INESSS
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REFERENCE GUIDE

for improving *autonomy* in *intellectually disabled* young people aged 6 to 21

Summary of the clinical practice guideline entitled: *L'autonomie des jeunes de 6 à 21 ans qui présentent une déficience intellectuelle*

Québec

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Introduction

This reference guide was produced following the publication in December 2019 of the practice guideline entitled Guide de pratique : l'autonomie des jeunes de 6 à 21 ans qui présentent une déficience intellectuelle. This knowledge transfer tool was designed to support practice environments and facilitate implementation of the recommendations included in the practice guide.

Clinical practice guideline

Several key documents have been published in Quebec in recent years to guide the provision of services to people with intellectual disability (ID); these include:

- *Equals in every respect: because rights are meant to be exercised*, published in 2009 by the Office des personnes handicapées du Québec (OPHQ); this is a government policy inviting all public and private stakeholders in society to support social participation of people with disabilities.
- *Cadre de référence pour l'organisation des services en déficience physique, déficience intellectuelle et trouble du spectre de l'autisme* [reference framework for organizing services for persons with a physical or intellectual disability or an autism spectrum disorder], published by the ministère de la Santé et des Services sociaux (MSSS) in 2017; this document reaffirms the need to consolidate the integration of care and services.

The above reference framework, together with the other ongoing work at MSSS on the range of services for disabled persons, promotes the notion of integrated care and services and defines a service organization model that is as close as possible to the persons concerned and to their living environments. The needs of people with disabilities are the cornerstone of the orientations that are driving the transformation within the Health and Social Services System.

Given the scarcity of reference works to guide interventions with intellectually disabled children and adolescents[1], the Institut national d'excellence en santé et en services sociaux (INESSS) was asked to produce a clinical practice guideline for developing autonomy in young people aged 6 to 21 with ID and supporting their parents in this regard.

Produced in collaboration with the various relevant stakeholders, this clinical practice guideline (in French) can be viewed in the Publications section of the inesss.qc.ca website.

1. The masculine gender is used throughout the report solely to lighten the text.

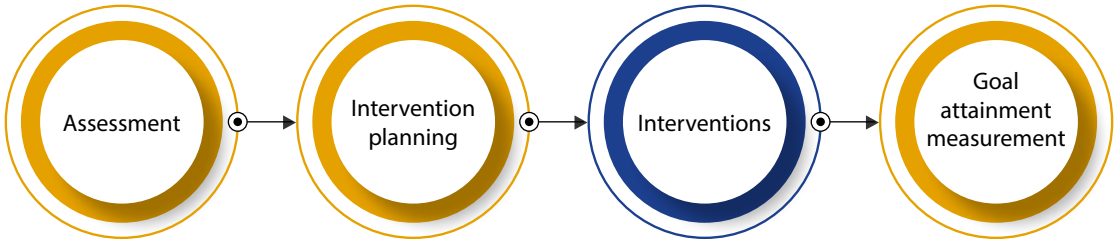
Objective and scope of the clinical practice guideline

The objective of this guideline is to promote informed and shared decision-making between intellectually disabled young people aged 6 to 21, their parents and practitioners regarding the interventions to be implemented to improve these youths' autonomy and support their parents in this regard.

The guideline covers the following:

- young people aged 6 to 21 with ID, and their families;
- autonomy in accomplishing life habits, as defined in the *Human Development Model – Disability Creation Process* (HDM-DCP);
- interventions for which the efficacy results have been reported in scientific literature;
- the third stage of the clinical process, i.e., the implementation of interventions, which follows the evaluation and planning phases. The choice of interventions must therefore be based on an assessment conducted in accordance with the fields of practice and the activities reserved for professionals. This choice must also be consistent with the needs and priorities expressed by the young person and his parents.

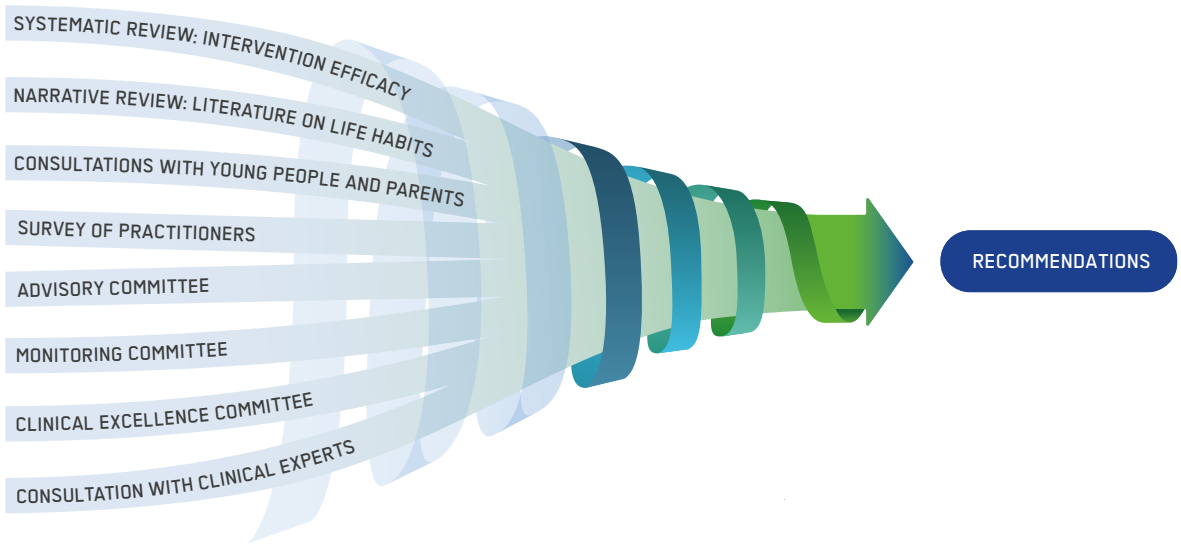
FIGURE 1
Clinical Process



Methodology

The recommendations in this guideline are based on a combination of scientific, experiential and contextual data collected from the following eight sources.

FIGURE 2
Sources of data



The recommendations were validated and enhanced through an iterative and deliberative process in collaboration with the members of the Advisory Committee.

An assessment was carried out to determine the evidence level of the intervention efficacy results. This assessment was based on an appraisal of all scientific data using four criteria: the methodological properties of the studies, the consistency and clinical impact of the results, and the possibility of generalizing these results to the relevant population. A high, moderate or low evidence level was then attributed to the results.

Results

Seven general intervention principles that need to be taken into consideration and 30 recommendations were identified. These recommendations are intended to improve the autonomy of young people in order to promote their self-determination and social participation, and to encourage the involvement of those around them. In addition, some useful resources have been identified.

Reference guide

Target users

This reference guide is intended in particular for specialized educators, psychoeducators, clinical supervisors and managers who work with intellectually disabled young people and their families. Professionals in the health and social services network as well as the practitioners in the education and community sectors may also find the suggested interventions and resources to be useful.

Contents

This reference guide is available in print or interactive digital format; both versions are offered as a practical and user-friendly tool and feature the following:

- values and general principles of intervention;
- a fact sheet for each of the 12 life habits;

  Each fact sheet includes:

				
a section entitled "Reasons for fostering autonomy in this life habit"	elements to be considered in intervention planning	the intervention efficacy results and evidence level	recommenda-tions	a list of useful resources

  NOTE: The life habits are presented in the order suggested by the HDM-DCP; this classification is not indicative of a clinical priority order.

- three recommendations that can be applied in whole or in part to all life habits:
  - behaviour intervention techniques such as those used in Applied Behaviour Analysis (ABA)
  - the use of a technological medium
  - interventions with parents
- definitions and key concepts;

- description of the Human Development Model – Disability Creation Process (HDM-DCP) and of the activities included in each of the 12 life habits;
- description of the activities included in each of the 12 life habits.

Legend for pictograms used in recommendations

The recommendations apply to the youth, his parents, the youth and his parents, or the youth and his family:

			
the youth	the youth and his parents	the parents	the youth and his family

Two pictograms refer to the objectives of intervention and means of intervention::

	
objectives of intervention	means of intervention

Three recommendations that apply wholly or partially to all the life habits:

		
behaviour intervention techniques	technological medium	intervention with the parents


These three icons are clickable

Values and general *principles of intervention*

Values

Both this reference guide and the practice guideline are based on the *United Nations Convention on the Rights of the Child* [United Nations, 1989] and on the universal values set out by the World Health Organization (WHO) in 2004 in the *Montreal Declaration on Intellectual Disabilities* [World Health Organization, 2004]. These values are as follows:

- dignity;
- self-determination;
- equality;
- social justice.

The practice guideline is also based on the principle that every person:

- can learn and develop throughout his life;
- is a valid partner in an equal relationship and that he can influence and question clinicians' positions;
- must be considered as a full citizen with the same rights and responsibilities as any other individual and be recognized as being free to self-determine in various areas of his life;
- must be respected with regard to his cultural, religious and sexual identity;
- must be supported so that he can actively engage in all areas of his life, based on both what he can and wants to do.

General principles of intervention

Seven general intervention principles that should be taken into consideration by practitioners and other professionals who work with intellectually disabled young people and their families were identified.

- Focus the intervention on the young person in order to promote his self-determination and ability to act.
- Maintain a partnership between the young person, parents and clinicians.
- Base interventions on an assessment carried out in accordance with the fields of practice and the reserved activities.
- Work towards a continuum of interprofessional collaborative practices.

- Use different child and adolescent developmental theories to guide the choice and implementation of interventions.
- Propose realistic learning challenges and take into consideration how they are connected to ID.
- Foster intersectoral collaboration..

In addition, the guideline reiterates the importance of ongoing training and clinical support for clinicians to ensure the development of their expertise and intervention skills with young people and their families..

RECOMMENDATIONS FOR IMPROVING *autonomy* OF YOUNG PEOPLE AGED 6 TO 21 IN *accomplishing* THE 12 LIFE HABITS OF THE HDM-DCP

COMMUNICATION

Involves the youth's oral and body communication, written communication and telecommunications.

LIFE-HABIT 1

REASONS FOR FOSTERING COMMUNICATION AUTONOMY

- Communication is a generic skill that promotes the development of all the life habits; it is also inseparable from the development and maintenance of interpersonal relationships.
- An ability to communicate enables a young person to have an impact on his environment, thereby promoting his social integration.
- A number of intellectually disabled people experience communication difficulties. It is estimated that between 4% and 12% of young people with mild ID and more than 90% of students with severe ID require a technical communication aid.
- According to the parents and practitioners surveyed, interventions aimed at improving communication represent the main intervention priority, especially among children aged 6 to 12.
- Communication difficulties increase the risk of developing behaviour and mental health disorders.

This information confirms the relevance of developing communication skills in intellectually disabled young people in order to promote their autonomy and well-being.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- It is important to conduct a multidisciplinary assessment when choosing interventions to improve communication, including interventions that require a technical aid.
- Communication autonomy is frequently promoted by the use of various modes of communication (e.g., oral, gestural, written), which may or may not benefit from the use of a technical aid.
- It is also important to coordinate interventions by taking into account the youth's various living environments.

Young people requiring a technical communication aid

- Factors that facilitate the use of technical aids are as follows: the commitment of adults from different backgrounds, access to the technical aids at all times, multidisciplinary work, technical support and training.
- The benefits of technical communication aids with assistive technology go beyond communication. They also help to improve self-esteem, reduce the young person's feelings of isolation and the frustrations associated with such feelings.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- An intervention that includes techniques such as those employed in Applied Behaviour Analysis and using a technological aid is effective in improving a youth's autonomy in accomplishing the life habit - communication; this finding applies to young people aged 6 to 21 with ID (evidence level: high).
- The Picture Exchange Communication System (PECS) is effective in increasing communication skills in youths aged 6 to 21 with ID and ASD (evidence level: moderate).
- An intervention that includes a voice-output device is effective in increasing communication skills in youths aged 6 to 21 with ID and ASD (evidence level: moderate).

- An intervention that includes another low-technology communication aid such as images or photos but does not follow the PECS system is effective in increasing communication skills in youths aged 6 to 21 with ID and ASD (evidence level: low).
- An intervention using the TEACCH Method is not very effective in increasing communication skills for students over the age of 16 with severe ID (evidence level: low).
- Providing training and mentoring to young people with neurotypical development and pairing them with intellectually disabled youths to promote communication and social interactions are not effective in increasing expressive and receptive communication for youths aged 10 to 21 with ID, with or without ASD (evidence level: moderate).

RECOMMENDATIONS FOR FOSTERING COMMUNICATION AUTONOMY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. Such interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 1.1 The youth, as well as his family, should be empowered from childhood to ensure that he develops such skills as the following:

- producing an effective message (e.g., answering "yes" or "no," making a choice, making a request, communicating his needs and desires, choosing and transmitting information that is appropriate for the purpose of the communication and for the receiving party);
- understanding a message (e.g., following instructions, a routine, a schedule) or a question;
- connecting with people in an appropriate manner (e.g., showing an interest, reacting to questions and comments from other people);
- participating in a two-person or group exchange (e.g., initiating, maintaining and completing an exchange and making appropriate adjustments for the context);
- dealing with unsuccessful communication situations (e.g., when the message is not understood);
- using various communication media (e.g., telephones, text messaging, email, social networks).

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

The combined use of several modes of communication (e.g., oral, gestural, written) should be encouraged for expressive and receptive communication, even if the young person partially uses oral language (e.g., learned signs, natural gestures, written language, pictorial illustrations, low-technology and high-technology technical aids).

The youth should be given maximum communication opportunities in all the living environments that he frequents (e.g., through games and play, by changing environmental conditions).

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the youth's communication skills.

YOUTH REQUIRING A COMMUNICATION AID

R 1.2 The youth and his family should be supported by a multidisciplinary team in choosing the types of communication aids:

- communication without a technical aid (e.g., oral language, natural gestures, learned signs);
- communication with a technical aid but without technology (e.g., symbolic objects, communication boards with images or pictograms or the use of written language, the Picture Exchange Communication System (PECS));
- communication with a low-technology technical aid (e.g., devices with recorded voices such as BIGMack or GoTalk) or with a high-technology technical aid (e.g., touchpads or smart telephones equipped with specialized oral communication software).

The methods (e.g., oral, gestural, written) and technical communication aids chosen should be available at all times and their use should be generalized to enable the youth to engage in effective expressive and receptive communication in his various environments.

The youth, as well as his family, should be empowered from childhood to ensure that he develops such technical communication aid skills as the following:

- knowing and understanding the content of the communication aid (e.g., images and their meaning);
- appropriately manipulating communication aids (e.g., moving the cursor, browsing various pages or communication boards);
- dealing with unexpected situations (e.g., breakages, forgetting devices);
- helping to adapt the communication aid content to suit changing developmental needs.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the ability to use communication aids.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Programme ministériel des aides techniques à la communication* (PMATCOM), [departmental program for technical communication aids], which is available to young people who are not attending school
- Centre de partage d'expertise en intervention technoclinique (CPEITC), a sharing centre for technoclinical intervention expertise
- *Guide to the education of your child with a disability: handbook for parents,* published by the OPHQ.

LIFE-HABIT 2

MOBILITY

Involves the youth's mobility within his immediate environment, and mobility using various means of transportation.

REASONS FOR FOSTERING AUTONOMY IN MOBILITY

- Autonomy in mobility notably enables the youth to:
  - participate in activities taking place in the community, such as attending school, going to work or taking part in recreational activities with friends;
  - visit family members or friends;
  - do some personal shopping.
- Autonomy in mobility facilitates social inclusion and provides opportunities to perform socially valued roles.
- For young people, getting around in their environments on their own is a priority. Parents are not always able to meet their child's transportation requests, especially for activities outside of school, and this can lead to tension at home and result in the young person's becoming dissatisfied.
- The youth's autonomy in his mobility can lighten the parents' burden.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- It is recommended that mobility skills be taught from the time of childhood.
- These skills need to include the learning of certain safe behaviours and basic social competences, such as those indicated below:
  - having a sense of place in the environment and knowing one's address;
  - keeping the seatbelt fastened while in a vehicle and not opening the door when it is in motion;
  - interacting in a suitable manner with other people and reacting appropriately when travelling to the inappropriate behaviour of other people.
- Parents may be concerned about their child's safety when travelling. Parents and clinicians should therefore seek a balance between the young person's need for autonomy and his safety.
- Educating and training bus and taxi drivers vis-à-vis the use of communication and interaction techniques with intellectually disabled people can facilitate youth mobility, safety and social inclusion.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- interventions that include a variety of intervention strategies (real-world practice, simulation, virtual reality or augmented reality, apps on portable technology devices, multimedia [videos]) are effective in improving skills related to walking, pedestrian safety, landmark recognition and transit use; this finding applies to young people aged 6 to 21 with ID (evidence level: moderate).
- an intervention that includes techniques such as those employed in Applied Behaviour Analysis is effective in promoting a youth's autonomy in accomplishing the life habit - mobility; this finding applies to young people aged 6 to 21 with ID (evidence level: high).

RECOMMENDATION FOR FOSTERING AUTONOMY IN MOBILITY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. Such interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 2.1 The youth, as well as his family, should be empowered from childhood to ensure that he develops such skills as the following (e.g., while walking, in a car, a school vehicle and public transit):

- having a sense of place and finding his bearings in both the interior and exterior environments;
- having a sense of time;
- recognizing and complying with road signage symbols (e.g., stop signs, traffic lights);
- complying with safety rules;
- adopting safe and socially acceptable behaviours when travelling (e.g., remaining quiet, respecting the privacy of other passengers);
- knowing how to ask for help safely and dealing with unexpected situations (e.g., knowing whom to contact in an emergency).

From adolescence on, the targeted skills also include:

- having familiarity with and knowing how to use public transit;
- planning his movements and adhering to this planning.

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis other interventions could be considered to develop the young person's mobility skills, e.g., using virtual reality or augmented reality, apps on portable technology devices or multimedia (videos).

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Guide to programs for people with disabilities, their families and caregivers*, published by the OPHQ. It includes a description of the measures available to meet various transportation needs.
- The guide entitled *L'apprentissage du transport en commun à l'intention des intervenants qui travaillent auprès des personnes ayant une déficience intellectuelle* [training in the use of public transit for professionals working with people with intellectual disability].
- *The Kit: Keeping It Together™ for Youth* (best known as *The Youth Kit*) allows young people to take control of their personal information and develop a deeper understanding of themselves and their capabilities.

LIFE-HABIT 3

NUTRITION

Involves habits related to the youth's diet, food preparation and meals.

REASONS FOR FOSTERING NUTRITION AUTONOMY

- Autonomy in nutrition has a positive impact on several other life habits of young people, including:
  - housing, since such autonomy allows the youth to make meals when his parents are not at home;
  - employment, when the young person is expected to autonomously take a meal break.
- A healthy diet is particularly important for intellectually disabled young people since they are 1.54 to 1.80 times more likely to be overweight and obese than other youths of the same age.
- Nutrition is an important concern for families worried about food selectivity, food allergies or diabetes in young people.
- Access to a healthy diet and meal preparation are major challenges for young adults with ID.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Providing training to young people and parents promotes the adoption of a healthy diet tailored to the characteristics and preferences of the youths and encourages them to take part in preparing food at home.
- Organizations that support people with disabilities and local communities can promote nutrition autonomy through a variety of activities, such as cooking courses, support and guidance from grocery partners or the preparation of potluck meals.
- Parents would like to have an interdisciplinary assessment of their child conducted on a regular basis so that emerging nutrition-related problems can be identified and considered in the intervention plan.
- The use of a technological medium, such as a tablet or smartphone, to facilitate the performance of everyday tasks is valued by young people and clinicians. The choice of medium will depend in particular on the tasks and the environment.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention that includes techniques such as those employed in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit - nutrition; this finding applies to young people aged 6 to 21 with ID (evidence level: high).
- a parent-empowerment intervention based on training in techniques such as those used in Applied Behaviour Analysis, e.g., modelling, task-breakdown support and real-world feedback, is effective in improving the child's autonomy in meal-preparation activities (e.g., making a recipe, setting the table); this finding applies to young people aged 6 to 9 with moderate ID (evidence level: low).

RECOMMENDATION FOR FOSTERING NUTRITION AUTONOMY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 3.1 The youth, as well as his family, should be informed of the principles of healthy eating and should be empowered from childhood to ensure that he develops such skills as the following:

- feeding himself self as autonomously as possible, with help if necessary;
- controlling food and fluid intake;
- adopting the expected table behaviours (e.g., using utensils, staying seated, eating with his mouth closed, refraining from spitting);
- participating in choosing and preparing food for snacks and meals;
- participating in meal-related tasks (e.g., setting the table and clearing it after meals);
- participating in meal preparation;
- using dining facilities and vending machines as needed.

From adolescence on, the targeted skills also include:

- applying the principles of healthy eating;
- planning meals;
- making and using grocery lists;
- shopping for food;
- preparing meals;
- safely using household appliances;
- safely storing food and leftovers.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the youth's nutrition skills.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Canada's Food Guide*;
- *Eat Well Plate*, a tool for managing portion sizes and integrating various food groups into the diet;
- *Je cuisine avec des images* by Anne Perrault and Anne Mitchell, a cookbook published by Carte blanche.

LIFE-HABIT 4

PHYSICAL FITNESS AND PSYCHOLOGICAL WELL-BEING

Involves habits that promote healthy sleep habits and the performance of physical activities and activities conducive to relaxation, concentration or other activities that contribute to the young person's psychological well-being.

REASONS FOR FOSTERING AUTONOMY IN PHYSICAL FITNESS AND PSYCHOLOGICAL WELL-BEING

- Adopting and maintaining an active lifestyle, preferably without tobacco, alcohol or drugs, promotes maintenance of good physical and mental health and facilitates autonomy in all the other life habits.
- It has been reported that more than half of children with Down syndrome have a level of physical activity below the 60 min./day threshold established by the World Health Organization for maintaining good health, compared to 25% of young people with neurotypical development.
- Promoting physical fitness and psychological well-being can help reduce behaviour problems in intellectually disabled young people.
- Sleep problems, which may have physiological or behavioural causes, are more common in young people with ID. These problems negatively impact their moods and cognitive functioning as well as their parents' quality of life.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- The engagement of young people with ID is facilitated by the following factors:
  - support and adoption by the parents of an active lifestyle;
  - social interaction opportunities;
  - structured programs that can be adapted to the young people's needs;
  - non-competitive activities that encourage play for its own enjoyment;
  - having rewarding experiences;
  - the quality of the relationship with the trainer;
  - access to transportation.
- Participation in activities organized by the Special Olympics movement produces positive effects on the physical development, motor skills, self-esteem and aggressive behaviour of a number of young people.
- Factors that positively influence parental participation in sleep interventions in a group setting are as follows: the support of a trusted practitioner, solutions to practical concerns (childcare, scheduling, locations, etc.), clear and comprehensive information, and the perception that the parents will benefit from such participation.
- However, the group setting is not suitable for all parents.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention including techniques such as those employed in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing this life habit; this finding applies to the majority of young people with ID aged 6 to 21 (evidence level: high).
- a parent-empowerment intervention based on didactic instruction, group problem-solving and the learning of simple routine-based tools to reduce difficulties associated with the child's sleep is effective in reducing night walking in young people aged 5 to 15 with ID. However, it is not effective in diminishing sleep problems during the night, bedtime anxiety and bedtime resistance (evidence level: low).

RECOMMENDATIONS FOR FOSTERING AUTONOMY IN PHYSICAL FITNESS AND PSYCHOLOGICAL WELL-BEING

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 4.1 The youth should be empowered from childhood to adopt a healthy lifestyle to ensure that he is able to develop such skills as the following:

- recognizing and expressing his needs, preferences and ideas;
- recognizing and expressing his emotions;
- developing strategies for self-control and calming;
- adopting healthy sleep habits;
- regularly practicing physical activities;
- practising activities for relaxing, unwinding and meditating;
- knowing the risks associated with drug and alcohol use and identifying his vulnerabilities and at-risk behaviours, as applicable.

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the youth's skills in the areas of physical fitness and psychological well-being.

R 4.2 Parents should be empowered to promote their child's autonomy with respect to his habits related to sleep, to physical activities and to activities promoting psychological well-being (e.g., relaxation activities and strategies for emotional self-regulation and calming).

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis, the following interventions in particular could be considered as a means of developing the parents' skills in promoting their child's autonomy vis-à-vis his physical fitness and psychological well-being:

- parenting skills support groups (e.g., to promote good sleep habits);
- strategies that can be implemented at home (e.g., observing a young person's sleep behaviours, establishing a sleep routine).

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Guide facilitant les interventions lors de la pratique d'activités physiques et sportives chez les jeunes ayant une DI* [guide to facilitate physical/sports activity interventions with intellectually disabled young people];
- nutrition and physical fitness programs of the Quebec Special Olympics movement;
- Evelyne Martello's *Enfin je dors et mes parents aussi*, in the CHU Sainte-Justine Series for Parents;
- Jacobson relaxation method;
- sleep clinics are accessible in a number of CISSS and CIUSSS throughout Quebec.

PERSONAL CARE AND HEALTH CARE

Involves habits related to the young person's body care, clothing, excretal hygiene and health care.

LIFE-HABIT 5

REASONS FOR FOSTERING AUTONOMY IN PERSONAL CARE AND HEALTH CARE

- Personal care is a priority for young people, parents and clinicians.
- Autonomy in the performance of body care activities is essential in promoting a person's social inclusion and even his social acceptance.
- Young people are aware of the positive role that good personal hygiene plays in fostering the development of social relationships.
- Young adults continue to experience some difficulties, e.g., choosing the right clothes for the temperature, brushing their teeth daily or taking the right dosage of their medications.
- Access to health care for intellectually disabled people can also be a challenge, particularly because of the difficulties they may have with understanding, communicating and organizing their time.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Clients' rights to confidentiality and consent and respect for their privacy are important issues that deserve to be better known and understood by all stakeholders concerned.
- Some intellectually disabled people are anxious when they have to undergo a medical examination or receive care. This anxiety can lead to "uncooperative" behaviours and compromise their access to treatment.
- The use of visual tools to represent task sequences is a type of intervention that is commonly associated with personal care.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- **PERSONAL CARE :** An intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit – personal care; this finding applies to the majority of young people aged 6 to 21 with ID (evidence level: high);
- **HEALTH CARE: :** A program that includes an educational intervention and development of self-advocacy and communication in intellectually disabled young people, together with education and communication tools for parents and health professionals and, ultimately, a medical record, is effective, though of moderate clinical significance, in improving self-advocacy at medical appointments and is not effective in improving self-advocacy related to preparing for medical appointments; this finding applies to young people aged 13 to 17 (evidence level: moderate).

RECOMMENDATIONS FOR FOSTERING AUTONOMY IN PERSONAL CARE AND HEALTH CARE

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

PERSONAL CARE

R 5.1 The youth should be empowered from childhood to ensure that he is able to develop such skills as the following:

- taking care of his body hygiene (e.g., taking a shower or bath, washing hands, face and hair, brushing teeth, keeping clean and cutting nails);
- being autonomous with respect to the body's elimination functions, making appropriate use of hygiene products;
- dressing appropriately for the temperature and circumstances, and undressing;
- using the sanitary facilities at home and elsewhere.

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis, other interventions could be considered to develop the youth's personal care skills, such as teaching him how to give a name to personal care needs.

R 5.2 Parents should be informed of the importance of respecting their child's privacy as related to personal care and should be empowered to promote his autonomy.

In particular, behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to empower parents.

SOINS DE SANTÉ

R 5.3 The youth and his parents should be informed of the rights to confidentiality and consent for young people aged 14 and older with regard to their health care, and should be supported in ensuring that these rights are respected and enforced.

R 5.4 The youth, as well as his family, should be supported in identifying and being referred to appropriate health services, and should be empowered from childhood to use these services to ensure that he is able to develop such skills as the following:

- recognizing and communicating his health needs;
- getting ready for the various stages of consultation and care and expressing any concerns;
- planning and attending appointments (e.g., scheduling an appointment, showing regard for his hygiene, waiting in the waiting room, taking part in the physical examination and any procedures that are carried out, answering questions);
- complying with prescribed dosages;
- identifying and communicating the effects of taking medication;
- learning and applying the concepts of first aid (e.g., cuts, allergic reactions).

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

The use of a health diary detailing the youth's communication and care preferences could be considered for purposes of developing his skills with regard to health services.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- the *Éducaloi* website devotes a page to the implementation of the provisions of the *Act respecting health and social services* that concern consent to care by a minor 14 years of age or older;
- computerized registries: *the Quebec Health Booklet*, the Quebec Health Record (QHR) and the Quebec Vaccination Registry are computerized tools available to users and clinicians of the healthcare system; they provide information on the health services received by a given individual;
- pain assessment scales: *Douleur Enfant San Salvadour* (DESS) [San Salvadour Child Pain Checklist] and the *Grille d'évaluation de la douleur en déficience intellectuelle* (GED-DI) [Non-Communicating Children's Pain Checklist];
- the *Surrey Place* website offers a number of health care tools for young people, families and clinicians;
- a program of *systematic desensitization for medical appointments* developed by the Estrie CRDITED [rehabilitation centre for the intellectually disabled and pervasive developmental disorders].

LIFE-HABIT 6

HOUSING

Involves habits related to the young person's choice, outfitting and maintenance of a home, as well as the use of furniture and household equipment.

REASONS FOR FOSTERING HOUSING AUTONOMY

- Young people express a desire to eventually have their own place where they will have the opportunity to exercise greater control over their lives.
- Parents are concerned about their child's quality of life when it comes to housing and safety.
- The challenges faced by intellectually disabled young adults who live on their own are numerous: difficulties in performing occasional maintenance tasks, forgetting simple and regular tasks, failing to complete household chores, problems with keeping the living environment safe.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Housing options should be explored during the transition from school to active life (TSAL).
- Care must be taken not to place too many demands on the young person's ability to adapt, i.e., the project to live on his own and the socio-occupational integration should not be pursued simultaneously.
- The choice of housing must promote a good quality of life, ensure that social ties are maintained and allow the performance of social roles.
- The intervention must seek to address specific disabilities so that the person can remain in his residential environment.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit - housing; this finding applies to young people aged 6 to 21 with ID (evidence level: high).
- a parent-empowerment intervention based on training in the selected techniques, such as modelling, simultaneous verbal prompting, error correction, immediate reinforcement and any required physical prompting, is effective in ensuring that parents will be able to improve their child's autonomy in accomplishing the life habit - housing; this finding applies to young people ID aged 6 to 12 with moderate ID (evidence level: low).

RECOMMENDATIONS FOR FOSTERING HOUSING AUTONOMY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. The interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 6.1 The youth should be empowered from childhood to ensure that he is able to develop such skills as the following:

- participating in and performing domestic activities, and assuming responsibility for these activities;
- complying with safety rules and dealing with unexpected situations (e.g., fire alarms);
- recognizing hazard symbols (e.g., for corrosive, toxic or flammable substances/materials);
- spending time alone at home;
- arranging his living space to suit personal tastes;
- maintaining his living space;
- staying occupied during periods of free time;
- living in harmony with neighbours (e.g., refraining from making excessive noise).

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the young person's housing skills.

R 6.2 A youth who is planning to leave his family home and parents should be:

- informed of housing options (e.g., apartments, subsidized housing, housing co-ops, rental rooms, alternative living environments);
- informed of the various services and accommodations that could be put in place to compensate for his disabilities;
- supported in preparing a transition plan that includes all required actions, e.g., registering for various resources and choosing preparatory activities that will enable the youth to acquire complementary life habits (e.g., nutrition, mobility, employment).

USEFUL RESOURCES

Some programs, tools and means of intervention were identified in the literature, but it was not possible to verify their efficacy and safety. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Inventaire des habiletés pour rester temporairement seul chez soi* [inventory of skills for remaining temporarily at home], and *Inventaire des habiletés pour la vie en appartement [inventory of skills for apartment living]*; both were published by the GREDD research group on developmental disability;
- *Guide to programs for people with disabilities, their families and caregivers*, published by the OPHQ. It indicates available measures supporting various housing-related needs;
- *fact sheets* for parents on housing transitions and options, produced by the CIUSSS de la Capitale-Nationale and available on the Internet (in French only);
- AccèsLogis Québec is a program supporting community housing start-up projects. It provides financial and technical support;
- *The Kit: Keeping it together for youth* (better known as The Youth Kit) is an information package enabling young people to take control of their personal information and to deepen their understanding of themselves and their capabilities.

RESPONSIBILITY

Involves the young person's financial, civil and family responsibilities.

LIFE-HABIT 7

REASONS FOR FOSTERING AUTONOMY IN MATTERS OF FINANCIAL RESPONSIBILITY

- Challenges involving financial responsibilities often arise in adulthood. These include having a limited income, being subject to impulse purchases and having difficulties carrying out bank transactions.
- Managing a budget and learning to spend responsibly are skills that young people perceive as essential to achieving their plan of having their own home as adults.
- Adolescents say that learning how to shop and pay for their purchases allows them to perform a number of important activities autonomously, such as helping their families, shopping at convenience stores or paying their way at recreational activities.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Parents appreciate being empowered to help their child function autonomously in various responsibilities-related tasks.
- According to parents, real-life instruction and immediate reinforcement are the most helpful elements in facilitating learning.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit - responsibility; this finding applies to young people aged 6 to 21 with ID (evidence level: high);
- a parent-empowerment intervention based on training in the selected techniques, such as modelling, simultaneous verbal prompting, error correction, immediate reinforcement and any required physical prompting, is effective in ensuring that parents will be able to improve their child's autonomy in accomplishing the life habit - responsibility; this finding applies to young people ID aged 9 to 12 with mild to moderate ID (evidence level: low).
- an intervention to enable parents to create a video for use in another intervention that includes task analysis, video modelling (iPad), simulated role-playing, verbal and physical prompting and generalization to real-world situations is effective in helping parents improve their child's autonomy in accomplishing the life habit - responsibility; this finding applies to young people aged 17 with moderate ID and ASD (evidence level: low).

RECOMMENDATION FOR FOSTERING AUTONOMY IN RESPONSIBILITY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 7.1 The youth should be empowered from childhood with respect to family, financial and civil responsibilities to ensure that he is able to develop such skills as the following:

- taking on responsibilities in order to help family members;
- accepting help from a family member or a loved one;
- looking after a pet;
- being able to distinguish various coins and paper bills;
- managing pocket money;
- making small purchases (e.g., buying milk at a convenience store);
- respecting other people's property and rights;
- complying with safety measures.

From adolescence on, the targeted skills also include:

- knowing the value of everyday goods and services;
- opening a bank account;
- carrying out banking operations (e.g., using an ATM);
- knowing the principles of saving money and handling debt;
- knowing safety rules, rights and financial responsibilities;
- establishing and managing his budget appropriately;
- paying bills on time;
- ensuring that his rights are respected;
- obeying the law;
- exercising the right to vote;
- assuming family responsibilities vis-à-vis his parents, spouse or child.

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis, other interventions could be considered to develop the young person's skills in the area of responsibilities, such as the use of payment strategies (e.g., safe payments).

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- the Associations coopératives d'économie familiale (ACEF) offers training, budget- planning charts and consultant support in the area of home economics;
- *Capable comme les autres*, a website that offers resources for professionals and parents on numbers and money (in French only);
- *Guide to programs for people with disabilities, their families and caregivers*, published by the OPHQ. It provides information about income-support measures and benefits that are available to parents of disabled children.

LIFE-HABIT 8

INTERPERSONAL RELATIONSHIPS

Involves habits related to the young person's social relationships, relationships with friends and romantic and sexual relationships.

SOCIAL RELATIONSHIPS AND RELATIONSHIPS WITH FRIENDS

(See p. 31 for romantic and sexual relationships)

REASONS FOR FOSTERING AUTONOMY IN SOCIAL RELATIONSHIPS AND RELATIONSHIPS WITH FRIENDS

- Young people, parents and clinicians all say that the life habit - interpersonal relationship is important; priority should therefore be given to helping young people develop their autonomy in this area.
- Interpersonal relationships are a decisive factor in promoting the social integration and participation of young people.
- Interpersonal relationships are associated with improvements in school participation, workplace performance and quality of life.
- People with ID experience difficulties in their interpersonal relationships because their reading of social situations and their ability to manage conflicts and stressful events may be deficient. Such deficiencies hinder the establishment of social connections and can lead to social isolation and mental health problems.
- Friendships exist primarily in a school setting – in part because of travel constraints. As a result, young people may experience social isolation after they leave high school.
- liées aux déplacements. De ce fait, un isolement social peut être vécu après l'école secondaire.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Factors facilitating interpersonal relationship interventions include the following: the young person's motivation; the degree to which his various environments are involved; the use of specific programs; participation in emotional management workshops for parents and children.
- Consideration should be given to the following suggestions: include social network development in the intervention plan; promote recreational or volunteer activities that match the young people's interests; and ensure that the youths recognize the importance of having a social network.
- Parents have an important role to play with respect to supporting expected behaviours in their child and applying the learnings in real-world contexts.
- Below are some actions that can facilitate social skills interventions:
  - increase the demands gradually;
  - provide numerous social reinforcements;
  - in partnership with adults from the various environments, ensure that the learnings are generalized.
- An intervention employing techniques such as those used in Applied Behaviour Analysis is considered to be socially acceptable, appropriate and effective. Such an intervention could be suggested to other relatives in the family circle and used in the home to reduce behaviour problems.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing social behaviours; this finding applies to young people aged 6 to 21 with ID (evidence level: high);
- social skills training that emphasizes recognition of the social behaviours expected by the young person, together with a combination of techniques such as those employed in Applied Behaviour Analysis, is effective in improving social behaviours in young people aged 9 to 17 with ID, with or without ASD (evidence level: low);
- a pairing or networking intervention with peers with neurotypical development is not very effective in increasing social interactions in young people aged 10 to 21 with ID, with or without ASD (evidence level: moderate);
- an intervention using the TEACCH Method is effective in improving adaptive socialization behaviours in young people aged 6 to 21 with severe to profound ID and ASD (evidence level: low);
- a Reciprocal Imitation Training intervention is effective in improving social functioning and reducing disruptive behaviours in young people aged 12 to 20 with ID and ASD and presenting communication difficulties and aggressive or disruptive behaviours (evidence level: low);
- an intervention employing narratives that are written and illustrated to reflect how the youth's disruptive behaviour functions and proposing alternative behaviours is effective in reducing disruptive behaviours and increasing school engagement in young people aged 17 with severe ID (evidence level: low);
- an intervention known as StorysharingTM is effective in encouraging youths aged 12 to 16 with ID and severe communication difficulties to talk more easily about themselves (evidence level: low);
- an intervention employing techniques such as those used in Applied Behaviour Analysis and carried out by the young person's close relations is effective in reducing overly familiar or overly frequent socialization behaviours in youths aged 17 with Angelman syndrome (evidence level: low).

RECOMMENDATIONS FOR FOSTERING AUTONOMY IN SOCIAL RELATIONSHIPS AND RELATIONSHIPS WITH FRIENDS

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 8.1 The youth, as well as his family, should be empowered from childhood to ensure that he is able to develop such skills as the following:

- affirming his needs, preferences or ideas with other people;
- developing and maintaining healthy emotional attachments to members of his family (e.g., respect for privacy);
- demonstrating play skills (e.g., sharing, respecting the turns of other players, cooperating to achieve a common goal);

- demonstrating empathic behaviour (e.g., decoding body language, understanding his emotions and those of other people);
- knowing what friendship is, how to make friends and maintain these relationships;
- maintaining safe social connections with the adults around him;
- participating in social events (e.g., birthday parties, family gatherings);
- observing social rules based on levels of relational proximity (e.g., friends, family, neighbours) and living environments (e.g., school, home, recreational);
- managing conflicts with other people;
- understanding bullying and defending himself, if need be;
- knowing how to react to cyberbullying and cyber solicitation;
- knowing the social codes used in social media;
- knowing the legal consequences of his online actions;
- knowing how to recognize risky social situations and which behaviour to adopt;
- using various media to stay in contact with other people.

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis, other interventions could be considered to develop the youth's skills in social relationships and relationships with friends, such as:

- various activities that promote recognition of expected/unexpected social behaviours and their consequences;
- social circles;
- an intervention carried out by peers (who have been trained and have received support in intervening with young people who are having difficulties with social relationships).

R 8.2 Parents should be empowered to support their child in his development of social and friendship skills in a real-world setting.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to empower parents.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *ADOPRO*, a program designed to improve social skills related to emotional regulation, pragmatic communication and social problem management. It is distributed by the Fondation DI-TSA de Montréal;
- the *Circles Curriculum*, a program intended to teach contextually appropriate socialization behaviours;
- *Élaboration d'un programme d'habiletés sociales - Quelques réflexions* [reflections on developing a social skills program], a backgrounder written by Lucie Leclerc-Arvisais and published by Pavillon du Parc;
- *I Belong!* website, a resource for young people with ID created by L'Arche Canada to empower them to develop and maintain friendships;
- Rules and social skills booklet (for people with severe behavioural disorders) included in the SQETGC.

ROMANTIC AND SEXUAL RELATIONSHIPS

REASONS FOR FOSTERING AUTONOMY IN ROMANTIC AND SEXUAL RELATIONSHIPS

- The romantic and sexual relationships of adolescents and young adults with ID are often constrained by social and environmental barriers. Young people report that, when it comes to sexuality, they are controlled by the people around them (in that these people make decisions for them, draw up rules and control their autonomy and intimacy).
- Intellectually disabled people are two to six times more likely to be sexually assaulted than members of the general population.
- Developing social skills and having access to sex education are protective factors against situations of sexual abuse.
- People with ID are also potentially at greater risk of becoming victims of cyberstalking.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- The prohibitions imposed on adolescents and young adults with ID cause them to feel frustrated and sad and may contribute to their adopting sexually risky or socially inappropriate behaviours.
- Generally speaking, intellectually disabled young people have gaps in their knowledge about sexuality.
- Parents want to receive psychosocial support and coaching prior to their child's first sexual relationship.
- There are many misperceptions by the various parties involved about the sexuality of people with ID.
- Sex education or sexual assault prevention programs intended for children, adolescents and adults with ID need to: offer broad coverage of topics related to sexual health; use various media, strategies and information sources; and include an assessment component to measure the participants' progress.
- Sex education programs need to be tailored to young people's characteristics, needs, learning styles and abilities.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- a short-term intervention offered in an individual setting and using various strategies (including the use of anatomical charts, colouring books describing a story of abuse, situation scenarios, instructions, role-playing, modelling, feedback and discussion) is effective in increasing the ability of adolescent girls to refuse inappropriate sexual requests, leave a situation and report it to an adult (evidence level: low).

RECOMMENDATIONS FOR FOSTERING ROMANTIC AND SEXUAL RELATIONSHIPS

Recommendations are intended to support the selection of interventions to be included in the intervention plan. The interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 8.3 The youth and his parents should be:

- informed of the fact that respect for emotional, romantic and sexual needs is a right;
- supported, as required, in becoming aware of this right and in ensuring that it is recognized in various living environments.

R 8.4 The youth, as well as his family, should be empowered from childhood to ensure that he is able to develop such skills as the following:

- knowing the anatomy of the body, the principles of reproduction and the physical changes that accompany puberty;
- developing his social and sexual identity.

From adolescence on, the targeted skills also include:

- developing his social and socio-sexual skills (e.g., in the private/public spheres, intimate circles, relational stages);
- understanding consent, i.e., that it must first be given voluntarily, that silence does not equal consent and that consent can be withdrawn at any time;
- understanding the nature of a healthy and egalitarian romantic and sexual relationship;
- knowing the various ways to achieve sexual satisfaction (e.g., masturbation, emotional intimacy);
- knowing his rights and legal responsibilities;
- knowing and using contraceptive methods;
- knowing ways to prevent sexually transmitted and blood-borne infections (STBBIs);
- being aware of the risks of exploitation, sexual assault and cyberstalking;

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis, the following interventions could be considered:

- using visual media (e.g., anatomical charts, books);
- observation activities, role-playing and situation scenarios when appropriate;
- discussion activities;
- problem-solving activities;
- sharing experiences and expressions of emotion among young people.

The choice of techniques and intervention method, i.e., whether it will be carried out in an individual or group setting, should reflect the matters discussed and individual needs.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Éducation à la vie affective, amoureuse et sexuelle* (ÉVAAS) [emotional, romantic and sex education], a program intended for young people aged 16 or older with moderate ID and available at the CIUSSS de la Mauricie-et-du-Centre-du-Québec;
- *Éducation à la santé sexuelle pour les adolescents présentant une déficience intellectuelle* (PÉSSADI) [sex health education for intellectually disabled adolescents], a program that helps parents offer their child the most relevant sex education, with support from practitioners; it is available at the CIUSSS de la Mauricie-et-du-Centre-du-Québec.

LIFE-HABIT 9

COMMUNITY AND SPIRITUAL LIFE

Involves habits related to the young person's participation in the life of his community and in his own spiritual life.

REASONS FOR FOSTERING AUTONOMY IN COMMUNITY AND SPIRITUAL LIFE

- Intellectually disabled people are hampered in their citizen participation by a variety of individual barriers (various fears, their perception of having fewer skills and limited influence) and by environmental barriers (structures, mechanisms for participation or poorly-adapted content).
- They feel that they have limited power over decisions that affect them.
- For intellectually disabled people, the fear of being judged and humiliated, the fear of not being up to a task and the fear of disappointing their peers are barriers to citizen participation.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- People with ID say that they need autonomy, respect and recognition of the social value of individuals in order to become more engaged as citizens.
- Citizen participation is facilitated by quality interpersonal relationships, a feeling of being welcomed, belonging to a group and developing skills and engagement opportunities.
- Citizen participation by people with ID can be encouraged by working with the various components of empowerment, focusing on active learning and creating a distribution of power that helps participants and balances support and freedom during the intervention.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit related to community and spiritual life; this finding applies to young people aged 6 to 21 with ID (evidence level: high);
- a multi-component program (including discussions, interactive presentations, problem-solving activities, games and mentoring by a former program participant) that is designed to develop an ability to identify physical or social environmental barriers and facilitators, to generate solutions for reducing these barriers and to request changes that will increase participation in activities at school, work or in the community is effective in improving a youth's autonomy in accomplishing the life habit related to community and spiritual life; this finding applies to young people aged 14 to 20 years with ID (evidence level: moderate).

RECOMMENDATIONS FOR FOSTERING AUTONOMY IN COMMUNITY AND SPIRITUAL LIFE

Recommendations are intended to support the selection of interventions to be included in the intervention plan. The interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 9.1 The youth and his parents should be:

- informed of opportunities to participate in organizations of various types (e.g., sports, cultural, school, religious, advocacy, interest groups, boards of directors, user committees, partnership offices);
- supported, as needed, in their efforts to take part in the activities.

R 9.2 The young person should be empowered from childhood to participate in community and spiritual life to ensure that he is able to develop such skills as the following:

- participating in associations as a member (e.g., Extracurricular Committee, Environmental Protection Group);
- taking part in activities related to religious or spiritual practices;
- making decisions;
- communicating his preferences, choices and world vision;
- being heard;
- solving problems;
- working in a team setting;
- knowing his rights;
- setting goals and assuming responsibilities.

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the youth's participation in community and spiritual life.

R9.3 If necessary, the young person should be supported in:

- identifying and overcoming personal barriers (various fears, his perception of having fewer skills and limited influence) and environmental barriers (structures, mechanisms of participation or poorly-adapted content) that may hinder his participation in community and spiritual life;
- developing quality relationships as part of his participation in community and spiritual life;
- facilitating his active participation in organizations.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Fédération des Mouvements Personne d'Abord du Québec* [federation of people first movements]. Established in a number of cities, this provincial organization is for individuals aged 18 or more with ID and uses peer support to promote and advocate the rights and interests of intellectually disabled adults .

EDUCATION

Involves habits related to the young person's psychomotor, intellectual, social and cultural development.

LIFE-HABIT 10

NOTE: interventions focusing on the school curriculum (e.g., reading, writing or arithmetic) are not covered because the planning guideline is intended primarily for health and social services workers.

REASONS FOR FOSTERING EDUCATION AUTONOMY

- Young people with ID are more often excluded from the classroom because of problematic behaviours.
- Parents are concerned because their child (aged 6 to 12) lacks autonomy during homework period.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Parents would like to see better communication as well as smoother and more systematic collaboration between the education network and the health and social services network.
- Parents appreciate when the CISSS/CIUSSS worker ensures that interventions in the school setting are connected, consistent and generalized.
- Good preparation and support during various periods of transition promote autonomy in education.
- Using a self-monitoring application during classroom tasks to increase engagement behaviours is viewed positively*.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention that includes techniques such as those employed in Applied Behaviour Analysis and a technological aid is effective in improving a youth's autonomy and engagement behaviours vis-à-vis accomplishing the life habit - education; this finding applies to young people aged 6 to 21 with ID (evidence level: high).
- an intervention consisting of a weekly meeting between the teacher and student (including a report on any disengagement behaviours observed by the teacher; proposals for new strategies; and a signature attesting to a proper understanding of those strategies scheduled for implementation the following week to teach recognition and promotion of task engagement behaviours) is effective in reducing avoidance behaviours and increasing school activity engagement in young people with mild ID aged 15 to 16 (evidence level: low);
- a mindfulness-based intervention is effective in increasing school work engagement and reducing disengagement behaviours in young people with mild ID aged 11 and 12 (evidence level: low);

* Self-monitoring of behaviour in task engagement situations allows the youth using this technique to become aware of his or her present behaviour and to assess whether it is the conduct expected at that specific time. If not, he or she can autonomously adopt the desired behaviour.

- a multi-component program (including discussions, interactive presentations, problem-solving activities, games and mentoring by a former program participant) that is designed to develop an ability to identify physical or social environmental barriers and facilitators, to generate solutions for reducing these barriers and to request changes that will increase participation in activities at school, work or in the community is effective in improving a youth's autonomy in accomplishing the life habit - education; this finding applies to young people aged 14 to 20 years with ID (evidence level: moderate).

RECOMMENDATIONS FOR FOSTERING EDUCATION AUTONOMY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 10.1 The young person and his parents should receive concerted and complementary support from practitioners in the health and social services system and from teachers and other practitioners in the education system for purposes of promoting the youth's well-being, participation in school life and success.

Such support should be offered especially at the following times:

- during school transitions (e.g., from the pre-school to the elementary level, from the elementary to the secondary level) or during any other time of change (e.g., moving to a new home) in which the youth may be more vulnerable;
- when implementing intervention plans;
- when transitioning from school to active life (TSAL);
- when problematic behaviours arise.

When necessary, an assessment of the factors that promote or hinder the youth's engagement and participation in school and extracurricular life should be carried out (taking into consideration such factors as his areas of interest, motor and sensory skills and communication skills).

R 10.2 The youth should be empowered from childhood to ensure that he is able to develop such skills as the following:

- following the instructions and rules that are currently in effect at the institution;
- making appropriate use of available infrastructure facilities (e.g., cafeteria, playground, gymnasium);
- participating in activities organized by the school or daycare (e.g., outings, special days);
- adapting to new situations (e.g., having a different teacher, being assigned to a different group in the gym);
- doing school assignments at home.

In the classroom, the targeted skills also include:

- following routines;
- adopting behaviours that allow interaction with peers and adults;
- recognizing his engagement behaviours;

- staying focused on tasks;
- performing team work;
- observing the activity operating rules;
- participating in academic learning (reading and writing);
- taking specialized courses (e.g., physical education, music).

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to facilitate the youth's engagement and participation in school and extracurricular activities.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Guide to the education of your child with a disability: handbook for parents*, published by the OPHQ. This guide provides information to parents on the school environment, the actions required for their child's schooling, the various stages involved, the role of the parents and useful resources;
- *Guide to programs for people with disabilities, their families and caregivers*, published by the OPHQ. This guide lists available measures supporting various education-related needs, such as school adjustment, paratransit services, special needs allowances, loans and bursaries.

LIFE-HABIT 11

EMPLOYMENT

Involves habits related to career guidance for the young person, job searching and occupations, whether paid or not.

REASONS FOR FOSTERING EMPLOYMENT AUTONOMY

- Being recognized as a worker promotes the social participation of a young person with ID because such a role is socially valued. This recognition can have a significant effect on the quality of life of the youth and his family.
- Young people say they need to work in order to pay their personal expenses and ultimately carry out their own personal projects.
- The last years of adolescence are a period when the youth and his parents are preparing for the transition from school to active life. Employment-related issues play a key role in planning for this transition.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- The transition to active life should be initiated early on, and the young person should play a central and active role in this transition.
- A number of factors are associated with the employability and job retention of intellectually disabled people:
  - the young person's motivation and self-determination;
  - prior experience in a part-time or summer job during the youth's teen years;
  - prior participation in job-related activities at school;
  - the ability to move about easily within the community;
  - reliable and dynamic support from parents;
  - collaboration between parents and practitioners.
- The school environment provides employment-based training paths for students with ID. Some of the preferred activities for these young people are exploring socio-professional areas of interest and participating in workplace traineeships.
- Young adults with ID have opportunities to access paid employment, but their parents often know little about the various government measures that allow this path towards employment.
- It is important to ensure that the workplace setting is aligned with a young person's aspirations, that supports are available from the outset of his integration (e.g., mentoring) and that integration is carefully planned.
- Employers are willing to teach job-specific tasks, but they expect that young people will already possess the social skills required for the workplace.
- Some parents question their ability to reconcile family and work obligations when their child is close to completing his schooling.
- Some parents are afraid that access to regular employment will deprive their child of the financial support programs that he might need.
- Intersectoral collaboration between the health and social services, education and employment systems fosters access to the labour market for young people with ID.

INTERVENTION EFFICACY

Below are the scientific study results on the efficacy of the interventions:

- An intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit - employment; this finding applies to young people aged 6 to 21 with ID (evidence level: high).
- An intervention employing techniques such as those used in Applied Behaviour Analysis and other strategies (e.g., showing videos of behaviours that are expected and not expected, guided practices and role-playing) that aims to promote the expression of expected social behaviours in the workplace is effective in improving social behaviours in the accomplishment of the employment life habit; this finding applies to young people with ID aged 12 to 21 (evidence level: moderate).
- A multi-component program (including discussions, interactive presentations, problem-solving activities, games and mentoring by a former program participant) that is designed to develop an ability to identify physical or social environmental barriers and facilitators, to generate solutions for reducing these barriers and to request changes that will increase participation in activities at school, work or in the community is effective in improving a youth's autonomy in accomplishing the life habit - employment; this finding applies to young people aged 14 to 20 with ID (evidence level: moderate).

RECOMMENDATIONS FOR FOSTERING EMPLOYMENT AUTONOMY

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 11.1 The youth and his parents should be:

- informed of available socio-professional or community programs and services;
- supported in:
  - developing a life plan and exploring the youth's socio-professional and community areas of interest;
  - having the youth take on tasks and responsibilities within the family;
  - the procedures involved in looking for a job or an occupation, by helping the young person to :
    - use the services of organizations that promote employability;
    - submitting job applications and his CV;
    - introducing himself to employers or organizations.

R 11.2 The young person should be empowered early on and throughout the socio-professional and community integration activities to ensure that he is able to develop such social skills as the following:

- arriving at work on time;
- asking for clarification of instructions that are not understood;
- following instructions;
- receiving feedback from the supervisor in an appropriate manner;
- discussing personal issues at the proper time and place;
- having physical and social contacts tailored to a real-world work setting.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the social skills that are expected in a socio-professional setting.

R 11.3 The youth should be empowered from adolescence to ensure that he is able to develop skills related to the current or projected socio-professional or community occupation, such as the following:

- choosing appropriate attire for his occupation;
- getting to the workplace;
- adopting expected behaviours during times of transition (e.g., when arriving at work, during breaks and meals);
- preparing his lunch;
- complying with the institutional rules (e.g., safety rules, schedules);
- using available infrastructure facilities (e.g., rest areas, cafeteria);
- performing his traineeship, volunteer or work activities, both paid and unpaid;
- going to a day centre as the main activity;
- coping with unexpected situations (e.g., task switching, a modified workstation, technical problems);
- following accident or emergency procedures.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to develop the youth's skills in the area of employment.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Guide for supporting the transition from school to active life* (TSAL), published by the Ministère de l'Éducation et de l'Enseignement supérieur;
- *Guide to programs for people with disabilities, their families and caregivers*, published by the OPHQ. It lists the measures available to support various work-related needs.

RECREATION

Involves habits related to the young person's participation in sports and games, arts and culture and socio-recreational activities.

LIFE-HABIT 12

REASONS FOR FOSTERING RECREATIONAL AUTONOMY

- Recreational activities that are aligned with the youth's tastes and preferences have a positive effect on his quality of life.
- Recreational activities allow young people to experience socialization outside the family setting.
- Participation in structured community activities and in free-time activities is a way for young people to explore their areas of interest.
- It has been observed that intellectually disabled adults have difficulty filling their free time.

ELEMENTS TO BE CONSIDERED IN INTERVENTION PLANNING

- Young people often report being hampered by transportation problems and the cost of recreational activities.
- Parents view such formalities as registering, completing various forms and providing relevant information to promote the integration of their child into recreational activities as obstacles.
- Parents are appreciative when a clinician takes the recreational needs of young people into consideration, informs them of available local resources and helps them involve their child in activities that he is capable of performing.
- Making day camp monitors more aware of the characteristics of youths with ID helps to promote their inclusion.

INTERVENTION EFFICACY

The scientific study results on the efficacy of the interventions are as follows:

- an intervention employing techniques such as those used in Applied Behaviour Analysis is effective in improving a youth's autonomy in accomplishing the life habit- recreation; this finding applies to young people aged 6 to 21 with ID (evidence level: high);
- an intervention based on an electronic application for reading aloud and on participation in discussions at a book club attended by young people with or without ID is effective in increasing their contributions to such discussions; this finding applies to young people aged 16 to 18 with mild or moderate ID (evidence level: low).
- a multi-component program (including discussions, interactive presentations, problem-solving activities, games and mentoring by a former program participant) that is designed to develop an ability to identify physical or social environmental barriers and facilitators, to generate solutions for reducing these barriers and to request changes that will increase participation in activities at school, work or in the community is effective in improving a youth's autonomy in accomplishing the life habit - recreation; this finding applies to young people aged 14 to 20 with ID (evidence level: moderate).
- a parent-empowerment intervention that uses training in modelling, task breakdown support and real-life feedback is effective in improving autonomy in recreational activities in young people aged 6 to 9 with moderate ID (evidence level: low).

RECOMMENDATIONS FOR FOSTERING AUTONOMY IN RECREATION

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results.

R 12.1 The youth and his parents should be:

- informed of the various recreational activities (sports, cultural and hobby activities) available in their community, and of the resources available to facilitate and maintain the youth's participation;
- supported, as required, in integrating and maintaining the youth in recreational activities.

R 12.2 The youth. as well as his family, should be empowered from childhood to ensure that he is able to develop the following skills:

- choosing sports, cultural and hobby activities;
- practising art, cultural and craft activities;
- practising physical or sports activities;
- participating in outdoor or tourist activities;
- participating in the activities selected for his home setting or in other indoor/outdoor settings;
- participating in group activities;
- understanding and following activity instructions (e.g., on the playground, at day camp);
- attending sports, art and cultural activities (e.g., soccer games, movies, shows);
- using the cultural recreational services in his community (e.g., libraries, municipal recreational centres, recreational clubs).

From adolescence on, the skills targeted are the same as those developed in childhood. However, they should be adjusted to the context of adolescence and young adulthood.

In addition to behaviour intervention techniques such as those employed in Applied Behaviour Analysis, other interventions could be considered to develop the young person's recreational skills, such as participating in group activities that include other youths, without or without ID.

USEFUL RESOURCES

Some programs, tools and means of intervention have been identified in the literature, but their efficacy and safety have not been verified. Below is a non-exhaustive list of useful resources (most are in French), some of which are available online:

- *Association québécoise pour le loisir des personnes handicapées* (AQLPH). The AQLPH promotes and contributes to the development of recreation for disabled persons. The AQLPH website offers information on resources and recreational destinations;
- *Companion Leisure Card*. Managed by the AQLPH; this card grants free admission to the accompanying party of a disabled person and is recognized by leisure, cultural and tourist organizations;
- *Guide to programs for people with disabilities, their families and caregivers*. Published by the OPHQ, this guide lists available measures that support access to recreation, sports, culture and community life.

RECOMMENDATIONS THAT COULD APPLY TO ALL LIFE HABITS

Results from the various sources consulted were used to formulate recommendations that can be applied to more than one life habit. These recommendations have been grouped into the following three topics:

- behaviour intervention techniques;
- use of a technological medium;
- interventions to empower parents to support their child's autonomy.

These three recommendations are followed by a glossary for easier understanding.

Recommendations are intended to support the selection of interventions to be included in the intervention plan. These interventions must be consistent with the preferences and needs agreed to with the young person and his parents, and with the assessment results. The behaviour intervention techniques presented here and other terms used in this reference guide are defined in the Definitions and Key Concepts section (p. 49).

BEHAVIOUR INTERVENTION TECHNIQUES

R 13.1 Behaviour intervention techniques, such as those employed in Applied Behaviour Analysis, should be used with the youth to teach him new behaviours (e.g., communication and social behaviours) or to reduce unwanted behaviours, if necessary.

The techniques listed below should be used:

- task analysis;
- reinforcement, including identification and use of the most effective reinforcers for the youth;
- prompting;
- modelling;
- feedback;
- error correction;
- total task training;
- discrete trial learning;
- self-directed education, including self-monitoring of behaviour.

The choice and combination of these techniques should be tailored to the characteristics and needs of the young person; they should also be appropriate for his family and cultural context and should evolve as the new behaviour is acquired.

Planning for the maintenance and generalization of acquired behaviours should be done from the beginning of the intervention.

The intervention should provide the means for measuring the youth's acquisition of the targeted new behaviour.

In addition to such behaviour intervention techniques as those employed in Applied Behaviour Analysis, other interventions could be considered to teach the young person new behaviours (e.g., communication and social behaviours) or to reduce unwanted behaviours:

- using picture media (e.g., photos, pictograms, anatomical charts, picture schedules, books), gestures or objects;
- organizing tasks, physical environment and time;
- teaching strategies to recognize desired or unwanted behaviours;
- problem-solving activities;
- discussion activities and role-playing;
- education through simulation;
- education in a real-world context;
- technology-supported education;
- individual or group education;
- pairing the youth with another young person with neurotypical development.

USING A TECHNOLOGICAL MEDIUM

R 13.2 A technological medium should be used with the youth as needed in order to foster his autonomy in accomplishing the various life habits, thereby enabling the youth to:

- learn new behaviours;
- maintain the desired behaviour in all settings or living environments;
- perform the behaviour with a technological medium.

The young person should be empowered in learning how to use a technological medium autonomously (e.g., be able to start the device, recharge it and open the application needed to perform the desired behaviour).

The practical functions available on these technological media (e.g., alerts, geolocation, telephones or dictaphones), the publicly available software and applications or the software and applications specifically designed for intellectually disabled people should be used as needed.

The youth and his parents should be:

- involved in choosing a technological medium with the features requested by the youth and meeting his needs;
- empowered and supported, as required, in using the technological medium selected;
- be supported, as required, in using the Internet and social networks.

USEFUL RESOURCES

- Centre de partage d'expertise en intervention technoclinique (CPEITC) (in French)

INTERVENTIONS WITH PARENTS

R 13.3 Parents should:

- be informed of the principles of Applied Behaviour Analysis and how these principles can be put into practice with their child;
- be involved in selecting which new behaviours are to be developed or which unwanted behaviours are to be reduced;
- also be involved in the selection of reinforcers and visual materials related to the features and needs expressed by their child;
- be empowered and supported, if necessary, in applying the techniques selected.

Behaviour intervention techniques such as those employed in Applied Behaviour Analysis should be used to train parents, particularly:

- prompting;
- modelling;
- feedback;
- error correction.

Most of these techniques can be taught in an individual or group setting. However, it may be necessary to observe and provide individual feedback on the use of these techniques directly in the family setting.

Definitions and *key concepts*

Applied Behaviour Analysis

Applied Behaviour Analysis (ABA) is a structured approach based on learning theory and behavioural science, the principles of which are systematically applied.

It has two main objectives:

A. to teach and increase the frequency of use of socially acceptable skills and behaviours;

B. to reduce unexpected behaviours (adapted from [Murphy, 2011; Cooper *et al*., 2007a]).

A rigorous assessment of the intervention effects is also a feature of Applied Behaviour Analysis interventions.

Applied Behaviour Analysis includes various steps; these can be broken down as follows (adapted from [Cooper et al., 2007a]).

1. Behavioural assessment: consists of selecting and characterizing the behaviour to be modified and defining how to measure it. It is essential to ensure that the youth or his parents have previously expressed a need and that the intervention process is understood by them. It may be necessary to carry out a functional assessment of behaviours that need to be reduced or eliminated. In addition, a preference assessment must be made to determine which reinforcers are most likely to ensure that the desired behaviour will be repeated.
2. Behaviour modification intervention: consists of a set of actions that aim to change a behaviour, promote maintenance of the new behaviour over time and generalize it, especially to new environments or new tasks.
3. Intervention efficacy assessment: measures and analyzes changes in behaviour.

Autonomy

The concept of autonomy used in this guideline consists of two important elements, i.e., the ability to decide on and perform the activities needed, on the one hand, to live within the community in an adequate manner and, on the other, to ensure one's physical and psychological well-being. Decision autonomy is about decision-making based on one's personal preferences, beliefs and values. Execution autonomy, on the other hand, involves fulfilling special needs by means of various actions, activities or tasks [Rocque et al., 2001].

Behaviour Interventions

Behaviour interventions are centred on behavioural change and are particularly focused on the following principles:

- All human behaviour is affected by the events that precede it (antecedents) and the events that follow it (consequences) (Skinner, 1938/1966, cited in Cooper et al. [2007a]).
- Enabling a behaviour to become more frequent or less frequent is a matter of intervening in the events that precede it (antecedents) or that follow it (consequences).

Thus, in a clinical practice context, the use of behaviour interventions should be based on a demonstrated knowledge of the operating principles of human behaviour and on appropriate skills.

Discrete trial training

Discrete trial learning involves intensively repeating the behaviour-modifying intervention over a specified period of time. The interventions evaluated for this guide relied very little on this approach.

Error correction

Error correction is used when a young person exhibits a different behaviour than what is expected and requires the use of prompting techniques.

Family

The term "family" needs to be understood in its broadest sense. It may include relatives, loved ones or other people who play a significant role in the young person's life, such as a foster family or members of another residential resource.

Feedback

Feedback consists of providing information about a specific aspect of the behaviour accomplished by an individual. It can act as a behaviour reinforcer or as a prompt to reproduce the behaviour at a later time.

Intellectual Disability

The American Association on Intellectual and Developmental Disabilities has established the diagnostic criteria for intellectual disabilities [AAIDD, 2011].

"*Intellectual disability* is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18.

The following five assumptions must be met when applying this definition.

- Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
- Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensorimotor and behavioural factors.

- Within an individual, limitations often coexist with strengths.
- A description of the limitations is important, particularly when developing a profile of needed supports.
- With appropriate personalized support over a sustained period, the functioning of a person with intellectual disability should improve."

It is important to note that the preceding three criteria must be present in order to pronounce a diagnosis of intellectual disability. Such a diagnosis cannot be established solely on the basis of intellectual functioning.

Modelling (a form of prompting)

Modelling involves presenting a model of expected behaviour to the youth, so that he can reproduce this behaviour. Stage 1: Demonstrate the appropriate behaviour (e.g., in person or indirectly by means of a video recording). Stage 2: The young person successfully reproduces the demonstrated behaviour.

Parent

The term "parent" refers to the person who has primary responsibility for the youth's well-being. It may be someone other than the youth's mother or father.

Prompting

Prompting is a technique that promotes the accomplishment and acquisition of a behaviour and contributes to individualizing learning support.

There are various types of prompts (e.g., gestural or verbal prompts); they can be used successively or in conjunction with one another.

The intensity of the prompting must be determined with a view to ensuring that the young person experiences success, but the intensity should also be as low as possible in order to foster learning development. An increasing prompt is one that gradually becomes more intense until the youth responds correctly; this kind of prompt can be used to enhance opportunities for success.

Reducing the prompts must be planned and carried out as the young person is becoming autonomous. Various procedures can be put in place for this purpose.

- Decreasing prompt: consists of gradually diminishing the level of prompting until the person can respond autonomously.
- Time delay: consists of increasing the time between the instruction given and the expected behaviour before offering a prompt; this is done while the individual is acquiring the expected behaviour (constant time delay; progressive time delay).

Reinforcement

Reinforcement consists of introducing a specific satisfactory consequence (called a reinforcer) following the manifestation of a desired behaviour. Reinforcement helps to increase the frequency of such behaviour.

Self-directed education

Self-directed education includes a number of strategies, such as self-monitoring and self-instruction. [Douglas and Uphold, 2014].

- Self-monitoring of behaviour in a task commitment situation allows the young person who uses this technique to become aware of his current behaviour and to assess whether it is the behaviour expected at that time. If not, the youth can autonomously adopt the desired behaviour.
- Self-instruction allows the young person to be autonomous in carrying out the intervention, thereby reducing the need for an instructor. For example, the youth can independently consult the directions for performing a task. Current technologies can be employed to foster the use of this strategy.

Task analysis

In the context of behaviour intervention techniques such as those used in Applied Behaviour Analysis, the task analysis is intended to determine the sequence of actions needed to effectively execute a complex behaviour. The task analysis must be individualized to reflect the characteristics of the youth (his level of physical, sensory and motor skills) and his environment.

Total task training

Total task training consists of providing a prompt at each step, if necessary, until the youth autonomously achieves the complete behaviour sequence. This is the technique that was used in the majority of interventions assessed for this guide.

Youth (or Young Person)

The terms "youth" or "young person" refer to children, adolescents and young adults aged between 6 and 21.

Human Development Model – Disability Creation Process (HDM-DCP)

Both this reference guide and the practice guideline are based on the Human Development Model – Disability Creation Process (HDM-DCP). This model is considered by MSSS to be "a common reference for a better understanding of the dynamic interaction between personal factors and environmental factors and their effect on the development of life habits and, ultimately, on social participation" [MSSS, 2017]. It has also been adopted by professionals at the Quebec CISSS and CIUSSS institutions for use in developing their intervention plans.

Model description

The HDM-DCP offers a classification of the causes and consequences of disabling situations. The accomplishment of a life habit is the result of interactions between personal factors (identity factors, organic systems and capabilities) and environmental factors (societal, community, personal). Under this model, the intervention goals are to improve capabilities, compensate for disabilities and reduce environmental barriers. Interventions influence the accomplishment of life habits, minimize disabling situations and promote optimal social participation.

A disabling situation is defined as the *difficulty* or *impossibility* of accomplishing a life habit resulting from the interaction between *personal* factors and *environmental* factors.

The HDM-DCP is thus structured around three concepts: life habits, the disabling situation and social participation (https://ripph.qc.ca/en/).

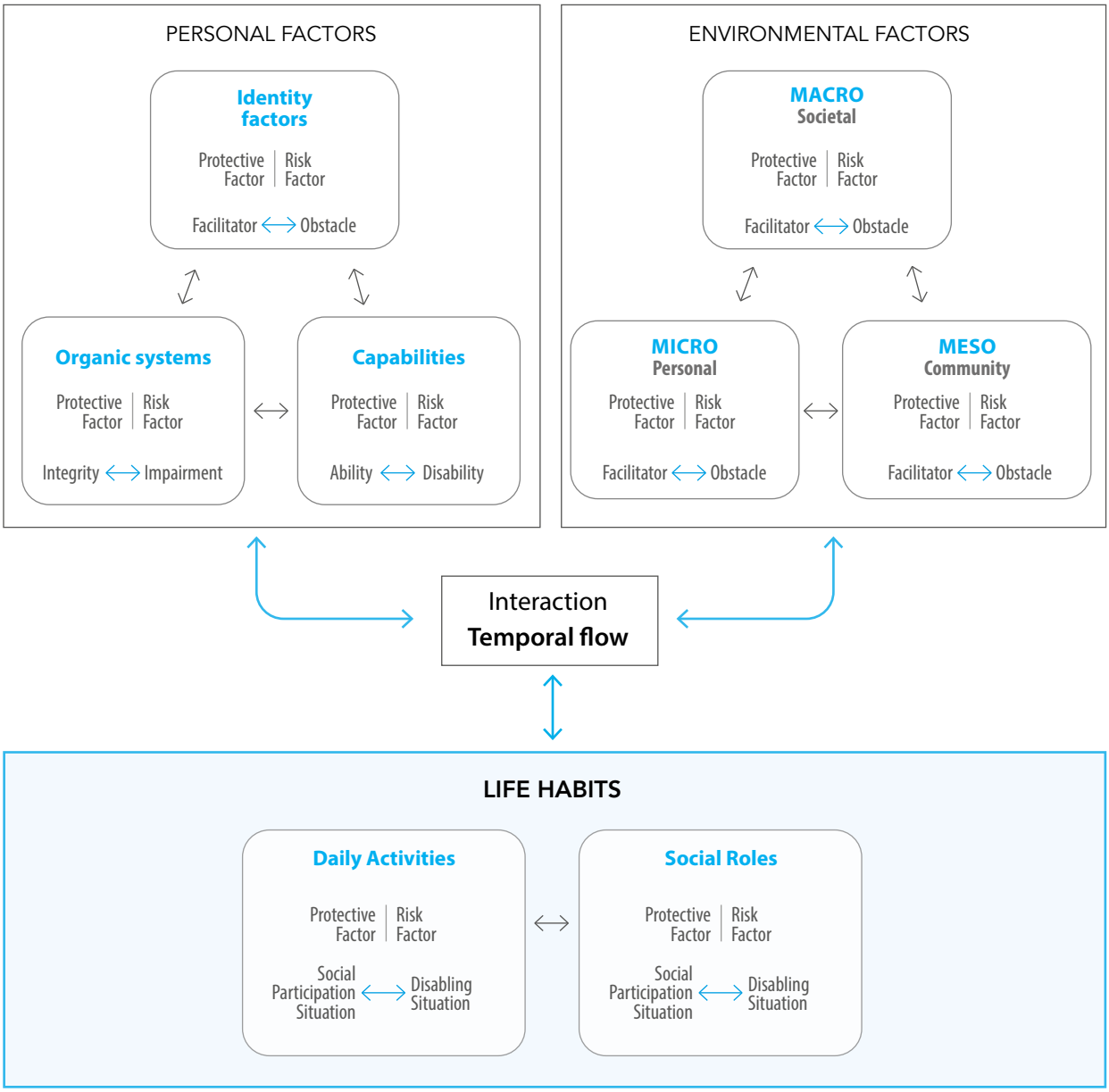
A **life habit** is defined as "a daily activity or social role valued by the person or his/her social-cultural context according to his/her characteristics (age, sex, socio-cultural identity, etc.). Life habits or performance in social life situations ensure a person's survival and wll-being in his/her society throughout his/her entire existence".

Life habits linked to current activities are as follows: communication, mobility, nutrition, physical fitness and psychological well-being, personal care and health care, and housing.

Life habits linked to social roles involve: responsibility, interpersonal relationships, community and spiritual life, education, employment and recreation.

A social participation situation "refers to the total accomplishment of life habits, resulting from the interaction between personal factors and environmental factors."

FIGURE 3
Human Development Model – Disability Creation Process (HDM-DCP)



Source: Adaptation of Fougeyrollas P, Cloutier R, Bergeron H, St-Michel G, Côté J, Barral C, et al. Classification internationale – Modèle de développement humain – Processus de production du handicap (MDH-PPH). Réseau international sur le Processus de production du handicap (RIPPH), published in Quebec City, 2018.

List of activities included in the *life habits* according to the Human Development Model – Disability Creation Process (HDM-DCP)

LIFE HABIT 1 COMMUNICATION

Involves the youth's oral and body communication, written communication and telecommunications.

It includes the following activities:

communicating with a person or group of people to convey one's needs and express one's ideas	holding a conversation and being capable of dialoguing while taking other people's opinions into consideration, and engaging in discussion and debate	written communication	reading and understanding written information	using various communication technologies, such as computers, the Internet, telephones, television, etc.

LIFE HABIT 2 MOBILITY

Involves the youth's mobility within his immediate environment, and mobility using various means of transportation.

It includes the following activities:

engaging in limited movement within the community, such as walking on the sidewalk and on the street, crossing at intersections with or without traffic lights, moving about on an uneven or slippery surface	using various means of transportation, such as riding as a passenger in a car or taking public transit, school transportation, taxis, trains, airplanes, boats (ferries);	using a bicycle, motorcycle or car as a means of transportation.

LIFE HABIT 3 NUTRITION

Involves habits related to the youth's diet, food preparation and meals.

It includes the following activities:

participating in the preparation of simple meals	choosing foods based on one's tastes and needs ("needs" refer here to a special diet required by the person's health condition, e.g., diabetes, allergies, etc.)	buying one's food	preparing meals (cooking simple or complex meals, using household appliances, setting and clearing the table, washing the dishes)	eating meals (using cutlery and dishes, having good table manners, cutting up one's food)

LIFE HABIT 4 PHYSICAL FITNESS AND PSYCHOLOGICAL WELL-BEING

Involves habits that promote healthy sleep habits and the performance of physical activities and activities conducive to relaxation, concentration or other activities that contribute to the young person's psychological well-being.

It includes the following activities:

going to bed and getting up	falling asleep, sleeping and waking up	practising physical activities to maintain or improve one's physical fitness	performing activities to ensure one's psychological or mental well-being (e.g., meditation, personal growth)	engaging in activities to relax or unwind (e.g., listening to music or a story, looking at the pictures in a book or reading a book)	performing activities requiring attention and concentration (e.g., memory and association games, checkers, chess)

LIFE HABIT 5 PERSONAL CARE AND HEALTH CARE

Involves habits related to the young person's body care, clothing, excretal hygiene and health care.

It includes the following activities:

looking after one's body hygiene	using the sanitary facilities at home and elsewhere	dressing and undressing oneself
putting on clean clothes	putting in/on, taking off/out and maintaining orthotic devices, prostheses, contact lenses, hearing aids, etc.	using the health services and caring for oneself: • recognizing and reporting health problems; • taking part in the treatment of one's health problems; • agreeing to take medications/vitamins, etc.; • renewing prescriptions; • using the health services (medical clinics, hospitals, dental clinics, rehabilitation centres, etc.).

LIFE HABIT 6 HOUSING

Involves habits related to the young person's choice, outfitting and maintenance of a home, as well as the use of furniture and household equipment.

In the case of children, it includes the following activities:

helping to decide on the layout of their room	participating in household maintenance (both interior and exterior)	participating in household chores	observing home safety rules	using household furniture and equipment

The activities for adolescents and young adults additionally include:

choosing a place to live and arranging it to suit their tastes and needs	maintaining the place where they live (both interior and exterior maintenance)	performing regular and occasional household chores

LIFE HABIT 7 RESPONSIBILITIES

Involves the young person's financial, civil and family responsibilities.

In the case of children, it includes the following activities:

shopping	managing their pocket money	respecting the property and rights of others	ensuring that their own property and rights are respected
remaining alone for brief periods of time	helping their parents or other family members	accepting help from their parents or loved ones	taking care of a pet

The activities for adolescents and young adults additionally include:

planning budgets and meeting financial obligations	voting, complying with legislation and regulations	taking care of their family members, including their spouse, and supporting them	providing for their children's education

LIFE HABIT 8 INTERPERSONAL RELATIONSHIPS

Involves habits related to the young person's social relationships, relationships with friends and romantic and sexual relationships.

In the case of children, it includes the following activities:

maintaining emotional relationships with their parents and family environment (expressing their emotions, feelings, joy, anger; cuddling, etc.)	maintaining friendships (establishing and maintaining relationships)	maintaining social relationships with people in their environment (teachers, coaches, other significant adults)	managing conflict with other people	having or participating in activities related to their sexual awakening (information, discussion, body discovery)

The activities for adolescents and young adults additionally include:

maintaining an emotional relationship with a romantic partner or a spouse	having sexual relations and using methods to prevent the spread of sexually and blood-borne infections, unwanted pregnancies and abuse

LIFE HABIT 9 COMMUNITY AND SPIRITUAL LIFE

Involves habits related to the young person's participation in the life of his community and in his own spiritual life.

In the case of children, it includes the following activities:

participating as a member in student associations (e.g., school councils, class councils, extracurricular committees)	participating as a member in sports or recreational associations (e.g., Scouts, clubs)	participating in the activities of support or special interest groups (e.g., human rights, ecology)	participating in activities linked to religious or spiritual practices (e.g., at home, in a church or in other places of worship)

The activities for adolescents and young adults additionally include:

participating as a member in associations, cultural and arts groups (e.g., theatre, dance, movies)	participating in the activities of rights-promotion organizations (e.g., human rights, ecology, labour unions)	participating in the activities of a political party	participating in the activities of social groups (e.g., Lions Club, Golden Age)

LIFE HABIT 10 EDUCATION

Involves habits related to the young person's psychomotor, intellectual, social and cultural development.

It includes the following activities:

participating in academic learning activities or occupational training	participating in team work	using school services and infrastructure	doing school assignments at home	participating in activities organized by the school

LIFE HABIT 11 EMPLOYMENT

Involves habits related to career guidance for the young person, job searching and occupations, whether paid or not.

In the case of children, it includes the following activities:

carrying out small tasks, either paid or unpaid, excluding those performed at home	looking for a small job

The activities for adolescents and young adults additionally include:

choosing a trade or occupation and looking for a job	carrying out work-related activities or undertaking a traineeship	having a main occupation (going to a day centre, engaging in volunteer work or performing domestic chores as their main occupation)	using the services available at the location of their main occupation (cafeteria, rest area, personnel services, etc.).

LIFE HABIT 12 RECREATION

Involves habits related to the young person's participation in sports and games, arts and culture and socio-recreational activities.

It includes the following activities:

choosing one's activities	engaging in sports and physical activities	playing indoor games (individual or group)	engaging in artistic, cultural or craft activities
attending sports, arts or cultural events	participating in tourist activities	participating in outdoor activities	using community recreational services

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