

Autonomy in intellectually disabled young people aged 6 to 21 years

English summary

Une production de l'Institut national
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Direction des services sociaux

SUMMARY

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Introduction

Over the years, a number of key documents have been published in Québec to guide the provision of services to people with intellectual disability.

The recently published, *Cadre de référence pour l'organisation des services en déficience physique, déficience intellectuelle et trouble du spectre de l'autisme* and other work in progress at the Ministère de la Santé et des Services sociaux aimed at determining the range of services to be offered. They promote the notion of integrated care and define a service organization model that is as close as possible to the persons concerned and to their living environments. The needs of the disabled people are the cornerstone of these goals, which are driving a transformation within the health and social services system (HSSS). It is in this context of evolving practices that this guideline is being published.

Given the scarcity of publications to guide interventions with intellectually disabled children and adolescents, 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 and supporting their parents in this regard.

Scope of this guideline

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

The clinical practice guideline is also in line with the government's policy *À part entière: pour un véritable exercice du droit à l'égalité*, which invites all public and private stakeholders to support social participation of people with disabilities.

The guideline is based on the following values:

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

It 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 clinician's positions;
- must be considered 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.

It was agreed with the stakeholders consulted that the guideline would cover the following:

- intellectually disabled people aged 6 to 21 years and their families;
- the implementation phase of the intervention, which follows the evaluation and planning phases in the clinical process;
- 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 guideline is intended primarily for specialized educators, psychoeducators, clinical supervisors and managers in the HSSS who work with intellectually disabled young people and their families. It may also be useful to different professionals in the HSSS, clinicians in the community and the education sector, and parents.

Methodology

The recommendations made in this guideline are based on a combination of scientific, experiential and contextual data collected through:

- a systematic review of the scientific literature on the efficacy of interventions;
- a narrative review of the literature on interventions' applicability and acceptability and, in particular, on the expectations and needs of young people, their parents and clinicians regarding interventions to improve the autonomy of young people with intellectual disability;
- focus groups and interviews with intellectually disabled young people and parents;
- a survey of Québec clinicians to better understand the intervention context;
- consultations with various clinical experts in Québec.

The recommendations were validated and enhanced through an iterative and deliberative process in collaboration with the members of the Advisory Committee. The members of the Monitoring Committee also helped guide the work and develop the recommendations. For their part, the members of the Clinical Excellence Committee provided a perspective on the project process and data synthesis.

Results

The overarching principles that clinicians need to take into consideration were identified. They are as follows:

- focus the intervention on the young person in order to promote his self-determination and ability to act;
- maintain partnership between the young person, their 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 the features of the person with intellectual disability into consideration;
- foster intersectoral collaboration.

In addition, this 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.

In this clinical practice guideline, the data are presented according to the 12 life habits as defined in the HDM-DCP. The reader can consult the various sections to understand the importance of autonomy for each life habit, the preferences and needs expressed by young people, their parents and clinicians, followed by the efficacy of the interventions evaluated. Lastly, the recommendations are presented, along with practical information and bibliographic references.

The recommendations are formulated in a way that encourages self-determination, and social participation of the youth, and parental involvement. They concern either "the young person...", "the young person and his parents", "the young person and his family..." or "the parents...". They are followed by recommended interventions for supporting the young person and his family. Their objective may be to inform, support, enable or direct and refer.

Since the guideline focuses on the third phase of the clinical process, the implementation of interventions, which follows the evaluation and planning phases, the choice of interventions must necessarily be based on an assessment conducted in accordance with the fields of practice and the activities reserved for professionals and respect the priorities expressed by the young person and his parents.

Most of the interventions recommended for improving young people's autonomy involve techniques such as those used in applied behaviour analysis (ABA). They are particularly suitable for learning new behaviours (e.g., communication and social behaviours) or for reducing undesirable behaviours, if necessary. With the clinician's support, parents who wish to do so can use these interventions to help their child. The use of technologies is

also effective in improving young people's autonomy in all the life habits, and parents greatly appreciate them.

Beside behavioural intervention techniques namely those used in ABA, other interventions may be considered, such as the use of pictorial supports, gestures or objects, or task, environmental or time organization.

It should also be noted that other objectives, types of intervention or theoretical trends may be taken into consideration before or in conjunction with these interventions.

The strength of the recommendations is expressed by the choice of the verb. Thus, "should" reflects a greater strength than "could". The recommendations can thus be taken into account in clinical reasoning. When the verb "must" is used, it indicates a legal obligation.

Conclusion

INESSS hopes that this guideline will promote a common vision of the issues related to the development of autonomy and that it becomes a reference for clinicians and managers working with intellectually disabled young people and their parents. The use of the HDM-DCP as a conceptual model is intended to facilitate the implementation of the recommendations, since it is part of an existing practice. By proposing the skills to be developed, the guideline also supports a long-term intervention perspective focused on the challenges that mark the young person's journey from childhood to adulthood.



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