear danger of the fire spreading to our facility or causing the air to become unbreathable due to smoke.

- Alert employees of the fire and its location. Activate the nearest fire alarm. Contact the local fire department by calling 911 and follow any and all instructions from the dispatcher.
- Keep low to the floor to avoid inhaling smoke.
- Once safely in the designated meeting area, assign someone to wait in a safe location to direct response personnel directly to the fire.
- If the fire is small, have an appropriately trained employee assess and extinguish the fire.
- If the fire cannot be extinguished, evacuate the building immediately.
- While evacuating, if safe to do so, assist anyone in danger or who cannot evacuate quickly. For those with mobility or accessibility needs, follow the plan established for evacuation.
- As the area is being evacuated, if it is safe to do so, take steps to contain the fire. For example, close all doors, fire doors, and windows near the fire. Shut off all fans, ventilators, and air conditioners. Evacuation should be the primary goal, so do not go out of your way to complete any of these tasks.
- Report to the designated emergency evacuation area at the muster point.
- Immediately report any employees, customers, visitors, contractors, or individuals who have remained in the building or refused to leave.
- Do not return until it has been declared safe to do so by the fire department.

Depending on the situation the Executive Director or supervisor may dismiss employees for the day.

Natural Disaster or Severe Weather

In a broad sense, a natural disaster or severe weather means any emergency caused by inclement weather conditions or tectonic activity and may include tornados, floods, earthquakes, blizzards, severe thunderstorms, and in some cases, may also include excessive periods of intensely cold weather, or intensely hot or humid weather.

The company will take all reasonable measures to be proactive in responding to emergencies and may send employees home where emergencies can be anticipated. The Executive Director or supervisor will notify employees of any such arrangements.

The primary purpose of the natural disaster or severe weather procedure is to inform employees and visitors of the procedure to follow in the event of a sudden or unexpected natural disaster or severe weather occurrence.

- Account for all employees and visitors, ensuring that everyone is inside the facility. Close all windows and close all curtains and blinds.
- Instruct all employees and visitors to move away from windows and doorways.
- If necessary, gather employees and visitors into the basement or, if no basement is available, into bathrooms or other enclosed area.
- Listen to all weather reports for updates. Do not leave the basement or enclosed area until the natural disaster or severe weather has passed.
- Stay calm. Encourage others to stay calm also.
- Isolate at the premises until the natural disaster or severe weather has passed.

Chemical, Biological, or Radiological

This response will be initiated for any release of hazardous materials, toxic chemicals, or other dangerous agents within the vicinity of Edmonton Down Syndrome Society, including natural gas leaks; the release of harmful bacteria, viruses, or other biological dangers; release of or exposure to radioactive materials. The purpose of the chemical, biological, or radiological procedure is to inform employees and visitors of the steps to take if a contaminant, virus, or other harmful agent poses an immediate threat. Standards and practices related to WHMIS should be followed whenever possible.

- Immediately notify anyone in the area that could be negatively affected by the hazardous release.
- Call 911 to report the situation and follow any instructions given by the dispatcher.
- Notify managers and the Executive Director as soon as safe to do so; and
- Commence evacuation procedures.

Structural Failure

The purpose of this procedure is to inform employees or visitors of precautions to be taken in the event of a structural failure. Structural failure may occur when the structural integrity of the building is compromised, leading to unsafe conditions. Failures or pending failures include (but are not limited to) collapsed walls, ceilings, or foundations, burst water mains, electrical power outages, and so on.

- In the event of a power outage, gather flashlights and other needed supplies. Check on all employees and visitors to ensure their safety. Ensure all backup or emergency lighting is fully operational. If emergency lighting fails, follow the evacuation procedure. If the power outage is prolonged, consult with managers to discuss dismissing employees for the remainder of the day.
- In the case of water, heat, or other utility disruptions, all attempts will be made to determine the cause of the disruption and the probable length of shutdown. Where required, the local utility provider will be contacted to assess and resolve the situation. If the shutdown is prolonged, the Executive Director may dismiss employees for the day.
- If the building itself fails, evacuate from the nearest available exit if safe to do so. If no safe exit is available, find shelter under a strong table or other structure.

Missing Employee or Visitor Procedure

The purpose of the missing employee or visitor procedure is to ensure that all necessary steps are taken if the whereabouts of an employee or visitor cannot be accounted for during an emergency.

- When necessary, shut down all equipment to allow the search to be undertaken safely.
- If safe to do so, employees will be directed by the response or assessment team member to systematically search the premises, both inside and outside, including rooms, bathrooms, offices, and other areas.
- If a search of the premises proves unsuccessful, the response or assessment team member will notify local law enforcement by calling 911. Give a description of the missing person, or a photograph (if available). The authorities will assume control of the search from this point.
- The family or responsible party of the missing person will also be notified. Explain what is being done to find the missing person and that the local law enforcement has been notified as well.
- All previously contacted persons and law enforcement will be notified if the missing person turns up due to search or of their own accord.

EDSS Drop-Off and Pick-Up and Transportation Policy

Purpose

EDSS is committed to providing a safe, supportive, and consistent environment for all participants. To ensure appropriate supervision and adequate staffing, participants and their families, caregivers, and transportation providers are expected to follow the designated program drop-off and pick-up times.

Drop-Off

Participants may arrive no earlier than 15 minutes before the scheduled start time of their program or service, unless prior arrangements have been approved by EDSS.

EDSS staff are not available to supervise participants outside of designated program or service hours. Families and caregivers are responsible for ensuring that participants are not left at the program before the permitted drop-off time.

Pick-Up

Participants must be picked up **within 15 minutes of the scheduled program or service end time**, unless alternative arrangements have been approved by EDSS.

Families, caregivers, and transportation providers are responsible for ensuring that participants are picked up promptly and safely.

If a participant is going to be picked up late due to an unexpected circumstance, the family or caregiver should contact EDSS as soon as possible.

DATS and Other Transportation Services

Participants using **DATS (Disabled Adult Transportation Service)** are expected to follow the same drop-off and pick-up time requirements as participants arriving by other forms of transportation.

Families and caregivers are responsible for scheduling DATS transportation to align with the participant's program or service hours and designated drop-off and pick-up times.

If a DATS vehicle is delayed, the family or caregiver should notify EDSS as soon as possible.

EDSS recognizes that transportation delays can occasionally occur. However, ongoing or significant delays may affect EDSS's ability to provide appropriate supervision.

Late Pick-Up

If a participant remains at the program more than 30 minutes after the scheduled program or service end time due to a late pick-up or transportation delay, a \$30 late pick-up fee may be charged to help offset the additional staffing costs required to supervise the participant.

The fee may be waived when the delay is due to an emergency or other circumstances beyond the family's or caregiver's reasonable control.

Repeated Late Pick-Ups

Consistent late pick-ups place additional demands on EDSS staffing and may affect the supervision and operation of other programs and services.

If a participant experiences **more than three late pick-ups during a program or service session**, EDSS will discuss the situation with the family or caregiver to identify appropriate solutions and establish reliable transportation arrangements.

If late pick-ups continue, EDSS may take additional steps, which may include:

- developing a transportation or pick-up plan with the family or caregiver;
- applying additional late pick-up fees;
- reviewing the participant's ability to continue attending the program or service under the current transportation arrangements; or
- temporarily suspending program or service participation until appropriate and reliable transportation arrangements are established.

Repeated transportation delays may also affect a participant's ability to use DATS transportation for EDSS programming or services.

Emergencies and Unforeseen Circumstances

EDSS understands that emergencies and unexpected circumstances may occasionally result in a late drop-off or pick-up. Families and caregivers are encouraged to communicate with EDSS as soon as possible when a delay is anticipated.

EDSS will consider individual circumstances and may make reasonable exceptions to this policy when appropriate.

Family and Caregiver Responsibility

Families and caregivers are responsible for:

- arranging transportation that aligns with scheduled program and service hours;
- ensuring participants arrive within the designated drop-off window;
- arranging for prompt pick-up at the end of the program or service;
- ensuring transportation providers are aware of EDSS program and service hours and expectations; and
- notifying EDSS as soon as possible if an unexpected delay occurs.

EDSS reserves the right to review transportation arrangements when ongoing delays affect participant safety, staffing, or the ability to provide programming or services to other participants.

Privacy and Confidentiality Procedure

EDSS collects personal information to support the delivery of programs and services and to ensure the safety and well-being of participants.

Information Collected

Depending on the program or service, EDSS may collect information such as:

- Participant and family contact information;
- Emergency contact information;
- Health, medical, medication, and allergy information;
- Communication, behavioural, and support needs;
- Program and service information;
- Funding information required to provide or bill for services; and
- Other information necessary to support participation.

Use of Information

Personal information is used only for purposes related to providing and administering EDSS programs and services. This may include:

- Planning and providing appropriate supports;
- Communicating with participants and families;
- Responding to health, safety, or emergency situations;
- Coordinating professional or other support services;
- Processing applicable funding or payments;
- Meeting legal, regulatory, or organizational requirements; and
- Improving or administering EDSS programs and services.

Sharing Information

EDSS will only share personal information with individuals or organizations when:

- The participant, parent, guardian, or authorized representative has provided appropriate consent or authorization;
- The information is necessary to provide or coordinate an EDSS program or service;
- The information is required for applicable funding or administrative purposes;

- Disclosure is required by law; or
- Disclosure is necessary to address an immediate safety or emergency concern.

Where information is being shared with another professional, service provider, school, or organization to support a participant, EDSS may require the appropriate **consent or authorization** before information is shared.

Storage and Protection of Information

EDSS takes reasonable steps to protect personal information from unauthorized access, use, disclosure, loss, or misuse.

Information is maintained using EDSS-approved systems and processes and is only accessible to individuals who require the information for their responsibilities.

Privacy Concerns or Questions

Participants and families who have questions or concerns about the collection, use, storage, or sharing of their personal information should contact EDSS.

Any suspected privacy breach or unauthorized disclosure of personal information should be reported to EDSS as soon as possible so that the concern can be reviewed and addressed appropriately.

Communication with Families – Procedure

EDSS uses clear, respectful, and appropriate communication to keep participants and families informed about programs, services, schedules, and matters that may affect participation.

1. Keeping Contact Information Current

Families are responsible for providing EDSS with current contact information, including:

- Email address
- Telephone number
- Emergency contact information
- Preferred method of communication, where applicable

Families should notify EDSS as soon as possible when their contact information or emergency contact information changes.

2. Receiving EDSS Communications

Families should regularly check the email address and other communication methods provided to EDSS. Important information may include:

- Program schedules and changes
- Registration information
- Appointment confirmations
- Program reminders
- Cancellations or changes to programming
- Requests for additional information or documentation
- Funding or payment information
- Health, safety, or emergency information

Families are responsible for reviewing information provided by EDSS and responding when a response is required.

3. Responding to EDSS

When EDSS requests information or a response from a family, families are expected to respond within the timeframe provided whenever possible.

If a family is unable to respond within the requested timeframe, they should contact EDSS to discuss the situation.

Failure to respond to important communication may affect registration, scheduling, participation, or the ability of EDSS to provide appropriate supports.

4. Communicating Changes

Families should notify EDSS as soon as possible of changes that may affect a participant's program or service, including:

- Absences or changes to attendance;
- Changes in health or support needs;
- Changes in medication or allergies;
- Changes to authorized pick-up arrangements;
- Changes to contact or emergency information;
- Changes to funding that may affect services; or
- Other circumstances that may affect safe participation.

5. Communication with EDSS Staff

Families are encouraged to communicate questions, concerns, or requests for support to the appropriate EDSS staff member.

EDSS staff will make reasonable efforts to respond in a timely manner and will communicate respectfully and professionally.

If a family is unsure who to contact, they may contact the EDSS office or General Inquiries and will be directed to the appropriate staff member.

6. Communication Outside Regular Business Hours

EDSS regular business hours are the primary time for routine communication.

Messages received outside regular business hours may not receive an immediate response.

In an emergency, families should use the appropriate emergency services or emergency contact process.

7. Communication Boundaries

EDSS maintains appropriate professional boundaries in communication with participants and families.

Staff may use EDSS-approved communication methods and platforms to communicate about programs and services. Families should use the communication method identified by EDSS or the applicable program or service.

Program-specific communication procedures, response times, and contact methods may vary depending on the program or service.

8. Communication Concerns

If a family has concerns about communication, including difficulty receiving information, accessibility of communication, or an unresolved communication concern, they are encouraged to contact the appropriate EDSS staff member.

Concerns may also be raised through the **EDSS Participant Complaints and Concerns Process**.

9. Confidentiality

Families should be mindful that communication with EDSS may contain personal or confidential information. Families are responsible for protecting their own personal information and respecting the privacy and confidentiality of other participants and families.

EDSS Program Fees and Refund Policy

Program and Service Fees

Program fees must be paid at the time of registration or by the date specified on the invoice.

For services or programs funded through **Family Support for Children with Disabilities (FSCD)**, families must provide their current FSCD agreement to the Director of Community and Family Services before any services or programs begin. This allows EDSS to confirm the approved funding and ensure that services are billed correctly to FSCD.

There are **no upfront fees to families for approved FSCD-funded services or programs**.

Once the program or service has been completed, families will receive a DocuSign agreement confirming the dates and times of service. Families are responsible for reviewing and signing the DocuSign agreement promptly and returning it to EDSS.

Once EDSS receives the completed DocuSign agreement, it is submitted to FSCD for payment. Once payment is received from FSCD, EDSS will provide the family with a paid invoice for their records.

Families are responsible for ensuring that required funding documentation and DocuSign agreements are provided or completed promptly so that services can be provided and billed without interruption.

EDSS reserves the right to delay or suspend services where required funding documentation or agreements are outstanding or where funding is not available or approved.

Refunds

Refunds are not automatic and are considered on a case-by-case basis.

Refund requests should be made as soon as possible and should be submitted to EDSS with the reason for the request. Refunds may be considered for circumstances such as:

- cancellation of a program or service by EDSS;
- duplicate or incorrect payments;
- overpayments; or
- other circumstances approved by EDSS management.

Refund eligibility may depend on the type of program or service, the timing of the cancellation, whether the service has already been provided, and any costs that EDSS has already incurred.

Refund requests require approval from the **Executive Director**.

Where a refund is approved, EDSS will process the refund using the original payment method whenever reasonably possible.

Some registration fees, deposits, program fees, or service fees may be non-refundable. Any non-refundable fees or cancellation terms will be communicated to families at the time of registration or before the service is provided.

EDSS Service Cancellation and No-Show Policy

1. Purpose

The Edmonton Down Syndrome Society (EDSS) recognizes that participants and families may occasionally need to cancel or reschedule a scheduled service or appointment.

This policy establishes clear and consistent cancellation and no-show expectations for EDSS services and helps ensure that staff and service providers are appropriately compensated for time that has been reserved for a participant.

2. Scope

This policy applies to scheduled EDSS services and appointments, including professional and therapeutic services where applicable.

Individual programs or services may have additional cancellation requirements, which will be communicated at the time of registration or booking.

3. Cancellation Notice

Participants, families, or guardians are required to provide at least 24 hours' notice when cancelling or rescheduling a scheduled service.

For the purpose of this policy, the 24-hour notice period is based on EDSS business days, Monday through Friday. Weekends do not count toward the required 24-hour notice period.

For example, a service scheduled for Monday requires cancellation by the appropriate time on the preceding Friday to avoid a cancellation fee.

Whenever possible, cancellations should be communicated as soon as the participant or family knows that they will be unable to attend.

4. How to Cancel

To cancel or reschedule a service, participants, families, or guardians must:

Email: contact@EDSS.ca

Phone: 780-944-4224

Cancellations may be left by voicemail after regular business hours.

The date and time that the cancellation is received by EDSS will be used to determine whether the required notice was provided.

5. Cancellations With 24 Hours' Notice

Services cancelled or rescheduled with the required 24 business hours' notice, Monday through Friday, will not incur a cancellation fee.

6. Late Cancellations

When a service is cancelled or rescheduled with less than 24 business hours' notice, the participant or family will be charged 50% of the scheduled service cost.

This fee recognizes that the service time has been reserved and EDSS or the service provider may not have sufficient notice to offer the appointment to another participant.

7. No-Shows

A no-show occurs when a participant does not attend a scheduled service or appointment and has not provided cancellation notice.

A no-show will result in a charge of 100% of the scheduled service cost.

8. Illness and Emergency Circumstances

EDSS recognizes that unexpected illness, emergencies, and circumstances beyond a family's control may occur.

Participants, families, or guardians are expected to contact EDSS as soon as possible when they become aware that they cannot attend.

EDSS management may use discretion in exceptional circumstances when applying cancellation or no-show fees.

9. FSCD-Funded Services

Where a service is being funded through Family Support for Children with Disabilities (FSCD), applicable cancellation and no-show fees remain the responsibility of the participant or family unless the funding arrangement specifically provides otherwise.

Cancellation and no-show fees are not billable to FSCD or other third-party funders.

Families are responsible for ensuring that any applicable cancellation or no-show fee is paid to EDSS in accordance with the invoice and payment terms.

10. Communication of Cancellation Fees

Cancellation and no-show fees will be communicated to families at the time of registration or booking whenever possible.

Families are responsible for understanding and following the cancellation requirements associated with the service they have booked.

11. Repeated Cancellations or No-Shows

If a participant has repeated late cancellations or no-shows, EDSS may discuss the issue with the participant and/or family to determine whether scheduling, communication, or other adjustments may help.

Where repeated cancellations or no-shows significantly affect the delivery of a program or service, EDSS management may review the participant's ongoing access to that particular service.

Any decision to restrict or discontinue a service will be made by EDSS management and communicated to the participant and/or family.

PROCEDURE

Service Cancellation – Quick Reference

24 BUSINESS HOURS = NO FEE

LESS THAN 24 BUSINESS HOURS = 50% FEE

NO-SHOW = 100% FEE

1. Need to cancel or reschedule?
Contact EDSS as soon as possible.

Email: contact@EDSS.ca

Phone: 780-944-4224

After regular business hours, cancellations may be left by voicemail.

2. More than 24 business hours' notice?
No cancellation fee will be charged.

3. Less than 24 business hours' notice?
A fee of 50% of the scheduled service cost will be charged.

4. No-show?
The full cost (100%) of the scheduled service will be charged.

5. Remember: The 24-hour notice period applies to Monday through Friday. Weekends do not count toward the required 24-hour notice period.

6. Emergency or exceptional circumstance?
Contact EDSS as soon as possible. Management may consider exceptional circumstances when determining whether a cancellation fee applies.

Example: A participant has a scheduled service costing \$90:

- Cancelled with at least 24 business hours' notice → \$0 cancellation fee
- Cancelled with less than 24 business hours' notice → \$45 cancellation fee
- No-show → \$90 service fee

This policy applies unless a specific program or service agreement states otherwise.

Service Termination/Discontinuation Procedure

Applies To: All EDSS programs and services

1. Purpose

To provide a consistent and respectful process for ending or discontinuing an EDSS program or service.

2. Reasons for Discontinuation

A program or service may be discontinued when:

- The participant or family chooses to discontinue.
- Service goals have been met.
- The service is no longer appropriate for the participant's needs.
- The participant's needs or circumstances have changed.
- Funding has ended, changed, or is no longer available.
- Program availability, staffing, capacity, or organizational circumstances change.
- Safety or support considerations require a change.
- The participant transitions to another service or provider.
- The participant no longer meets the requirements of the specific program or service.

3. Procedure

When a service is being discontinued, EDSS will, where appropriate:

1. Review the reason for discontinuation and consider whether the service can reasonably continue with adjustments or additional supports.
2. Discuss the change with the participant and/or parent, guardian, or authorized decision-maker.
3. Provide reasonable notice whenever circumstances permit.
4. Discuss other EDSS programs, community resources, or transition options where appropriate.
5. Address any outstanding appointments, fees, invoices, or funding requirements.
6. Document the decision, communication, effective date, and any follow-up required in the participant's record.

Fees and refunds: Discontinuation of a program or service does not automatically result in a refund. Any refund request will be handled in accordance with the EDSS **Program Fees, Payment and Refund Policy**.

Where an immediate safety concern requires action, EDSS may temporarily pause or discontinue a service without advance notice and will communicate with the family as soon as reasonably possible.

4. Family-Initiated Discontinuation

Participants or families may request to discontinue a service. EDSS will respect the decision and, where appropriate, assist with transition planning or information about other available supports.

Any applicable fees, payments, cancellations, or refund requests will continue to be subject to the EDSS **Program Fees, Payment and Refund Policy**.

5. Documentation

Significant service termination or discontinuation decisions will be documented in accordance with EDSS records management and privacy requirements.

EDSS Parent & Participant Handbook

Last Review Date: August 27, 2026

Next Review Date: August 27, 2027

Approved By: Janet Tryhuba