

**SUICIDE AMONG INDIVIDUALS WITH AN INTELLECTUAL
DISABILITY OR AUTISM SPECTRUM DISORDER:
RECOGNITION, INTERVENTION AND PREVENTION**
CHALLENGES AND ISSUES FACING SPECIALIZED REHABILITATION SERVICES

RESEARCH REPORT

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Centre de recherche et d'expertise sur la déficience
intellectuelle et le trouble du spectre de l'autisme

Québec 

Suicide Among Individuals with an Intellectual Disability or Autism Spectrum Disorder: Recognition, Intervention and Prevention Challenges and Issues Facing Specialized Rehabilitation Services was prepared by the Centre de recherche et d'expertise sur la déficience intellectuelle et le trouble du spectre de l'autisme of the Direction de l'enseignement universitaire et de la recherche of the CIUSSS du Centre-Sud-de-l'Île-de-Montréal.

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Highlights

This study aims to achieve a better understanding and documentation of suicidal manifestations (SM) among the users of specialized ID-ASD services of the CIUSSS du Centre-Sud-de-l'Île-de-Montréal and thereby support identification, estimation and intervention practices.

- Carried out in 2013, the SM identification activity pinpointed 120 users, representing 2.8% of the organization's users as a whole, a proportion that is comparable to or greater than that observed in the general population.
- The SMs were mainly recognized by means of user statements (77%) and recurred in the majority of these users, in particular among those with an ASD. User file analysis led to the identification of 289 different SMs. There were no deaths among these users, but there were 30 suicide attempts (12% of those with SMs).
- A direct and explicit expression of the will to die was the most commonly identified SM.
- The highlighted dynamics show that user distress is associated with a general unhappiness, a weakening of relational networks, an application of measures perceived by users as being too restrictive or, finally, a dissatisfaction arising from the gap between actual and expected experience.
- Recognizing the suicide problem among individuals with an ID or an ASD who receive specialized rehabilitation services is a challenge with regards to the practice. One of the main issues is the doubt and persistent hesitation of workers and managers to assign a suicidal tendency to manifestations of distress. Several aspects of these manifestations, including their recurrence, the will to die, the inability to understand death, limited communication and planning skills, and the low lethality of the means used encourage reluctance to consider signs of distress as suicidal.
- Despite such uncertainty, workers still fear for the physical integrity of users in the presence of certain vulnerability factors, in particular impulsiveness, provocative behaviours, self-mutilation, as well as aggressive behaviours, mental health disorders and the degree to which they live independently. In general, interventions are developed from a risk management perspective.
- To enhance the effectiveness of preventive measures, we recommend the following:
 - the establishment of a clear and systematic organizational guideline for identifying SMs and intervening among individuals with an ID or an ASD;
 - the development of information tools on the suicide-related problem among individuals with an ID or an ASD;
 - the implementation of awareness campaigns directed at specialized workers and partners such as families and managers of housing resources (substitute living environments).

Table of Contents

Acknowledgments	3
Highlights	4
List of Figures	6
List of Tables	6
List of Abbreviations	7
Introduction	8
Background	10
Aspects of the organizational context.....	10
Some facts about suicidal manifestations in Quebec	11
Significance of suicidal manifestations among individuals with an ID or an ASD	11
Methodology	13
Objectives of the study	13
Target population.....	13
Recruitment procedure.....	13
Collection and analysis of the user file data	14
Perceptions of workers and managers	14
Portrait of suicidal manifestations occurring during the provision of specialized ID-ASD services ..	16
Scope of the suicide phenomenon within the organization	16
Characteristics of users	17
Characteristics of the identified suicidal manifestations	19
Recognition of the suicide-related problem.	26
Reluctance to assign a suicidal meaning to manifestations.....	26
Concern for the users’ physical integrity	29
Intervention practices in the management of suicidal risk	31
Intervention characteristics	31
Perceptions of intervention practices.....	32
Recognize, intervene and prevent suicidal manifestations	36
Challenges related to perceptions of suicidality	36
Challenges related to the practice framework	37
Challenges pertaining to training and access to expertise.....	39
Conclusion	40
References	41

List of Figures

Figure 1. Distribution of users with suicidal manifestations according to their level of ID	17
Figure 2. Distribution of users with suicidal manifestations according to their principal diagnosis and living environment.....	19
Figure 3. Proportion of identified suicidal manifestations by type.....	20
Figure 4. Proportion of users with recurrent suicidal manifestations according to the principal diagnosis.....	22
Figure 5. Proportion of suicidal manifestations by type according to the source of information	32

LIST OF TABLES

Table 1. Scope of the suicide phenomenon within the organization.....	16
Table 2. Comparison of user distribution according to principal diagnosis and age between the entire client population and the group with suicidal manifestations.....	18

List of Abbreviations

ID	Intellectual disability
ASD	Autism spectrum disorder
CRE – DI-TSA	Centre de recherche et d’expertise sur la déficience intellectuelle et le trouble du spectre de l’autisme
CIUSSS – CCSMTL	Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l’île-de-Montréal
CRISE	Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practices
SM	Suicidal manifestation
RAC	Resources with continuous assistance
IR	Intermediate resource
SAM	Suicide Action Montréal
UQAM	Université du Québec à Montréal
BPD	Borderline personality disorder

Introduction

Little attention was paid to the everyday realities of individuals with an intellectual disability (ID) or autism spectrum disorder (ASD) before the great waves of deinstitutionalization. It seems clear, however, that these individuals, long left by the wayside, have much in common with the population as a whole, including the need for freedom and autonomy, to be connected to the world, and to live in their own homes. Suicide among these individuals seems like a new phenomenon as we “discover” that they too experience difficult life events, including times of distress that can be expressed as suicidal manifestations (SMs).

Thus far, and in a context where such manifestations seemed infrequent – or not often recognized – workers¹ specializing in rehabilitation indicate that they have called on their clinical experience to handle these situations. Clinical follow-up on suicide problems requires the ability to detect risk situations, adequately assess the degree of suicide risk, and establish intervention and follow-up procedures relevant to the prevention and reduction of suicide risks among these individuals. Workers are increasingly stating that they deal with reports and expressions of SMs in contexts with no practical guides or tools specifically adapted for individuals with an ID or an ASD renders the related evaluation and intervention process more complex. Indeed, while publications on preventing suicide in various populations² have become increasingly numerous in the broader health and social services network since the early 2000s, none of them specifically address populations with an ID or an ASD. The most complete Ministry guide, *Prévention du suicide : guide de bonnes pratiques à l'intention des intervenants des centres de santé et de services sociaux* (Ministère de la Santé et des Services sociaux, 2010), includes a chapter on interventions adapted to special needs groups, but does not consider individuals with an ID or an ASD. This is a significant omission in the literature and suicide prevention guides and it creates a challenge for interventions among this part of the population.

The goal of the ID and ASD programs of the Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal (CIUSSS – CCSMTL) is to provide interventions that meet the highest quality standards. Suicide prevention and suicide risk management are included in this objective. Several projects have been launched in these areas to fulfil clinical practice mandates of service specialization and continuous improvement, including the completion by the team of the Centre de recherche et d'expertise sur la DI et le TSA (CRE – DI-TSA) of the CIUSSS – CCSMTL of a research project³ whose goal is to understand and document

¹ In the French version of this report, the term *intervenante* (worker) is used to designate all health and social services network professionals (special educators, nurses, speech therapists, psychoeducators, psychologists, clinical activity specialists, social workers, etc.) who work with users. Since a majority of people working in these employment categories are women, the feminine forms of the job titles are used in the French text to reflect this reality are inclusive.

² Particularly, but not exclusively, children, adolescents, men, LGBT individuals, the elderly, people with addictions or mental health issues, and Indigenous peoples. The guides in question are listed in the references.

³ Morin, D., Ouimet, A.-M., Mongeau, C., & Fortin, D. (2013). *Les manifestations suicidaires chez des personnes ayant une DI ou un TED : exploration du phénomène dans un contexte d'offre de services spécialisés. (Suicidal manifestations among individuals with an ID or an ASD: an exploration of the*

suicides among the organization's users (2013-2015). This report presents the main findings of this research project. It has four parts. The first presents a portrait of the SMs identified by the ID-ASD services organization (scope of the phenomenon, portrait of the affected users, and characteristics and expressions of identified manifestations); the second groups the study results on problems in recognizing a suicide phenomenon in these populations; the third summarizes the study results of the analysis of intervention practices used to manage suicide risk within the organization; and the fourth discusses issues and challenges in light of the study results and makes recommendations for practice. The results of this work will help support the development of evidence-based suicide intervention and risk management practices.

phenomenon in the specialized services context) Research design. Centre de réadaptation en déficience intellectuelle et en troubles envahissants du développement (CRDITED), Montreal. Research ethics compliance certification – CÉRC research project- 0172.

Background

Aspects of the organizational context

Certain situations have been commonly associated with SMs by specialized ID and ASD social rehabilitation services, but little attention has been paid thus far to suicide in the field of ID and ASD. However, some of these situations have led to investigations (by complaints commissioners or coroners, for example) and consequently recommendations that suicide risk management procedures be established for these intervention settings.

It was against this backdrop that the Montreal CRDITED undertook significant work in 2010 that has continued since the 2015 merger that created the CIUSSS – CCSMTL engaging the clinical and research communities, with the formation of an interdisciplinary work team dedicated to the suicide-related problems among individuals with an ID or an ASD. The initial findings revealed, on the one hand, a wide variety of practices from one program and site to another within the organization and, on the other, a lack of screening tools specifically tailored for individuals with an ID or an ASD.

Given the complexity of the problem that emerged, the work has continued on two fronts. On the clinical level, the need for intervention despite the known limitations led to the use of the *Grille d'estimation de la dangerosité d'un passage à l'acte suicidaire* (suicide risk estimation tool) developed by Suicide Action Montréal (SAM) and the Centre Dollard-Cormier – Institut universitaire sur les dépendances (Lavoie, Lecavalier, Angers & Houle, 2012), even though it does not appear suitable for this clientele (Ouimet, Morin & Mongeau, 2014). It has also been agreed to continue the work of developing and implementing a management process that encompasses suicide risk identification, estimation and prevention and subsequently support this process by establishing a community of practice. This community brings together professionals leading the CIUSSS – CCSMTL DI-TSA clinical programs responsible for estimating suicide risk in support of their clinical teams.

A number of efforts have also been initiated on the research level. Since there have been few scientific studies of the suicide problem among individuals with an ID or an ASD and no assessments of populations and specialized services in Quebec, a variety of initiatives have been launched in order to develop knowledge and practices. A summer 2013 consultation of ID, ASD and suicide experts organized in close collaboration with members of the Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practices (CRISE – UQÀM) confirmed the importance of the problem, in particular among individuals with an ASD or mild ID as well as the absence of particularly discriminant risk and protection factors for ID-ASD populations. Indeed, it appears they have several risks or protection factors in common with the general population, but for some their impact is greater for individuals with an ID or an ASD (Bardon, Morin, Ouimet & Mongeau, 2014). Identification, estimation and intervention practices have also been broached.

In addition, the practical use of the *Grille de dépistage de la dangerosité d'un passage à l'acte suicidaire* on individuals with an ID or an ASD was studied in a working session piloted and organized by CRE – DI-TSA and CRISE members that brought together specialized ID-ASD workers

who had tested its use as well as a SAM representative and certified trainer. The result analysis of this consultation concluded that the estimation tool seems impractical in its current form with users of specialized ID and ASD services (Ouimet, Morin & Mongeau, 2014) and suggests ways to adapt it for ID and ASD populations.

The outcome of this work has been the development of two research projects. One is a research partnership initiative by the CRE – DI-TSA team has been implemented with universities to develop and evaluate adapted tools or practices that put to use the scientific knowledge and experience of health and social services network researchers, workers and managers. A large-scale research project is underway.⁴ The other is an exploratory study by the CRE – DI-TSA team whose goal is to better understand suicide in the context of specialized ID-ASD services. This report summarizes the results of the analysis conducted as part of this last project.

Some facts about suicidal manifestations in Quebec

The troubling number of suicide deaths among the Quebec population at the turn of the millennium, with 22.2 per 100,000 inhabitants in 1999 (Institut national de santé publique du Québec, 2016), led to the identification of suicide as a serious public health problem in the *Plan d'action en santé mentale du Québec* (Quebec Mental Health Action Plan, 2005-2010). The suicide death rate has since decreased in Quebec, reaching 13.3 per 100,000 inhabitants in 2013 and involving three times more men than women and, in greater proportions, older individuals in and around their fifties (Institut national de santé publique du Québec, 2016).

In addition to its deadly consequences, the suicide problem reveals itself in various ways and raises a number of issues. According to the Enquête québécoise sur la santé de la population (Population Health Survey) conducted in 2008 (Ministère de la Santé et des Services sociaux, 2012), 2.3% of the Quebec population had seriously contemplated suicide in the year under consideration, and 0.5% had attempted it. Both men and women appear to have suicidal thoughts, but women attempt suicide three times more often than men and are also hospitalized more often after injuring themselves intentionally (55% for women compared to 45% for men). Moreover, these statistics refer to only one aspect of the problem as a whole. If we consider the families, friends, support and other health and social services involved in providing the support, follow-up and care, the suicide-related problems affect a large number of individuals and in this respect it is considered a significant social problem in Quebec.

Significance of suicidal manifestations among individuals with an ID or an ASD

Few studies to date have considered the extent of the suicide problem among individuals with an ID or an ASD. Study methodologies vary considerably, in particular with regard to the population

⁴ Mishara, B. Morin, Di., Weiss, J., Bardon, C., Morin, Da, & Mélineau-Côté, J. *Comprendre et estimer le risque suicidaire chez les personnes présentant une déficience intellectuelle ou un trouble du spectre de l'autisme*. (CIHR, 2014-2016). Research ethics compliance certification – CÉRC research project – MP-CRDITD-14-01.

types under study, which range from community service users to individuals placed in psychiatric hospitals because of suicide attempts (Bardon, Morin, Ouimet & Mongeau, 2014; Bardon et al., 2015).⁵ A single population study, carried out in Finland, reports a suicide death rate among individuals with an ID of 16.2 per 100,000 inhabitants (Patja, Iivanainen, Raitasuo & Lonnqvist, 2001). This rate is lower than the one observed in the general population in Finland for men with an ID, but equal in the case of women. A review of the literature shows that while the prevalence of suicide deaths among individuals with an ID is lower than it is in the general population, the prevalence of SMs (ideation and behaviours) appears similar and the presence of risk factors is greater (Dodd, Doherty & Guerin, 2016). The situation is more alarming for individuals with an ASD. A recent Swedish population-based study of the causes of death among individuals with an ASD found they were 7.55 times more likely to die by suicide than members of the general population (Hirvikoski et al., 2016). A review of recent literature indicates that out of all the consulted studies, 21.3% of individuals with an ASD report suicidal ideas (Huguet, Contejean & Doyen, 2015). It clearly appears that the reported rates concerning individuals with an ASD are significantly higher than those observed in the general population, and in this respect, they highlight the importance of better understanding the suicide problem among these individuals.

⁵ See Bardon, Morin, Ouimet & Mongeau, (2014; 2015) for a full review.

Methodology

Objectives of the study

The main objective of this study is to document and better understand SMs among specialized ID-ASD service users in order to inform efforts to develop clinical suicide prevention tools and procedures tailored to these populations.

The specific objectives are to:

- I. Document SMs (type, range, psychosocial profiles, circumstances);
- II. Define the main SMs management methods
- III. Reveal the dynamics at play between SMs and the intervention practices of specialized ID-ASD services.

Given the current state of knowledge, an exploratory and descriptive approach with a mixed quantitative and qualitative methodology was chosen. Achievement of the project objectives is based on the completion of two phases of data collection and analysis. The first phase is a quantitative and qualitative analysis of data from the files of service users with SMs in 2013. The second aims to achieve a better understanding of how the organization's workers and managers perceive the suicide phenomenon by means of a qualitative analysis. The entire process was authorized by the Directorate of Professional Services and approved by the research ethics committee (CÉRC certificate 0172).

Target population

The study was conducted in 2014 at the Montreal CRDITED.⁶ This establishment provided specialized ID-ASD adjustment and rehabilitation services to about 4,300 users of all ages. The study targeted two participant groups: (1) users of the organization who had had at least one SM between January and December 2013, and (2) clinical team workers and managers of the organization who had intervened with a user during the same period.

Recruitment procedure

The recruitment process was based on the collaboration of all the establishment's clinical team workers and managers. They all retrospectively identified situations in 2013 in which they encountered SMs among service users. They had to identify any form of SM, whether expressed by a change in condition (mood, emotionalism, aggression, etc.), presumed or verbalized thoughts or behaviour associated with the will to deliberately end one's life. Due to a lack of in-depth knowledge of the suicide phenomenon within this population, the definition was intended to be open and flexible in order to capture a wide variety of expressions. This process led to a review of

⁶ The name of the organization providing specialized ID/ASD social rehabilitation services before the 2015 merger of health and social services network institutions. It is now designated under the name of Programmes en déficience intellectuelle, trouble du spectre de l'autisme et déficience physique (Intellectual Disability, Autism Spectrum Disorder and Physical Disability Programs) of the Centre intégré universitaire de santé et de services sociaux du Centre-Sud-de-l'Île-de-Montréal (CSMTL).

137 user files, 8 of which were excluded because they were closed and the information was no longer accessible, and 9 others because there was no trace of SMs in the files for the year in question.⁷ A total of 130 user files were therefore analyzed. In addition, the workers and managers who participated in the semi-guided discussions (the second project phase) were recruited from among those who helped identify the SMs in the first phase.

Collection and analysis of the user file data

The data was collected by directly consulting files in the user database (*SIPAD*) on the identified users in the initial SMs identification procedure via a coding grid from which the names had been removed. This grid allowed to collect information that was relevant to the individuals' psychosocial characteristics (age, gender, principal and secondary diagnoses, and living environment), the characteristics of the SMs (type, date, location, witnesses, means evoked or used, and associated circumstantial events), as well as the characteristics of the interventions and follow-ups specifically in relation to the problem (individuals involved, intervention type and time, assessment tools used, and internal or external resources consulted). The collected information was converted using an appropriate digital coding system for its statistical processing by SPSS software. Open fields were also used to collect descriptions of the identified SMs and the contexts in which they occurred. This material was subjected to qualitative analysis.

To meet the primary project objective, namely to document SMs and the related profiles, descriptive analyses of the proportion of all of the organization's users who had expressed SMs, based on the principal diagnosis, gender, age and living environment were done. These proportions were compared to those of the organization in accordance with variables of the principal diagnosis (ID, ASD, and ASD with ID), age and gender using a Z-score calculation of the proportional difference. The presence of particular psychosocial profiles was explored by means of chi-square tests between the principal diagnosis variables, secondary diagnosis, gender, age and living environment compared to the related SMs types, the presence of interventions and the presence of follow-ups. This series of analyses contributes to the study of the SMs management methods that are the second study objective.

Also, the 283 excerpts taken from each of the SMs descriptions noted by workers on case changes is a literal transcription of the information linked to their identification and context. Working inductively, the excerpts generated using NVivo content analysis software were analysed and used to interpret these situations within the organization's practice.

Perceptions of workers and managers

This component of the study considers the perceptions of the clinical team workers and managers engaged by the suicide phenomenon and their intervention practice. It follows an inductive analytical approach. The study is interested in the actors involved (users, friends and family,

⁷ Seven files in which the SMs had occurred prior to the target period and two others in which the SMs did not meet the selection criteria.

workers, partners, etc.) and in the processes deployed when SMs are reported, in particular the interventions that are made. Two main data sources were used for this part: (1) semi-directed interviews with the organization's workers and managers, and (2) the observation of meetings between workers to discuss suicide risk management practices within the organization.

Methodology

Semi-directed interviews with workers and managers. The interviews were intended to collect the viewpoints expressed by workers and managers in discussing their experience. The discussion topics covered their perceptions of the following: scope of the suicide phenomenon, profiles of the involved users, types of SMs, triggers, preferred interventions, screening tools and procedures used, suicide risk estimation or evaluations and follow-up, clinical support, collaboration and partnership. Using an inductive method, the principles of diversification and saturation inherent in the qualitative method guided the content analysis (Pires, 1997). The number of interviews was also determined based on these two principles. A thematic analysis of the discussions was conducted using NVivo software. A total of nine interviews lasting an average of one hour each were held.

Observation of the worker discussion meetings. Observations made during the worker discussion meetings about intervention practices during SMs constituted a second data source. On the clinical level, the purpose of these meetings was to develop and consolidate expertise on interventions in this particular context. They brought together professionals in the organization who had received training in estimating suicide risk. The meetings were held at a rate of approximately six per year. An observation log was used to record the participants' perceptions during the meetings. Content analysis was done using the observations in this log. The inductive approach was again chosen as the analytical strategy.

Portrait of suicidal manifestations occurring during the provision of specialized ID-ASD services

Lacking any systematic approach to documenting SMs that occurs in the provision of these services, there are no known data to confirm the scope of the suicide problem among the population using specialized ID-ASD social rehabilitation services. Yet the need to better understand the phenomenon and offer better interventions has been expressed by several workers and managers in this network (Bardon et al., 2014). One of the objectives of the CRE – DI-TSA research project is to document the presence, importance and forms of SMs among the population the organization serves and refers to the following questions:

- Is the proportion of users with SMs comparable to that in the general population or not?
- Is the expression of SMs observed in all of the clientele or in certain user sub-groups?

Scope of the suicide phenomenon within the organization

As shown in Table 1, SMs were identified in a total of 120 users, representing 2.7% of those with an ID, 3.9% of those with an ASD, and 1.7% of those with a combined diagnosis. Thus the overall proportion of users identified as having had SMs of any type is therefore 2.8%. Thirty manifestations also meet the criteria to be considered as suicide attempts (committing an act associated with the will to die), corresponding to a proportion of 0.7% of users. To summarize, the proportions of 2.8% with SMs and 0.7% with suicide attempts among those with an ID are slightly higher than the rates of 2.3% with suicidal thoughts and 0.5% with suicide attempts observed in the *Québec Population Health Survey* conducted in 2008. Note, however, that the Survey figures were obtained by directly questioning respondents, while those for the SMs in our services were identified by workers by means of a retrospective process. This methodological difference is significant because it lets us assume that the rates derived from the organizational process are undoubtedly conservative insofar as, on the one hand, the presence of a significant number of suicidal thoughts that were not externalized could not be identified by the workers and, on the other, some manifestations could not be reported because of professional confidentiality.

Table 1. Scope of the suicide phenomenon within the organization

Diagnosis	CRDITED	Suicidal	% suicidal
ID	3,112	85	2.7%
ASD	673	26	3.9 %
ID-ASD	533	9	1.7 %
Total	4318	120	2.8 %

Finding: The extent of the suicide problem is comparable to or greater than that observed in the general population.

Characteristics of users

The distribution of users with SMS⁸ was analyzed based on their principal diagnosis, age and gender, as well as the presence of particular secondary diagnoses. This approach aimed to discover whether some user sub-groups are more represented than others among those with SMS. If we compare the distribution of the latter with that of the organization’s other users based on the principal diagnosis of ID, ASD, or ASD with ID, we find that the proportion of users with an ID among the identified individuals is comparable to that of the individuals with an ID in the organization as a whole (71% identified vs. 72% total, Z=0.29, p=0.76). The findings are the same for the individuals with an ASD (22% identified vs. 16% total, Z=1.80 p=0.07) and an ASD with ID (8% identified vs. 12% total, Z=1.60 p=0.11). So, despite a slightly higher prevalence of SMS among individuals with an ASD (3.9%) and a tendency for this sub-group to have a greater representation among the identified individuals, we cannot claim that the presence of an ASD or an ID can be used to guide the identification of individuals who are at risk of SMS. In the same line of thought, the ID level of users with SMS is variable (see Figure 1). While users with an ID qualified as mild are included in a greater number, a significant proportion of individuals identified with SMS have a moderate ID (17% of the sub-group), or of an undetermined level (17% of the sub-group). A very low proportion of users with a severe ID was also identified. However, and since it was the workers who performed the identification in this project, it is impossible to determine of this finding results from a low prevalence of the problem among these individuals or instead from difficulties in identifying them.

Secondary diagnoses were identified in 85% of users with SMS. Among the identified users, 45% had physical disorders (occasional or permanent metabolic problems), 41% had mental health issues (including 8% with borderline personality disorder, or BPD), 32% had learning or language disabilities (attention deficit disorder, information processing, elocution, etc.), 27% had neurological disorders (epilepsy, Tourette’s syndrome, etc.), 23% had behavioural disorders

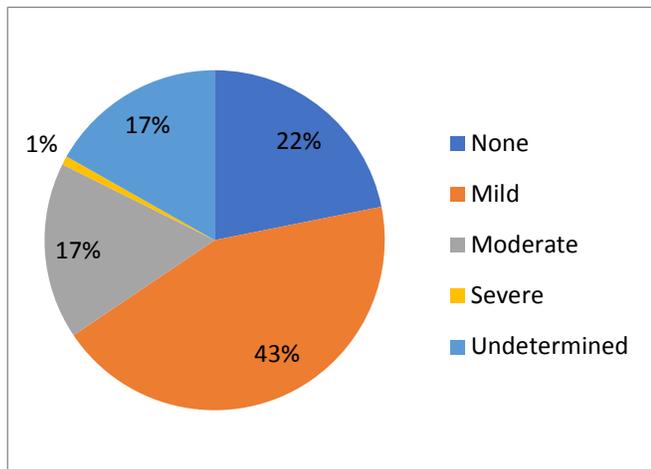


Figure 1. Distribution of users with suicidal manifestations according to their level of ID

⁸ In this study, all the presumed SMS were identified by the workers following the instructions presented in the methodology. To make the text easier to read, we have used the expressions “users with SMS,” “suicidal users” and “identified users” to designate users identified as such.

(hyperactivity, oppositional defiant disorder, disturbance of conduct), 18% had motor disorders (musculoskeletal) and 12.5% had sensory disturbances (vision or auditory impairments, etc.). To date, no portrait of the prevalence of secondary diagnoses of all users that would enable us to analyze if this proportion is higher among suicidal users than among others. The significant presence and wide range of secondary diagnoses among users with SMs nevertheless accounts for the heterogeneous nature of this population and the presence of multiple adaptation challenges that can serve as risk factors. More in-depth studies of this matter appear necessary to better understand the impact of secondary diagnoses on the development of suicidal problems among individuals with an ID or an ASD.

Analyses have also been done to determine if the distribution of users with SMs by age is comparable to that of the organization’s users as a whole. Table 2 shows that there are individuals with SMs in all age groups, except for very young children. Overall, suicidal individuals are found in greater proportions among the adolescent ($Z=1.99$, $p=0.05$) and young adult groups ($Z=3.83$, $p=0.00$) and in lesser proportions among those aged 45 to 64 ($Z=-2.62$, $p=0.01$) and those over 65 ($Z=-1.98$, $p=0.05$). The greater prevalence among adolescents is particularly marked among those with an ASD (with or without an ID), while among young adults it is more often associated with the presence of an ID (with or without an ASD).

Table 2. Comparison of user distribution according to principal diagnosis and age between the entire client population and the group with suicidal manifestations

Age	Main diagnosis						Total	
	ID		ASD with ID		ASD			
	Total (n=3,112)	Suicidal (n=85)	Total (n=533)	Suicidal (n=9)	Total (n=673)	Suicidal (n=26)	Total (n=4318)	Suicidal (n=120)
0-4 years	2.7%	0.0 %	1.3 %	0.0 %	6.2%	0.0 %	3.1 %	0.0 %
5-17 years	11.0 %	14.1 %	33.4 %	44.4 %	70.6%	80.8 %	23.0 %	30.8%*
18-21 years	5.1 %	15.3 %	10.3 %	33.3 %	8.3%	7.7 %	6.3 %	15.0%**
22-44 years	34.4 %	41.2 %	32.3 %	11.1 %	12.9%	11.5 %	30.8 %	32.5 %
45-64 years	40.5 %	28.2 %	21.4 %	11.1 %	1.9%	0.0 %	32.1 %	20.8%**
65 years +	6.3 %	1.2 %	1.3 %	0.0 %	0.0%	0.0 %	4.7 %	0.8 %*
	100 %	100 %	100 %	100 %	100 %	100 %	100 %	100 %

*p < 0.05; **p < 0.01

Finally, there are slightly more men (57.5%) than women (42.5%) among the users with SMs; this distribution is proportional to that of the organization’s users as a whole (55.3% men and 44.7% women, $Z=1.07$ $p=0.28$). Men represent 84.4% of the users with an ASD and, proportionally 85.6% of the users with an ASD and SMs are men. In the presence of IDs, the

male-female distribution is equivalent and this representation is maintained in the group of suicidal individuals with an ID. The fact of being male or female can therefore not be used as an indicator of SMs.

Finding: The suicide-related problems is found in all groups served by the organization and the characteristics that have been studied do not reveal any distinctive profiles except in the case of adolescents and young adults, among whom the problem is significantly more common.

The distribution of users with SMs according to their principal diagnosis and living environment shows that users with an ID are found more often in alternative living facilities, while users with an ASD typically live in a family environment (see Figure 2). To date no portrait of the living environments of users overall has been made that could enable us to determine if living in certain environments is more often associated or not with the identification of SMs. However, since 52% of suicidal users live in alternative living environments and 34% in family environments, it appears essential that this fact be taken into account when developing adapted practices relating to the suicide problem.

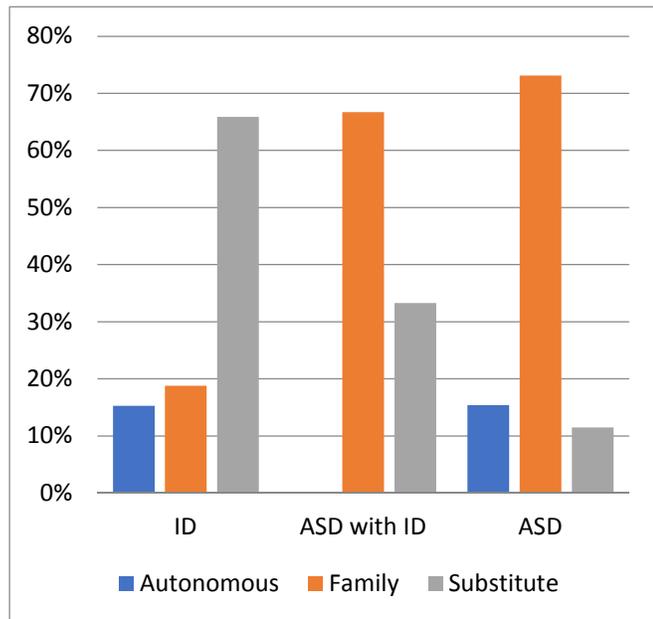


Figure 2. Distribution of users with suicidal manifestations according to their principal diagnosis and living environment

Finding: The majority of users with suicidal manifestations live in family or alternative living environments

Characteristics of the identified suicidal manifestations

Analysis of the progress notes in 120 user files led to the identification of 289 SMs. These notes were analyzed in two distinct processes: an initial quantitative analysis based on the application of SMs categorization operational criteria associated with the application of the coding grid, and

a second, based on a qualitative analysis of the emerging thematics derived from file excerpts and bearing on the expression of SMs and the contexts in which they occurred.

Types of suicidal manifestations

The identified manifestations included verbalizations (77%), behaviours associated with suicide (17%), and changes in condition associated with the will to end one's life (6%). There were no significant differences in the distribution of verbalizations and behaviours between the ID, ASD, and ASD with ID diagnosis groups. The presence of learning disabilities was, however, more often associated with the expression of SMs in the form of behaviours. The analyses also show that the proportion of individuals with a principal diagnosis of ID with ASD is greater in the presence of a change in condition than for the two other forms of SMs ($\chi^2(2)=13.89$ $p=0.001$). The presence of a change in condition is also associated with a greater proportion of behavioural disorders ($\chi^2(2)=10.36$, $p=0.006$) and mental health issues ($\chi^2(2)=5.72$, $p=0.057$).

The SMs types were categorized to account for suicide risk: (a) presumed ideation (intention detected by the worker without verbal or behavioural confirmation); (b) verbalized ideation (general reference to the will to die); (c) suicidal threat (introduction of an element tied to the means, location or time); (d) planning (presence of the three elements: means, location and time); as well as the act itself. No suicide deaths were reported in 2013. Figure 3 shows the proportion of each type of SM. We can see that 12% of the identified manifestations involve suicide attempts. These attempts were in the generally known forms of suicide attempts that can cause death (such as taking an overdose of a medication or slitting one's wrists) or heterogeneous forms that are not particularly lethal (such as strangling oneself with one's own hands). The distribution of SMs types does not vary in accordance with the users' principal diagnosis, age or living environment. The analyses show, however, that presumed ideation was identified more often among women (11%) than men (2%) ($\chi^2(4)=9.93$, $p=0.04$).

Moreover, more than 54% of the users had recurrent SMs during the same year. The recurrences were observed: (1) when a suicidal episode was clearly over (statement, for example, that the user was feeling better) and another was then observed; or (2) during a change in form of the SM (such as from a verbalization to an action); or (3) in a sequence toward a suicide attempt; or (4) in the location of its expression (verbalization at home, then verbalization at school).

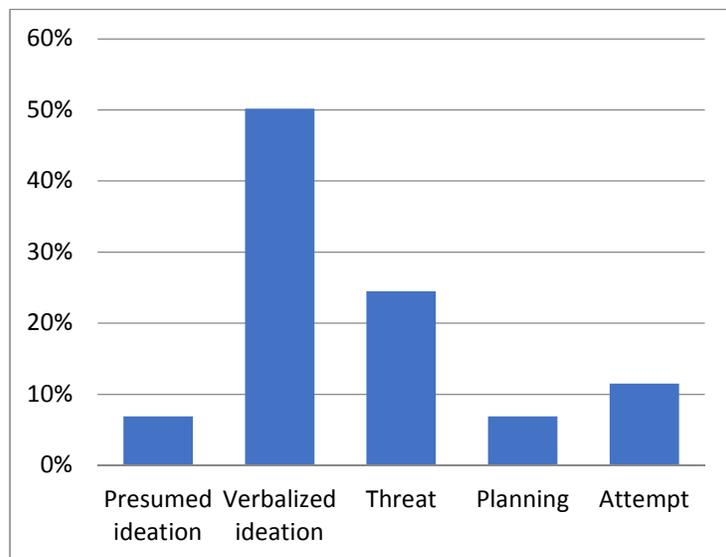


Figure 3. Proportion of identified suicidal manifestations by type

As Figure 4 shows, the patterns of recurrence are more significant for individuals with an ASD (89% of those with a combined ASD/ID diagnosis and 64% of those with an ASD) than for individuals with an ID. The recurrence of SMs is not, however, associated with the users' level of ID, gender, age or place of residence. The patterns of recurrence are not significantly associated with the presence or absence of particular secondary diagnoses, except for individuals with behavioural disorders, among whom the recurrence of SMs is significantly higher (78%, $\chi^2(1)=7.82$, $p=0.005$).

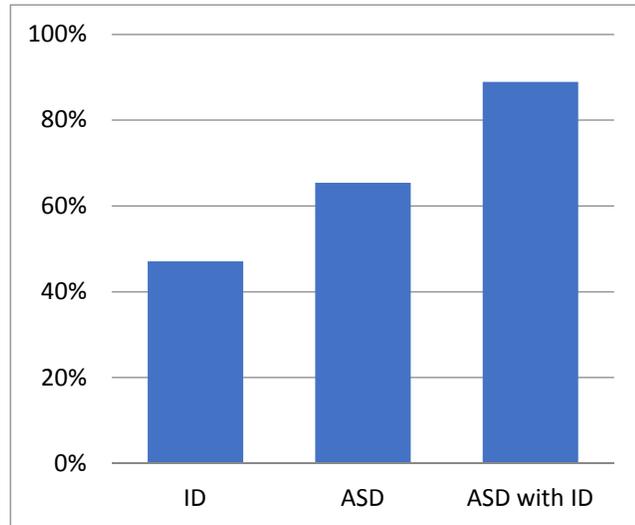


Figure 4. Proportion of users with recurrent suicidal manifestations according to the principal diagnosis

Finding: The suicidal manifestations were mainly recognized by means of user verbalizations and were recurrent in the majority of them, in particular those with an ASD.

Expression of suicidal manifestations

A thematic analysis of the description of SMs also identified two main forms of expressions of distress: either direct and explicit SMs, or implicit references to the will to end one's life.

A direct and explicit expression of the will to die was the most commonly identified SM. Explicit references to the will to die are expressed in different ways, either by direct verbalization of the will to put an end to one's life, for example: *"I don't want to live anymore, I want to die,"* or by indicating or using a means or specifying a moment to carry out an attempt: *"I'm going to jump out the window,"* or *"I want to die when I'm 17."* It is also important to emphasize that the means identified or used by the users correspond for the most part to the means commonly referred to by the general population, such as using sharp objects, medications or toxic products, suffocation, or a voluntary fall or a collision (car, subway) (Bardon et al., 2014). References to imaginative personal means specific to some users were encountered at times, but remained infrequent. Implicit SMs are for their part deduced from changes in condition, verbalizations or behaviours in which death is posited as a desirable option. Users may refuse to eat or say, for example, that *"people who die are lucky."*

Finding: Workers mainly reported the expression of direct and explicit suicidal manifestations, but sometimes distinguish implicit references to a will to die, particularly based on changes in a user's condition.

In the file notes, a link is made between the SMs and the context in which they were expressed. For analytical purposes, 283 excerpts from user files concerning SMs were categorized and distributed according to four contexts: general unhappiness, weakening of relational networks, application of measures perceived by users as being too restrictive, and finally dissatisfaction arising from the gap between actual and expected experience. These contexts are numerous and may reflect one-time events or be part of the individual's ongoing life experience. The examples in the boxes were selected from the excerpts compiled for the study.

General unhappiness

When SMs are associated with general unhappiness, workers have noted the pathologizing nature of the SMs. They then describe how profound weariness, signs of depression and other mental and physical health issues lead users to express a will to die (see Box 1).

Box 1: Examples of SMs associated with general unhappiness.

- She often cries. She says she doesn't feel well [and she's] always sad. The user seems to be depressed, according to the psychiatrist.
- Says he's depressed and wants to die because he feels like a [loser].
- The user talked about suicide to another user, but then told the educator that he meant to say he was tired.
- The user says she can no longer bear it (losing sight) and wants to die.
- Paranoid statements: "They talk about me behind my back; they say bad things about me; they mistreat me." Signs of depression: crying, shouting, raising the tone.

Absence or weakening of the relational network

Users' relational networks vary in composition, ranging from those that include many people to others consisting almost exclusively of specialized workers. The workers describe numerous situations in which SMs occur after a user's relational network has been weakened. The death of a loved one, the prolonged absence of an important individual, a marriage breakdown, and disagreements or conflicts that sometimes add up are the main relational network events associated with SMs (see Box 2).

Box 2: Examples of SMs associated with weakened relational networks.

- [The user] says that seeing his uncle in a coffin took away his will to live, that he sees himself dead, and that he won't have the strength to see his mother and loved ones die.
- Saying he hasn't had any news from his father, thinking he may be dead, he said he wanted to take his own life.
- The user's solitude is palpable. [...] the father has cut all contact with his son and the workers.
- [According to the user] her family doesn't care what happens to her.
- [The user] finds that no longer going out with her boyfriend is difficult. There are students who take her lunch at school, and she misses her mother.
- [The user] says he doesn't know what to do anymore about his conflict with a student at school.
- Two police investigators went to meet [the user] at her residence to tell her she must no longer contact one of her friends. There's a complaint against her and the next time they'll have to arrest her.

Application of measures perceived as being too restrictive.

In a context of specialized interventions, users regularly find themselves in situations where they feel they are being subjected to overly restrictive measures. In the user file notes, workers report situations in which dissatisfaction created by the application of measures perceived as restrictive are expressed as SMs. The SMs noted in the files occur in the context of circumstances involving restrictions, expulsions, refusals or unanswered requests (see Box 3).

Box 3: Examples of SMs associated with the application of measures perceived as being restrictive.

- User: "I'm going to kill myself if I can't leave." [...] Hospitalized [for] for several months, no places available in a RAC (Resources with continuous assistance).
- User is informed that his Holiday season stay at his girlfriend's will be five days shorter.
- Forced retirement, for health reasons, but that wouldn't do it for him.
- [The user] made suicidal statements in school after receiving instructions he didn't agree with.
- After refusing to eat [dessert], she threw her [drink], tried to hit her sister and sat down on the floor [...] after her father tried to restrain her physically. [...]. Once she was with her parents, she didn't want to go back to the residence and wanted to get hit by cars.
- [The user] isn't happy, she wants to move, go live with her mother. When the educator answers her questions and it isn't what she wants to hear, she gets angry, she bites and pinches herself, she gets a stern look on her face, she gets angry, and she makes suicidal statements.

Dissatisfaction arising from the gap between actual and expected experience.

Still in accordance with the interpretation suggested by the worker's notes in the users' file, among certain users, the SM context is tied to deep dissatisfaction arising from the gap between their life experience and the personal and social goals they're attempting to reach. In these

situations, SMs occur when users feel that their life projects are out of reach, “that they aren’t doing something with their lives,” they don’t have enough power over their destinies, or that they’re aware of the difference and associated limitations (Box 4).

Box 4: Examples of SMs associated with dissatisfaction arising from the gap between actual and expected experience.

- He says his life is going nowhere, [that] that nothing works like he wants it to.
- Objective expected (have a lover or school success for example) in a set time.
- She feels overwhelmed by her family responsibilities.
- He failed his English course and is afraid he won’t find an internship.
- He’ll kill himself within five years if he doesn’t make a career in music.
- The user says it’s because she’s [physically] disabled and has another disability and that her life is over. Confrontation with her mother and acceptance of her diagnosis: “I’d like to be severely disabled so I wouldn’t realize anything.”
- He says he finds his syndrome hard to accept.

With the exception of general unhappiness, which is more often associated with a person’s pathological condition than specific contexts, workers have associated a variety of contextual elements that lead to episodes of user distress. While SMs may not always predict an imminent attempt, they nevertheless express distress among users. A cross-section analysis of the excerpts shows a link between the SMs and the users’ social integration difficulties. From a sociological viewpoint, the weakening of the relational network is part of a broader phenomenon, the social isolation of so-called vulnerable populations; the application of measures perceived as being too restrictive shows the limits of the self-determination principle that nevertheless guides rehabilitation intervention, while dissatisfaction with one’s actual experience is tied to the feeling of being different, dysfunctional or limited in a society that counts on the achievement of a valued and gratifying social role based on dominant standards. Independently of the risk associated with SMs, it is important to recognize and consider the dynamics highlighted in this study, which emphasizes that beyond the immediate context associated with SMs, user distress refers to the living conditions in which they develop and the real possibilities of accessing to full citizenship status.

Finding: The contexts associated with SMs express the multiple integration difficulties faced on a daily basis by people who receive specialized services.

Recognition of the suicide-related problem.

The objective of the second part of the research process was to shed light on the team workers' and managers' viewpoints on the suicide problem among those with an ID or an ASD. Opting for an inductive approach, it explored the meaning given to the phenomenon by those who work with this population on a daily basis. So, through the words of voluntary respondents collected in semi-guided individual meetings, this part of the project focused on the perceptions of specialized ID-ASD rehabilitation service professionals who reported cases of SMs among their clients in the first part of the study. The discussion topics included: (1) users impacted by the problem and how they were perceived by the participants (Whom are we talking about?); (2) SMs among individuals with an ID or an ASD (What are we talking about? How are the SMs described? What forms do they take? Are they different from the manifestations in other populations? Etc.); and (3) intervention practices (How do we deal with the problem within this specialized intervention setting, especially regarding the identification and estimation process of suicide risk, intervention, follow-up and, more generally, suicide prevention?).

Analysis shows two dominant views of the ID-ASD suicide problem that coexist in the remarks of the interviewees: the first, where managers and workers are reluctant to assign a suicidal meaning to expressed manifestations; the second, which is built on the expression of their concerns for the users' physical integrity. These hard-to-reconcile views highlight two conflicting perspectives on this problem: the recognition of user distress and accounting for it in intervention practices, on the one hand, and, on the other, the imperative need to ensure the physical integrity of individuals at all times, that is risk management.

Reluctance to assign a suicidal meaning to manifestations

One of the main issues involving the suicide problem among individuals with an ID or an ASD lies in the doubt and persistent hesitation of workers to assign a suicidal meaning to manifestations of distress. Like other highly subjective experiences, the suicide phenomenon includes a dimension that is hard to communicate. *"So it's complex, suicide is very complex. There are a many mysteries,"* said one respondent. The more severe the ID, the more the content of the individual's emotions will seem obscure. The enigmatic nature of suffering feeds the participants' ambivalence towards the distress they witness. The participants rely on various elements to interpret the suicidal meaning of identified manifestations, such as the assignment of a will to die, the recurrence of SMs, the low lethality of the means used, the limited communication and planning skills, the misunderstanding of death, the presence of mental health issues and, finally, the instrumentalization of SMs.

Intentionality. The intention issue is one of the main ambiguity factors. The assumed absence of a will to die is interpreted as an indication of the non-suicidal nature of the behaviours or verbalizations. According to the respondents, most individuals with an ID or an ASD with ID would not have the cognitive skills needed to consciously want to die.

It is quite complex with individuals who have a more severe and profound ID. [...] And yes, they can experience depression, but there is no intention, it is a state, there is no intention

behind it because in any case, they don't have the cognitive ability to move on to the intention. But they can demonstrate psychological suffering, but they won't demonstrate it at that level, through suicidal behaviours.

The impossibility that a person with a moderate to profound ID could consider suicide is associated with the individual's diagnostic. Then, the lack of consistency in expressing a desire to die is interpreted as a clue of the non-suicidal character of the manifestations. While participants admit that a momentary intention can be deeply felt by the person in distress during a crisis, this intention would subside once the episode has ended and this disappearing intention is interpreted as a sign of non-suicidality.

Recurrence of suicidal manifestations. Surprisingly, the recurrence of manifestations seems to interfere with the assignment of a suicidal meaning by workers and managers. They perceive repetitive actions or statements as signs aimed more particularly at drawing attention on unmet needs rather than a "real" will to commit suicide. The comments collected suggest that recurrent manifestations could cause a habituation effect among workers, thus reinforcing the non-suicidal interpretation of such situations.

Low lethality of the means used. The low lethality of the means used for suicide attempts would, according to the respondents, express the absence of a "real" will to die. As such, while they can pose a risk for the individuals' physical integrity, self-destructive behaviours are not seen as suicidal actions, but rather as means to express unhappiness:

[A person does something] for example, with a knife, but with a butter knife. So it will be more of a scratch, but it did not go any further than distress. Insofar as the person had steak knives, sharp knives were present, but the person took, I think, this is an interpretation, but the person had the choice between the butcher knife and the butter knife and the person took the butter knife to leave marks.

Limited communication skills. The communication deficits frequently encountered among individuals with an ID or an ASD create some confusion regarding the meaning of distress manifestations. Knowing the users' limits in terms of communication and sociability, workers tend to consider suicidal verbalizations as indirect ways to express negative emotions. The following excerpt illustrates this conclusion:

Individuals with an intellectual disability have a smaller vocabulary: "I'm bored, I want to do something with you," will be harder to express than... "I am sad," or "I don't feel good." "I am sad, I don't feel good, it's hard," will right away go to "I want to die, I hate life." I don't know, sometimes, if it's not just a lack of vocabulary, or the inability to explain their condition.

The restricted range of expression and the sometimes limited vocabulary of individuals with an ID or an ASD help support this interpretation. Among individuals with an ASD, communication or emotion management difficulties can go hand in hand with what is considered "learnt speech," such as a propensity to repeat statements they have heard without really grasping their meaning.

Limited planning skills. The notion of planning capability is prominent in the workers' and managers' comments. The assumed inability to plan a suicide or attempt suicide is used to

explain the non-suicidal character of the manifestations of distress. In the following excerpt, a respondent explains how the planning of an attempt constitutes, according to her, the very essence of suicidal behaviour. Lacking the necessary cognitive skills to devise a plan, individuals with an ID would seemingly try to express “something else” through these manifestations:

When there is no plan as such, it is because the intention is not as... it is not at the same level, I would say. (...) It was more, at that time (for that user), a way to express suffering, but with a lack of words to express it. So the suicidal intention was not that present, because there were rarely any plans (associated with the behaviours). To devise such plans, one needs a highly organized intellect, which is often lacking among the clientele.

Thus, while recognizing the suffering experienced by some users, the worker gives no credibility to the helplessness manifestations because there is no plan.

Inability to understand death. The assumed inability of individuals with an ID or an ASD to understand death also fuels ambiguity. The perception that this clientele has a limited or different understanding of death is common among participants. The doubt expressed as to the users’ ability to grasp the definitive nature of death is particularly persistent. In this context, the manifestations are considered more as means of expressing suffering. The suicidal meaning is therefore evaluated and assigned based in part on the users’ level of understanding of death. Nevertheless, some workers or managers recognize that the concept of death varies with each individual, which could suggest that the distress is sometimes suicidal in nature. The reluctance to address the issue of death with individuals with an ID or an ASD out of fear of fostering the emergence of suicidal thoughts is also present in the respondents’ statements.

Mental health disorders. Mental health disorders (such as depression, anxiety disorder, BPD, etc.) are yet another aspect that may at times support a suicidal interpretation and make it credible, and at other times nourish doubts about associating conducts with a suicide problem. Thus, the collected statements indicate that workers are more likely to assign a suicidal meaning to the manifestations of users who have one or more of these comorbidities. If there has been a diagnosis of depression, distress is more likely to be associated with a “real” suicide problem:

Those with associated diagnoses, which is really not uncommon, those among others who have associated diagnoses such as depression, often do have actual suicidal thoughts.

The emotional instability tied to mood disorders is also associated with a greater risk of suicide. In the case of individuals with a BPD that is comorbid with an ID or an ASD, there will rather be a tendency to see SMs as a means of attracting attention.

Instrumentalization of suicidal manifestations. Verbalizations or behaviours can be seen as levers used by the users in order to receive attention or care. The participants were concerned by this assumed instrumentalization of SMs. Noting the mobilizing effect of such actions, some user profiles, such as children with an ASD and individuals with a BPD that is comorbid with an ID or an ASD would be, from the respondents’ viewpoint, particularly inclined to use this strategy to attract attention. The manifestations are then attributed to behavioural disorders rather than a suicide problem.

Finding: The representations of ID, ASD and suicide contribute to the reluctance among workers and managers to assign a suicidal meaning to users' manifestations of distress.

Concern for the users' physical integrity

Despite ambivalence among workers and managers about the meaning to be assigned to behaviours or verbalizations of distress, the discussions reveal a concern for the users' physical integrity in the presence of vulnerability factors. Thus, impulsiveness, aggressive, provocative or self-mutilating behaviours, mental health disorders, as well as the degree to which users live independently are factors that have been identified as presenting significant risks to the users' physical integrity without raising the assumption of suicidal meaning. A risk management approach based on a supervision and protection rationale is then recommended: attend to the most urgent need, protect the user's physical integrity, and limit the dangers.

Impulsiveness. Impulsiveness is generally considered to be a suicide risk factor. This personality trait is frequently encountered among persons with an ID or an ASD:

Presently, I see it this way, but in two hours, it can be quite different. Our clientele in particular... I come out of my office and he is trying to reach his girlfriend and his girlfriend does not answer, and right there, it's the end of the world. So our clientele encompasses all of that. She is so impulsive, unpredictable, fragile and helpless in coping with her emotions, that sometimes she comes out of the office and you are like "issshhh."

This characteristic makes them likely to adopt dangerous behaviours, even in the absence of the will to die. In the same line of thought, the consumption of psychotropic substances is perceived as a risk factor, since it would, in many cases, exacerbate impulsiveness.

Provocative behaviours. Provocative behaviours raise workers' vigilance because of a potential behavioural escalation and the risks it represents for the safety of users. These dangerous actions would be particularly frequent in children with an ASD and among people with a BPD. Respondents fear the consequences of actions the scope of which does not always seem to be well understood by users:

It sure makes us react when they tell people they want to die, particularly those with BPD, they often use this to make people react, if they see that you react to it and panic, that's it, they have found their window of opportunity.

Although they try to avoid reinforcing provocative behaviours, participants highlight the importance of responding adequately. Ignoring the behaviour intentionally or responding inappropriately could exacerbate escalation and cause accidents.

Self-mutilation and aggressive behaviours. If the respondents do not associate self-mutilation acts and aggressive behaviours to SMS, they recognize that they reflect a significant feeling of unhappiness among users. Faced with self-mutilation behaviours, the most common practice is to consider the probable causes of the problem by formulating assumptions to be tested in an intervention situation. However, since the suicidal hypothesis is rarely considered, the problem is, most often, excluded from the intervention scenarios. For their part, aggressive behaviours are most of the time interpreted as behavioural disorders that can threaten the

physical integrity of the person and of those around this person. Paradoxically, suicidal verbalizations seem to decrease the perception of suicide risk among workers and managers, since words appear less dangerous than actions that can lead to injuries and even death.

Residential autonomy. Users' residential autonomy may be a risk factor from the participants' point of view because this living condition limits the supervision and protection opportunities for the person. This environment somehow eludes the preferred risk management strategies. The workers are particularly concerned about access to the means of suicide attempts that are available to those individuals who live alone in an apartment. The isolation that can arise from this residential option, as well as the possible exposure to situations of abuse or rejection, accentuate, from their point of view, the vulnerability of these individuals. They feel limited in the protection that they can provide since the risk management opportunities are much more restricted than in an alternative living environment (housing resource, family-type resource, resource with continuous assistance, etc.). From the respondents' perspective, people who live alone have less support and supervision and are, therefore, more likely to jeopardize their physical integrity.

Finding: Despite their reluctance to assign a suicidal meaning to manifestations of distress, workers and managers fear for the users' physical integrity. Consequently, interventions are developed from a risk management perspective.

The results of this analysis reflect the beliefs that the presence of a suicide-related problem is hardly conceivable among individuals with an ID or an ASD. The interviews revealed that workers and managers adopt an empathic stance with regard to the users' suffering. However, they seem to have difficulty dealing with the uncertainty surrounding the nature of this suffering which, moreover, is often explicitly associated with suicide by the users, as demonstrated by the qualitative analysis of the manifestations, as well as the circumstances of their expression. Although the respondents have been able to identify manifestations of distress among users, they remain reluctant to assign them a suicidal meaning while still strongly concerned for their physical integrity. This double interpretation brings about challenges with regard to recognizing the phenomenon and is, therefore, likely to restrict the use of adequate prevention and intervention tools.

Intervention practices in the management of suicidal risk

Intervention characteristics

The exploration of SM management methods (objective II) can take several forms. An initial exploration of this dimension is carried out through the documentation of interventions directly related to the SMs listed in the file.

The exploration of interventions related to each SM was limited to two steps, namely (1) the intervention carried out directly with the user when the SM was discovered, and (2) the second intervention carried out in relation with the SM, presented here as a follow-up. For example, it could be a request for a psychiatric consultation or for the assessment of suicidal risk, just as well as a direct follow-up to see how the user is doing.

The data extracted from the records show that in 62% of SMs, an initial intervention was carried out directly with the user (among those, the intervention was done within 24 hours 95% of the time). The analyses show that more interventions are done for users with an ID than with an ASD ($\chi^2(1)=9.74$ $p=.007$), and more interventions are done with adolescents and young adults than with younger or older users ($\chi^2(3)=13.04$ $p=.005$), regardless of the user's living environment. The interventions carried out by the workers are primarily done in the user's presence (46%), by telephone (15%) or through emergency services (2%). Furthermore, emergency services have been called by the different stakeholders involved with the users (family, housing resource, partners and workers alike) for 18% of the SMs. The use of emergency services is more frequent in the presence of behaviours, compared to verbalizations and changes in users' condition ($\chi^2(2)=17.11$ $p=.000$), as well as more frequent in a planning or attempt situation rather than any other type of SM ($\chi^2(4)=12.56$ $p=.01$). It is important to note that this is mainly carried out by partners (16%) rather than specialized services (2%). The analyses also show that when SMs resulted in a call to emergency services, there were less direct interventions from the worker (44%) ($\chi^2(1)=8.17$ $p=.004$) and more cases managed in the form of follow-ups (88%, $\chi^2(1)=7.47$ $p=.006$).

If the intervention-follow-up sequence is analyzed, we find that 86% of SMs resulted in at least one form of intervention. Among these SMs, nearly half (48%) lead to both a direct intervention with the user and a follow-up. The SMs that involve planning are those that have generated the most continuous follow-ups (78%). Surprisingly, suicide attempts represent the smallest proportion in this category, with only 37% of the attempts that would have led to both a direct intervention with the user and a follow-up. However, the finding indicating that 90% of suicide attempts are not discovered by the workers, but rather reported by third parties after the episode could explain this result. In this regard, Figure 5 shows, for each SM type, to what extent these attempts are discovered or reported after the episode. The average proportion of SMs that are reported is 53%. There are significantly more interventions in the presence of direct discovery of a SM (82%), while there are more follow-ups (75%) in the case of reported situations ($\chi^2(3)=47.05$ $p=.000$).

There are also 24% of identified SMs that resulted exclusively in a follow-up, without any immediate intervention with the user. Among those, we mainly encounter SMs in the form of verbalized ideations (42%) or threats (26%). It is also in this category that we find the most significant proportion of suicide attempts (40%). Once again this is the result of the deferred disclosure of the suicide attempt.

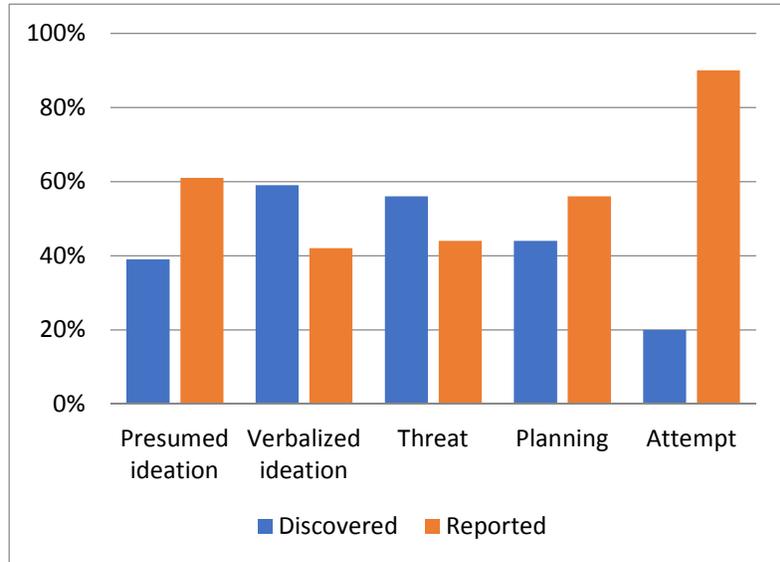


Figure 5. Proportion of suicidal manifestations by type according to the source of information

Also, 14% of the SMs only lead to a direct intervention, without any follow-up. Among these, there is a significant proportion of verbalized ideations (64%). Finally, for 14% of the SMs reported on file, no intervention or follow-up was documented during the year under review. This finding could be the result of the data collection method limitations for the study, namely, the exploration of the progress notes for the targeted year only (some follow-ups could have been delayed). It could also be that the suicidal episode was reported during the research project, considering the concordance between the SMs and the selection criteria, but that the user was not recognized as suicidal during the clinical follow-up. This would result in no intervention specifically dedicated to the suicide-related problem being recorded on file. The documented interventions on file were then linked to the general problem having justified the request for specialized services.

Finding: The users' suicidal manifestations do not all lead to an intervention or follow-up from specialized services.

Perceptions of intervention practices

Besides the issues related to the recognition of suicide-related problems among users of specialized ID-ASD services, the workers and managers interviewed raised several challenges they are faced with in their practice. These mainly involve the deployment of interventions in a SM context and the service organization.

Identification by third parties. From an empirical perspective, the quantitative analysis presented in this report has demonstrated that more than the majority of SMs are reported to the patient navigator by a third person. Indeed, the worker is notified of the situation by the

people who are frequently in contact with the user, such as the housing resource staff where the user lives, the user's family or school educators, sometimes workers from a partner organization, such as a hospital, or another worker from the organization. More rarely, the user will communicate his or her desire to die or will try to do so in the presence of the worker. Thus, the multiple partners involved in the identification or reporting of SMs complicate the management of SMs for several reasons, including the possibility of differently interpreting the problematic situation due to different frames of reference, information transmission requirements, communication delays, leadership related to patient management and the follow-ups required.

Necessary consultation efforts. According to government policies on the social participation of individuals with an ID or an ASD (Office des personnes handicapées du Québec, 2009; MSSS, 2003, 2001), the service delivery method is based first on a principle of shared responsibility between the user, the user's family and relatives, if applicable, the health and social services system partners, as well as other community partners within (e.g. crisis centres, Suicide Action Montréal, etc.). From a political and organizational point of view, the suicide risk management method therefore involves important consultation efforts. The multiple partners involved in the identification and intervention associated with SMs must be taken into account in the problem management framework, which implies an important coordination effort.

Access to assessment expertise. To date, from an organizational point of view, the preferred management method to address suicide-related problems among the management team of the CIUSSS – CCSMTL DI-TSA programs is to apply the general clinical process, with the exception of a special measure, namely the designation as assessors of 30 professionals (psychoeducators, clinical activities specialists, social workers, psychologists) responsible for responding to suicidal risk assessment requests. In order to update this measure, these assessors have received training in 2013 to apply the *Grille d'estimation de la dangerosité d'un passage à l'acte suicidaire*, which is widely used in Quebec, particularly within frontline services of the health and social services system.

In a SM context, the assessor, at the request of the patient navigator and his or her manager, determines the suicidal risk level and provides recommendations for the immediate and eventual management of the problem. The implementation of these recommendations is the responsibility of the clinical team. The patient navigator is, however, responsible to relay the relevant information concerning the results of the assessment and the intervention recommendations that need to be implemented with the other workers within the organization, the housing resources, if applicable, and, if necessary, the partner organizations (e.g. school educators, youth centers) involved in the case.

Nevertheless, access to assessors, the timing of their intervention, their role with the teams and expertise concentration on suicide raise questions among participants. Indeed, at the time of data collection, the procedure to access the assessors' expertise varied greatly according to the teams, and some workers mentioned they had encountered difficulties in accessing assessment services. In addition, since the assessors are called when there is a doubt about the suicidal risk,

it seems that their intervention depends on an initial identification of the SM, which is carried out by the patient navigator or by a third party. Some respondents had questions regarding the consistency of the intervention sequence, where an initial assessment of the suicidal risk must be carried out by the patient navigator to determine whether the situation requires immediate hospitalization or the use of an assessor's services. The assessors are therefore called upon to assess the risk *a posteriori*, according to an initial assessment based on the patient navigator's clinical judgment. Moreover, since the assessors are not part of the user's regular clinical team in the majority of cases, they have little chance to be involved in the follow-ups relating to the implementation of the interventions. Finally, the analyses have shown that the respondents are concerned with the concentration of expertise on suicide among a few people designated as assessors. Although these professionals are perceived as points of reference on suicide, some respondents pointed out the importance of raising awareness among all workers with regard to suicide-related problems in order to facilitate the identification of SMs.

Impacts of the users' living environment on the management process. Whether the user lives in a natural environment, an intermediate resource (IR), or in a resource with continuous assistance (RAC)⁹, the SM management method will depend on the more or less extensive sharing of responsibilities between the CIUSSS - CCSMTL workers and the third parties involved in the intervention process. Thus, from the respondents' point of view, in the natural living environment, the management of people with SMs will mostly be the responsibility of frontline general services (non-specialized in ID or ASD) using an ad hoc crisis management approach, without necessarily carrying out any specific follow-ups along with specialized services. For individuals with SMs who live in supervised apartments or who do not benefit from the organization's residential services, hospitalization appears rather as a preferred, short term means of ensuring the security of these users. The workers then rely on the medical teams to perform the necessary assessments. However, the respondents express doubts regarding hospital staff knowledge on ID and ASD, and are concerned about the ability of these workers to take into account these conditions in the assessment of the suicidal risk. For individuals living in an IR or in a RAC, it is more likely that workers specializing in ID-ASD rehabilitation services will manage the SMs, in consultation with the various partners. Thus, the management method, imposed by governmental policies, organizational orientations and procedures within the health and social services system, makes sharing the actions and responsibilities between the different groups of stakeholders concerned more complex, particularly as it relates to the status of users of specialized ID-ASD services. In these circumstances, a single situation can lead to many different visions and understandings, present communication, mobilization and synergy challenges as part of the interventions and follow-ups, and sometimes, can bring confusion among the workers and the partners.

⁹ Natural environment: e.g. with the user's family, in an apartment; in an intermediate resource (IR): e.g. family-type resource, housing resource managed by independent individuals having contractual relationships with the CSMTL to provide services to users; or, in a resource with continuous assistance (RAC), e.g. highly supervised resource under the CSMTL's responsibility.

The weight of responsibility that rests on patient navigators. Patient navigators have major responsibilities. As part of their mandate, it is expected that they identify the risks, ensure the person's safety and carry out the necessary follow-ups after an SM episode. When a potentially suicidal manifestation of distress is identified, the clinical team, coordinated by the patient navigator, agrees on the interventions to be deployed through the intervention plan. However, consensus as to the orientation of the action to be taken is not always possible. Some intervention strategies raise questions, including those in connection with the exploration of the suicidal option with these populations, which raises concerns as to the damage they could cause to users. Again, the patient navigator must implement the interventions that have been determined, in collaboration with the other stakeholders concerned, ensuring that they understand their respective roles. To ensure safety, the patient navigator must collect enough information in order to determine the urgency of the situation and the possible actions to limit the risk of a suicide attempt. The patient navigator is also mandated to coordinate the follow-up, through different procedures that can be deployed individually or simultaneously: problem resolution, environmental adaptation, return to a desire to live, development of a better understanding of the concept of death, and development of the person's adaptive capabilities. In principle, the interventions agreed upon will be integrated into the user's intervention plan. However, this ambivalence in the interpretation of the situations among the staff is not without consequences. The rejection of the suicidal assumption limits the use of adequate prevention interventions allowing to reject this option from the list of solutions offered to the person. SMs could then be expressed again in another difficult context.

This predominant role played by patient navigators in responding to SMs poses many challenges, as they seem to have few tools, little knowledge in the field of suicide prevention, and support to guide their interventions. What the respondents said demonstrates a need to create appropriate intervention tools to detect the suicidal risk and address the question of the death with the users. The absence of specific training on suicide is also a pitfall in practice, insofar as workers may feel caught off-guard when faced with the suicidal distress of users. At the present time, only those professionals designated as assessors have received such training. Finally, some respondents were deeply concerned about the lack of support offered to patient navigators, who assume concurrent responsibilities and must make up with increased accountability, without always receiving all the support they need from their team and the organization.

The challenges of constant vigilance. The interviews revealed the presence of certain obstacles to the prevention of suicidal risk. One of them relates to the inadequate nature of the intervention plan, which is the main clinical tool at the workers' disposal to structure and integrate a preventive strategy. The second issue relates to the anticipated negative effects of vigilance practices regarding the suicidal risk. Indeed, and paradoxically, the interviewees are concerned about the harm that the user might suffer from systematic follow-up measures of SM; in bearing the "suicidal label", they fear that the freedom and self-determination of these users could be compromised. In this matter, several workers are reluctant to consolidate such a systematic vigilance approach.

Recognize, intervene and prevent suicidal manifestations

The exercise of identifying SMs among users having an ID or ASD, in which all the organization's clinical teams have participated, demonstrates the existence of a suicide-related problem. In fact, the estimated prevalence rates of SMs among the organization's users would be equal to or higher than those of the general population. Also, the existence of SMs in the presence of ID or ASD, among both men and women, in the majority of age groups and in the presence of multiple and diverse secondary diagnoses, confirms the heterogeneity of user population experiencing distress associated with this problem. Such diversity complicates the necessary prevention, identification and intervention work in practice. The findings from this study clearly demonstrate the importance of better supporting practices pertaining to suicide-related problems within specialized ID-ASD services, regarding particularly the challenges related to perceptions of suicidality, the practice framework and the development of specialized expertise.

Challenges related to perceptions of suicidality

The interviews conducted with workers and managers revealed ambivalence toward the assignment of a suicidal meaning to identified manifestations. Thus, despite direct and explicit expressions of a willingness to put an end to one's life, the perceptions associated with what would be a "real" SM as well as the characteristics associated with ID or ASD, including the difficulty in conceptualizing death, of expressing themselves or of planning a suicide attempt, seem to overshadow the recognition of a suicide-related problem. This ambivalence also limits the assessment of such an option, the use of specialized expertise for the assessment of suicidal risk or the implementation of appropriate interventions. In general, interventions fall within a risk management approach rather than a distress acknowledgment approach.

Thus, awareness work is required in order to update the conceptualization of suicidality in people with an ID or an ASD, in light of suicidology models and recent data. In the first place, it seems essential that the very concept of SM should be given special attention. In this regard, some authors recommend replacing the "intention of committing suicide" criterion by the "intention to put an end to an unsustainable situation" criterion (De Leo, Burgis, Bertolote, Kerkhof and Bille-Brahe, 2006); a criterion less subject to interpretation and more easily applicable in an intervention context. Recognizing distress, instead of the intention to die, also implies that suicidal credibility should not be established based on the means used or planned, which is not necessarily representative of the experienced suffering. The choice of a non-lethal means, or even, in some cases, a strange means, could be a response to imperatives other than the presence of suicidal distress, such as reflecting the person's limited knowledge or understanding of the concept of death, or suggesting the absence of means at the person's disposal. Although this lack of means may be considered as an indicator of risk management effectiveness, it does not necessarily mean that this approach will contain distress. Finally, distress recognition is also echoed in the perspective linking the expression of SMs in the broader framework of social isolation realities, the limitation of the self-determination principle and the achievement of a satisfactory social participation.

Recommendation: Adopt a definition of suicidality as a part of distress recognition rather than the interpretation of the person’s intent or capacity to commit suicide.

Challenges related to the practice framework

The challenges identified concerning the patient navigator’s role, access to expertise, information sharing, responsibilities shared with third parties at the identification and intervention levels reflect the practice setting’s need for an institutional policy on suicide-related problems. This policy should as a matter of priority rule on the prevention and intervention procedures, from the SM identification stage to the implementation of follow-up measures. Suicide prevention guidelines all agree on the fact that a follow-up must be carried out with individuals after an episode of SM (Medium and Mork, 2011), whether recurrent or sporadic. As far as staff is concerned, the organization is responsible for clarifying the roles and responsibilities of the different worker and manager categories, assigning the follow-up responsibility to people with the time and the expertise required to do so, as well as specifying the accountability of each stakeholder. Furthermore, inasmuch as the majority of SMs is reported to the patient navigator by a third person (the staff of the residential resource where the user lives, the family or school educators, the workers from a partner organization or those from a hospital), this policy should also take into account the intersectoral component inherent to this issue (multiple stakeholders involved, roles and responsibility of each one of them, different interpretations of the situation, information transmission, communication delays, and leadership within the whole sequence).

Recommendation: Establish an organizational policy relating specifically to SM response

The results of this study show that the workers and, particularly, the patient navigators play a primary role in managing suicidal distress. In particular, they must recognize the SMs, collect enough information to evaluate the urgency of the situation, and determine whether an immediate response is required. In addition, they are responsible for the coordination with other stakeholders (families, relatives, other partners) in the collection or sharing of key information to ensure adequate follow-ups. Due to sometimes harsh practice conditions and the emotional charge that accompanies suicidal distress, this role can be difficult to keep. It is therefore important to ensure that the workers receive the support required to fulfil their role.

Recommendation: Provide support to workers faced with SMs and share the responsibility of the intervention with the whole team.

The analysis reveals the existence of a feeling of uneasiness among participants surrounding interventions specifically associated with the issue of death. Different intervention procedures are deployed by patient navigators to address user distress. With the exception of interventions aimed at promoting the development of a better understanding of the concept of death, all these procedures are commonly included in the users' intervention plans, without any link to suicidal distress. What the interviewees said indicate that there is a consensus regarding the application of these procedures, due to their familiar nature. However, analyses show that interventions directly connected with the issue of death cause a feeling of uneasiness among workers. They seem reluctant to address this topic, being afraid of fostering the emergence of suicidal ideation among vulnerable users, or not knowing how to do so. The same finding was also identified during the consultation with experts organized in 2012 (Bardon et al., 2014).

In this regard, Dusart's study (2004) on the mourning experience of people with a mild to moderate ID is enlightening. This research shows that these people have, for the most part, a good capacity to grasp the implications of death, including its definitive nature. The author suggests that prevention measures, including discussions addressing directly the question of death, do not support the emergence of morbid ideation among this population, while the reluctance to address the issue of death during the interventions helps maintain the taboo surrounding it.

Furthermore, the workers' and managers' discomfort surrounding the suicide prevention issue seems associated with several other factors, including the limited effectiveness of generic risk assessment tools with populations with an ID or ASD, which limits practice. In the absence of satisfactory options, workers must deal with poorly adapted tools which jeopardize the reliability of risk assessments and can raise doubts as to the choice of appropriate interventions. In this regard, an applicability analysis of the *Grille d'estimation de la dangerosité d'un passage à l'acte suicidaire* with people who have an ID or ASD, the application of which is recommended by the MSSS in the *Guide des bonnes pratiques des intervenants des centres de santé et de services sociaux* (Ministère de la Santé et des Services sociaux, 2010), indicates that this tool, in its current format, seems difficult to apply with users receiving specialized ID-ASD services (Ouimet et al., 2014). The absence of guidelines to guide practice also represents an obstacle insofar as the interventions, including follow-ups, are not encompassed within an institutional policy. Finally, the question of accountability of the professionals involved in the intervention also raises some discomfort. Faced with the uncertainty surrounding the interventions required in the presence of SMs, workers have difficulty dealing with their responsibility in this respect. In these circumstances, they will tend to favour an approach focusing on risk management to avoid compromising the users' physical integrity.

Recommendation: Develop tools to assess suicidal risk as well as intervention practices specifically adapted for people with an ID or ASD.

Challenges pertaining to training and access to expertise

Currently, the organization is making efforts to increase available knowledge on suicide-related problems among people with an ID or ASD. Some professionals have attended a training session offered by Suicide Action Montréal (SAM) to develop their skills in terms of suicide risk assessment and intervention in the context of SMs. Although this training is not specifically geared to the characteristics of specialized adaptation and rehabilitation services as well as ID and ASD clients, it nevertheless allows the development of essential knowledge related to this type of intervention. However, the results of the study show that it is mainly patient navigators (mostly specialized educators) who are at the heart of all types of intervention deployed in the presence of SMs. Yet they currently have to rely on dedicated professionals (assessors) for support in those situations, which seems challenging when suicidal risk must be assessed immediately. It is relevant to plan the development of patient navigators' knowledge and skills relating to suicide-related problems of people with an ID or ASD due to their predominant involvement at each step of the intervention process.

Recommendation: Provide training to patient navigators in order to promote knowledge development on suicide and intervention skills in the context of SMs.

The prevention perspective could be complemented by an awareness campaign for staff members who are likely to witness cases of SMs in carrying out their work. Due to the importance of partners (living environments, school environments, crisis centres, etc.) for the identification of suicide-related problems and their follow-up, their inclusion in this awareness campaign would promote the adoption of a vigilance approach applied to all the organization's users. This awareness could also draw attention on the importance of exercising increased vigilance during significant periods of transition, at adolescence for people with an ASD, and during the transition to adulthood for people with an ID.

Recommendation: Develop information and awareness tools on the suicide-related problems among individuals with an ID or ASD for staff and partners

Finally, analyses have shown that access to the assessors' expertise varied greatly from one team to another. To promote better accessibility, a single window system is currently being tested within the organization. This system is designed to centralize suicidal risk assessment requests in order to better allocate resources and reduce delays in obtaining an assessment. The evaluation of the single window system will help determine if this procedure proves to be effective in achieving the organization's objectives.

Recommendation: Facilitate access to the suicide risk assessment expertise.

Conclusion

While documentation on preventing suicide in various populations has increased in the health and social services system since the early 2000s, no research specifically addresses suicidality among individuals with an ID or ASD. This research report compiles a series of analyses and presents a set of results likely to fuel ongoing reflection in the field of clinical practice improvement based on scientific data. The results pertaining to the importance of the number of SMs identified, their types, the heterogeneity of the affected users' profiles, the perceptions of the suicide phenomenon in ID and ASD, as well as the findings related to the challenges associated with the establishment of an intervention structure adapted to clinical realities, offer a relevant contribution in terms of knowledge advancement and the development of evidence-based organizational orientations. This series of analyses is a knowledge systematization effort on suicide-related problems in ID and ASD, and it raises new issues which feed the research team's work.

This study nevertheless presents limits which must be taken into account. The first relates to the non-representative nature of all the populations with an ID or an ASD. Focusing exclusively on the SMs identified by specialized services workers, this research may not reflect the reality of individuals who do not use such services. Moreover, it has not collected any data on what the individuals themselves have experienced. To provide another perspective on this issue, it would be appropriate to continue the research by giving individuals with an ID or ASD who have experienced suicidal distress the opportunity to speak in order to gain their perspective on this issue. This type of research, however, holds particularly sensitive ethical implications and major methodological challenges that could limit its scope.

To identify the SMs and provide an appropriate response to the distress experienced by some users, it seems essential to support workers' commitment and organizational mobilization. If the comments collected reflect the workers' empathetic attitude toward users and their desire to prevent threats to their physical integrity, the results also show their discomfort as they are still reluctant to interpret signs of distress that they witness as SMs. Therefore, the implementation of generalized vigilance requires the recognition of the existence of this dual perspective in the treatment of this issue in order to be able to act on the representations in question within these dynamics. To deploy effective prevention measures, the analyses show the importance of listening to what is being said by the people who receive services. As Mishara and Tousignant rightly point out, while it is obvious that suicidal individuals experience distress, "it would still be important to know how this despair comes about in order to successfully defeat it" (Mishara and Tousignant, 2004, p. 65).

The contextual analysis surrounding the expression of suicidality shows that users' distress is intrinsically linked to the dimensions of the social participation and self-determination, whether through a weak relational network, the application of measures perceived as restrictive, or the dissatisfaction with regards to the full achievement of a life project. As such, corollary to the suicide-related problems, the manifestations identified among users overwhelmingly highlight the barriers that lie in their journey toward full and complete social integration.

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