



# Psychological Mistreatment and Material and Financial Mistreatment of Older Adults with Disabilities

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Executive summary



Chaire de recherche sur la maltraitance  
envers les personnes âgées

Research Chair on Mistreatment of Older Adults

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This is why your research is so important.  
[...] I know how important it is [the research], then...  
You know, (hesitation) your research, it...  
I only hope that it will not end up in folder number 13,  
in the back of a minister's drawer, like it happens too often.  
Then, after that, change of government, the new minister finds it.  
Then goes public with it, like he discovered it himself.  
When he did not at all.  
(Free translation of Participant 2's words).

## Problem, goal and context

Even though the field of countering mistreatment of older adults has seen development for fifty years, research that clearly links “mistreatment”, “older adults” and “disabilities” are rare. Even rarer are the works that give a voice to older adults with disabilities who went through mistreatment, so they can talk about their experiences and speak about their services trajectory.

From 2019 to 2022, research was conducted with the goal of academically and practically documenting the psychological mistreatment as well as the material and financial mistreatment of older adults with disabilities, which classifies them as disabled in Québec. It was done with the intention to contribute to the understanding of a problem by relying on experimental material. This research concretizes the 49<sup>th</sup> measure<sup>1</sup> of the *Governmental action plan to counter mistreatment<sup>2</sup> of older adults 2017-2022*. It has three objectives: review the pool of knowledge based on the scientific literature, describe situations of mistreatment and services trajectory in the light of statements from older adults with disabilities, and elaborate recommendations. Each of these objectives is clearly stated in this summary. This work was possible due to the meeting and the participation of people from the University research community, social workers from the Health and social services network (RSSS) and community organizations, as well as associations or groups of disabled people (see Annex 1).

## Conceptual framework

The conceptual framework of the *Human Development Model - Disability creation process* (HDM-DCP) was chosen because it facilitates the global understanding of the mechanisms limiting social participation and the exercise of citizen rights for people of all ages. This model conceptualizes, with the help of three broad categories, the factors that can produce or not an instance of disability: the personal factors, the environmental factors and the lifestyle (INDCP,

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<sup>1</sup> “Support the realization of research on psychological and financial mistreatment experienced by disabled people, with the grant program for experimentation of the Government agency that helps increase the social participation of people with disabilities in Québec” (free translation of *Soutenir la réalisation d'une recherche sur la maltraitance psychologique et financière vécue par les personnes handicapées, au moyen du programme de subventions à l'expérimentation de l'Office des personnes handicapées du Québec*, Government of Québec, 2017 : 65).

<sup>2</sup> “Mistreatment is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older adult, whether the person deliberately wants to cause harm or not.” (free translation of *Il y a maltraitance quand un geste singulier ou répétitif, ou une absence d'action appropriée, intentionnel ou non, se produit dans une relation où il devrait y avoir de la confiance, et que cela cause du tort ou de la détresse chez une personne aînée*, Government of Québec, 2017: 15).

2021). The use of the HDM-DCP to understand the context of mistreatment of people with disabilities, a first as far as we know, has reinforced the systematic analysis of the question by linking explicitly the individual and environmental factors in play for each of the situations brought up by the participants of this study. With the purpose of integrating the HDM-DCP to the terminology about mistreatment used by the *Research Chair on Mistreatment of Older Adults* and being coherent with the literature on the subject, it is agreed to use the terms *vulnerability factors* and *risk factors*<sup>3</sup> to refer respectively to *personal factors* and *environmental factors* of the HDM-DCP. The lifestyle, in this case, will be discussed in the conclusion.

## Objective 1: State of the scientific knowledge

Because of the lack of studies on specific types of mistreatment<sup>4</sup>, a summary of the general knowledge on mistreatment of older adults with disabilities was made following steps inspired by a systematic process in nine digital databases<sup>5</sup>. Two corpora<sup>6</sup> were created following an inter-rater agreement approach: the main one contains 66 scientific articles and the second, 111. Almost half of the studies in the main corpus were realized by researchers from the United States<sup>7</sup>. Five highly scientific articles can be found, which are systematic reviews or meta-analyses. Only two articles reveal accounts of older adults with disabilities (Fulmer, Paveza, Vandeweerd et al., 2005; Walsh, Olson, Ploeg et al., 2010), which shows the absence of their point of view in scientific literature, even though it is the main data collection strategy for this here research. Of the 66 articles from the main corpus, 44 are exclusively about people with disabilities, whereas the other 22 address it while including data from people without disabilities. In these articles, the notion of disabilities is treated as a vulnerability factor (n = 33) or as a consequence of mistreatment (n = 7). None of them makes it the main subject of the study. Within the 44 articles specifically about people with disabilities, the majority (n = 25) talk of risk factors and vulnerability. The most studied relational dynamics between the mistreating person and the mistreated are those of care giving (n = 11) or those of service providers and residents in nursing homes (n = 4).

This review of the scientific literature has brought up some realizations on the pool of knowledge. First of all, on the matter of the prevalence of mistreatment of older adults, no standard measure exists. To this day, it is estimated worldwide at 15,7 % for older adults living at home, in the year

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<sup>3</sup> Conceptually, the *vulnerability factors* refer to the personal characteristics of the older adult (intrinsic), while *risk factors* of mistreatment refer to environmental characteristics (extrinsic) in which the older adult evolves (Fulmer, Paveza, Vandeweerd, et al., 2005).

<sup>4</sup> In Québec, two types of mistreatment are recognized, which are violence and neglect. They are divided in seven types of mistreatment: physical, psychological, material and financial, sexual, organizational as well as violation of rights and ageism.

<sup>5</sup> Abstracts in social gerontology (Social Gerontology), AgeLine (Gerontology and geriatrics), CAIRN (French-speaking) (Social sciences), CINAHL (Nursing sciences), ÉRUDIT-Repère (French-speaking) (Social sciences), Medline (Medicine), PsychArticles (Psychology), PsychINFO (Psychology), Social Work Abstracts (Social service).

<sup>6</sup> The main corpus includes texts linking mistreatment with disability and older adults whereas the second includes texts which covers two of these three themes but can still enrich our study.

<sup>7</sup> The works come from five worldwide regions, listed in descending order of study in the main corpus: North America (United States, Canada, Mexico), Europe (United Kingdom, Spain, Portugal, Finland, Ireland, Romania, Sweden, Turkey), Asia (South Korea, China, Japan, India, Hong Kong), Oceania (Australia) and South America (Brazil). No research was published by researchers of Africa.

prior to data collection (Yon, Mikton, Gassoumis, & Wilber, 2017), and at 5,7 % in Québec (Gingras, 2020). A Mexican study gives a fragmented preview of the mistreatment of people with disabilities based on an important sample of 1,089 participants with long-term physical disabilities (more than six months) aged 60 and over by revealing that 32,1 % of them were mistreated during the year prior to data collection (Giraldo-Rodriguez, Rosas-Carrasco, & Mino-Leon, 2015). Psychological mistreatment (28,1 %) is the most self-reported, followed by financial or material (11,9 %), physical (7,0 %) and sexual (2,5 %). These results from Mexico allow stating the hypothesis that mistreatment could be more prevalent among older adults with disabilities than among older adults in general, a hypothesis that will need to be validated by subsequent studies. However, these results concur with elements from a literature review conducted in Québec based on Canadian data: “the most frequent form of mistreatment suffered by older adults with disabilities are psychological or emotional mistreatment and financial mistreatment (Analysis of data from the General Social Survey of 2009)” (Dugas & Lamotte, 2015: 39, free translation).

A lot of **vulnerability factors** of older adults for mistreatment are evoked in the literature, with many related to disabilities. For example, a systematic review of the literature has identified cognitive deficits, behavioural problems, mental health disorders, functional dependence as well as poor physical health as being meaningful vulnerability factors for older adults living in the community (Johannesen & LoGuidice, 2013). A review of the literature names physical problems, which includes physical disabilities and functional dependence to accomplish everyday activities, mental health problems, particularly mental health disorders, personality disorders and cognitive deficits, and the dependency to the mistreating individual as vulnerability factors of mistreatment (Storey, 2020). A Canadian research specifically studied the notion of oppression and its impacts on reported mistreatment by marginalised older adults including those with disabilities. Ageism, ableism<sup>8</sup>, sexism, racism and heterosexism are identified as complex oppressions, omnipresent and interlinked who have impacts on the presence and invisibility of mistreatment of these people (Walsh, Olsen, Ploeg et al., 2010).

A lot of research about **risk factors** of mistreatment of older adults with disabilities only revolves around the relational dynamics between caregiver and person in care. Personal characteristics of the mistreating person are also explored, as well as the support offered to caregivers. However, mistreatment happens in a variety of other relational dynamics, such as between family members, with care and services providers, and with friends (Dong, Chen, & Simon, 2014).

Few studies were dedicated to **protective factors**. A high scholarship level is one of them among older adults with depressive symptoms, diminishing the risks of being mistreated (Dong, Chang, Wong, Wong, & Simon, 2014). Furthermore, empowerment (Nahmiash, 2004) and resiliency (Hamby, Smith, Mitchell, & Turner, 2016) can also act as protective factors and possibly diminish the psychological consequences of mistreatment. Finally, formal help (care and services) act as protective factors by diminishing the severity of mistreatment of older adults with disabilities (Lee, 2008), but also by diminishing the risks of mistreatment from a caregiver (Serra et al., 2018).

The papers on the **consequences** of mistreatment of older adults with disabilities focus mostly on the medical and psychological consequences, and more specifically, on mental health (Acierno et al., 2019; Fulmer, Terry, Rodgers, & Pelger, 2014; Fang, Yan, Chan, & Ip, 2018; Park, 2019; Şen & Meriç, 2020; Weissberger, Mosqueda, Nguyen, Samek, Boyle, Nguyen, & Han, 2020). The dependency to essential services provided by the mistreating person makes the mistreated person

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<sup>8</sup> Ableism refers to oppression of people with disabilities.



less likely to react and can thereby make it difficult to identify the consequences of these acts (Ansello & O’Neil, 2010). Nevertheless, the literature about the mistreatment of older adults in general states that the consequences can be of financial, psychological, physical and social nature, such as the loss of financial resources and of belongings, financial burden, temporary or permanent physical aftermaths, health deterioration, decline of functional abilities, death, loneliness, loss of contact with surroundings, etc. (Beaulieu, Leboeuf, Pelletier, & Cadieux Genesse, 2018). It would be surprising if this vast inventory of consequences did not apply to older adults with disabilities. The suffered consequences whether of short-, medium- or long-term, the mistreating person’s characteristics and their relational dynamic with the mistreated person, in a different context than a caregiver relationship, are to be further documented.

The **help seeking** or the denunciation of mistreatment of older adults with disabilities is not well documented. However, the presence of cognitive deficits and intellectual disabilities increases the possibility that the older adult does not recognize acts of mistreatment, that they will not know where or how to seek help or to denounce and that no one will believe them if they do (Frazão, Silva, Norton, & Magalhães, 2014; Frazão, Correia, Norton, & Magalhães, 2015; Kamavarapu, Ferriter, Morton, & Völlm, 2017).

Concerning interventions or **services trajectory**, the information is fragmented. No research specifically about the prevention of mistreatment of older adults with disabilities has been found. The majority of identified research focus only on detecting financial mistreatment, more specifically of older adults with cognitive deficits. Furthermore, very little research adds to the question of direct intervention, or any other form of follow-up. Finally, only one research, realized with file analysis presents services trajectory among older adults with disabilities (Gassoumis, Navarro, & Wilber, 2015). Thereby, older adults’ reports on their services trajectory and their evaluation of the latter are not documented. In short, the field of practice is heavily under documented in the matter of older adults with disabilities.

## Methodological approach

Diverse strategies were used to recruit participants for this research<sup>9</sup>, which demanded a lot of time and ingenuity. Recruitment was suspended in March 2020 because of the first wave of COVID-19. The data collection was realized in the participants’ place of choice, whether at home or at the Research Centre on Aging, with an average duration time of 101 minutes, started by completing a short sociodemographic questionnaire (survey) and was then followed by a semi-directed interview. Because of the sensitive subject matter, each interview was conducted in duos in which a senior researcher was present. By the demand of the participants, three interviews were realized in the presence of an accompanying person: a relative (n = 2) and a psychosocial practitioner (n = 1). A member of the duo drew the services trajectory on the spot and made sure of its validity with the participant. After it was photographed, the trajectory’s drawing was given to the participant. Some participants gave documents to the research duo, in which many of them testified about the different procedures that were taken to receive support. The transcribed interviews in the form of verbatim were analysed through NVivo software using a thematic approach (Paillé & Mucchielli, 2012).

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<sup>9</sup> The research proposal was approved by the Ethics Committee of Research of the CIUSSS of Estrie-CHUS.

Eleven participants<sup>10</sup> recounted 18 instances of mistreatment suffered during the last five years. This group was composed of eight women and three men aged on average of 73.5 years. The average age of disability declaration is 41.7 years, varying from birth to old age. The types of disabilities are hearing, intellectual, memory, psychological health, and mobility with combination of agility and mobility. The participants live in a traditional home, private seniors' residence (PSR), family type resource (FTR) or in a long-term care centre (LTCC). Even though the interviews were specifically about two types of mistreatment, psychological or material and financial, suffered during the five years prior to data collection, the interviewees spontaneously recounted events of physical mistreatment, organizational mistreatment, violation of rights and ageism.

## **Objective 2: Documenting, through cases, of psychological and material and financial mistreatment of older adults with disabilities**

Among the 11 participants, three of them suffered two instances of mistreatment and two suffered three since the last five years, which explains the total of 18 instances. Even though it is impossible to draw a conclusion on the prevalence of mistreatment from such a sample, almost half of them has suffered more than one instance in five years. Only three of the 18 instances recounted did not include either psychological mistreatment or material and financial mistreatment. Among the 15 instances of psychological mistreatment or material and financial mistreatment, only three exclusively included material and financial mistreatment and only one psychological mistreatment. All the other instances presented combinations of different types of mistreatment where the most frequent, in nine instances, mixed psychological mistreatment and material and financial mistreatment. Therefore, it was impossible to make a nuanced analysis based on the type of mistreatment suffered.

As for the **location** and the **mistreating people and organization**, two thirds of the instances of mistreatment occurred in the participants' living environment. They were the results of people or public, private or community organizations and even from the older adult's informal network. In 10 of the 18 instances, the participants directly link the mistreatment to the fact that they have a disability. In the eight other instances, they link it either to their older age, to context where they are more vulnerable or to factors related to the mistreating person. Furthermore, 14 of the 18 instances of mistreatment occurred in a context of care and services provision, either by a caretaker from the RSSS at home or in a hospital, by the owner or administrator of a FTR, by an administrator of a PSR, by a caregiver or by at home services of the private, community or social economic sector. The variety of mistreatment location is therefore richer than what was found in the literature.

The main **vulnerability factors** for mistreatment recounted by the participants are: one or more past experiences of victimization, monetary problems, dependency on services to properly function, health problems, one or more disabilities, trouble with understanding and analysing circumstances, and inability or difficulty in managing belongings and heritage. These results tie in

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<sup>10</sup> We warmly thank each of the person who participated to this project. Doing it in their own way and respecting who they are, each of them has welcomed us and accepted to recount difficult moments of their lives. This certainly stirred and made revisits darker periods. We felt such generosity and open-mindedness from each of you.



with what was found in the literature review. Particularly, in our sample, the difficulties with managing belongings and the increase in mistreatment risk are noteworthy among one participant with a mental disability. The latter suffered material and financial mistreatment. Other types of mistreatment were also experienced many times during this person's life course and it did not stop with aging.

The main **risk factors**, which are extrinsic to the person, are the mistreating person's characteristics: drug and alcohol use, financial problems, personality traits, troublesome life path. To this can be added conflicts or death in the family, isolation, living environment's characteristics as well as the lack of help resources and services. Globally, these results corroborate the fact that the presence of certain types of disabilities is a vulnerability factor for mistreatment. They also support the recent Québec studies which note that functional dependence, as well as home services, are vulnerability and risk factors for mistreatment (Gingras, 2020). The results of this study do not allow to identify **protective factors** for mistreatment because the data collection only relates on past events. However, the presence of relatives is presented as a form of protection as much for procedures that were undertaken as for prevention of mistreatment recurrence.

Mistreatment has resulted in many short- and long-term **consequences**. The latter are of a physical, psychological, material and social nature. For example, they take the form of incomprehension, guilt, stress, anticipation, fear, loss of self-confidence, potential health threatening decision-making, severe exacerbation of mental health problems, suicidal thoughts, difficulty mourning. These consequences corroborate what was found in the literature review. Relatives were also directly affected, whether they were directly targeted by the mistreatment or had to get involved to accompany the mistreated person. There is very little documentation on the subject in studies on mistreatment of older adults with disabilities. Resiliency can be seen in many adaptation processes of the participants, beyond the harmful short- and long-term consequences. Furthermore, empowerment is notably witnessed as a tool for help seeking. It is interesting to note that the reactions of resiliency and empowerment among participants who suffered more than one instance of mistreatment can change from one instance to another. This result is a reminder that there is a need to take into account many circumstantial factors related to the person, the mistreating person or organization and the nature of the events.

Many of the **hindrances to help seeking or denunciation** mentioned by the participants, such as fear of the consequences and feelings of shame, embarrassment, and guilt, concur with the general literature on the mistreatment of older adults (Beaulieu, Pelletier, & Dubuc, 2018). Nevertheless, other hindrances were identified. Some are directly linked to the presence of disabilities, like the fear of losing an essential service and the loss of energy associated with the presence of a disability and/or the presence of multiple victimizations. Closely related to disability instances, these hindrances can prevent the use of procedures to put an end to the mistreatment instances.

Each of the 18 documented instances of mistreatment occurred in a particular context which led to a unique **services trajectory**, often sinuous and complex which renders it impossible to extrapolate a uniform pattern. The participants applied to multiple services to seek help and support. Which leads us to assert that a "typical trajectory" of services, when psychological or material and financial mistreatment instances occur, does not seem to exist or at least was not shown in this study. Though, different types of support were identified: help from the informal network, the public sector, the community sector as well as the private sector. These services mainly act individually or in collaboration in certain cases. No matter the severity of the disability, the

presence of a key person in the older adults with disabilities' services trajectory constitutes a major supporting factor in the steps to stop mistreatment.

This help can be formal, as in the case of a psychosocial practitioner of the RSSS or a community organization countering mistreatment, or can be informal if it comes from a relative. Moreover, relatives were the first people to be informed of the mistreatment instances, for 10 of the 11 participants. This conclusion taken from the analyses of the data corroborates the results previously presented in the literature, where the presence of formal help (care and services) acts as a protective factor to diminish the severity of mistreatment suffered by an older adult with disabilities (Lee, 2008). However, our research shows the utmost importance of formal help in supporting undertaken procedures or emotional support even though this subject of accompaniment of mistreated people was not studied to this day. Three organizations were particularly appreciated because of the way they coordinated their procedures: Service Quality and Complaints Commissioner, certain social workers of the RSSS and the community organization dedicated to counter mistreatment of older adults in Estrie. Multiple parts of the follow-up are appreciated, for example, the rapidity, the availability, the reception quality, the recognition of the mistreatment instance, the active listening, the fast-tracking of the indicated hints and an approach allowing to diminish guilt during the first contact. Among the depreciated parts, a lot of them are of communicational nature, in addition to a lack of compassion, of support, of information on the procedures undertaken or not, as well as their results, such as the ending of services without any resolution and the limits of services offered.

### **Objective 3: Recommendations**

Leaning on the findings from the literature reviews and the analysis of data, a series of recommendations were elaborated. To make sure not to lose any of the richness of these factual elements and the multiple recommendations, this section of the research summary is entirely reproduced in Annex 2.

### **Conclusion**

This research is the first in Québec aiming to document the experience of psychological mistreatment and material and financial mistreatment of older adults with disabilities as well as their services trajectory to end it. By giving a chance to older adults with disabilities to speak about their experiences, this research adheres to an emancipatory aim of countering ableism, where the voice of the main concerned people is put to the forefront. Like every pioneering work, it comes with certain limits. The first concerning the small number of participants, the second, coming directly from the first, is linked to the lack of diversity among the participants, and the third results from the active role of certain organizations in the recruitment, which leads to the latter being necessarily named more often by the participants. Finally, since it happened in the Estrie region, certain results cannot be generalised to the broader population of Québec, because service offering, notably in the community sector, varies according to regions.

Our research shows the importance of monitoring the mistreatment that occurs in particular contexts, being the providing of cares and services to people with disabilities. In this case, our

results stand out from other previous works talking about the context of caregiving and accommodation.

The use of the HDM-DCP to place the mistreatment of people with disabilities has allowed a systemic analysis of the question by linking the personal factors to those associated with their living environment. The lifestyle of older adults with disabilities is turned upside down by mistreatment. Whether it is during the event itself or after, from short- to long-term, the people undergo a series of feelings and have reactions that affect their everyday life on a psychological, physical, social and financial level. In short, no part of their life is spared.

Our research is the only one to distinguish the consequences post-events in two parts. Recognizing the extent of the short-term consequences, we note that on the long-term, the participants also reported after-effects such as a lasting incomprehension, guilt, stress, fear, lost of trust, decision-making that could endanger their health, suicidal thoughts, difficulty mourning, increased nervousness, a change in their self-esteem, isolation, the aggravation of pre-existing health problems and indebtedness. Even if the majority of the participants are satisfied by the way the mistreatment has been settled, we are forced to notice that psychosocial accompaniment to promote resiliency could be optimized. It is certainly an approach advocated by multiple organizations who accompany victims of criminal acts, such as the Québec Association Plea-Victims (free translation of *Association québécoise Plaidoyer-Victimes*) (2018), which insists on the necessity of understanding the consequences of victimization with the goal of offering adequate interventions.

The defense of rights was at the forefront of this research. It was first expressed by certain participants who stated that they participated to this research because of their desire to put to contribution their difficult experiences to prevent such ordeals from happening to others. The participants also stated their willingness to have their rights respected through the multiple procedures they undertook to obtain help, to demand a change of care provider to free themselves from the one who mistreated them, to improve their understanding of the situation (especially in instances of mistreatment where insurance, legal or other documents are involved), to provoke, maintain or modify a contact with the mistreating person or other. This research shows the importance of accompaniment in the defense of rights, especially by paying special attention to what was revealed by the people who undertook procedures by themselves, as well as having to overcome many hurdles. They did not all have the feeling that their rights were finally recognized, and that the situation was settled satisfactorily. However, the rights of the RSSS users seemed to have been taken into account in a satisfactory way. For most, the care provider considered to be abusive was quickly removed from the file and the older adult was reassigned to another care provider. Furthermore, in multiple instances, the file was processed by the local Service Quality and Complaints Commissioner. Nevertheless, certain participants did not know their rights. Among those who knew them, certain recounted difficulty in affirming them and having them recognized.

The final word is given to a participant who undertook multiple procedures, often with limited success, to be heard, to assert their rights and to stop the mistreatment and its financial consequences. Their testimony was shared to encourage everybody to act upon what they must or can do to change something in the life of someone with disabilities seeking help. This observation is addressed to care providers as much as organizations to stop the feeling of going back and forth that many people have when seeking help, which shows the need to have more coordination between the answers to stop mistreatment from organizations and care providers:

As for me, I can tell that there are a lot of flyers, there are a lot of groups, there is a lot of things. But, when you arrive, and it is a real case: “Oh, this would not really be for us to do something, you would be better off to call there.” “You would be better off to call there.” You get transferred from one to the other, in short. You have no one, you know... In the end, they are here to help you, but... [...] it looks like, sometimes, they cannot be bothered. (Free translation of Participant 3’s words)

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## Annex 1 – Scientific Committee and Advisory Committee

### Scientific Committee

#### Research team

- Marie Beaulieu, Ph. D. – Main researcher (entire project)
- Hélène Carbonneau, Ph. D. – Co-researcher (entire project)
- Julien Cadieux Genesse, M.S. s. – Project coordinator (November 2018 to June 2019)
- Anabelle Rondeau-Leclaire, M.S. s. – Project coordinator (September 2019 until the end)
- Marie Crevier, Ph. D. – Collaborator (January 2019 to the end)
- Lyson Marcoux, Ph. D. – Collaborator for additional analysis (summer 2020 until the end)

#### Local Service Quality and Complaints Commissioner of CIUSSS of Estrie-CHUS

- Denis Beaulieu (January 2019 to May 2020)
- Sophie Brisson (May 2020 until the end)

#### Direction Intellectual Disabilities (ID) – Autism Spectrum Disorder (ASD) and Physical Disabilities (PD) of the CIUSS of Estrie-CHUS (free translation of *Direction Déficience intellectuelle (DI) – Trouble du spectre de l'autisme (TSA) et Déficience physique (DP) du CIUSSS de l'Estrie-CHUS*)

- Alain Gagnon (February 2019 to November 2019)
- Chantal Richer (February 2020 to August 2020)
- Véronique Lévesque (September 2020 until the end)

#### Direction of the coordination of the University assignment of CIUSSS of Estrie-CHUS

- Stéphanie McMahon (January 2019 until the end)

#### Direction Support for the Autonomy of Older Adults of CIUSSS of Estrie-CHUS (free translation of *Direction Soutien à l'autonomie des personnes âgées du CIUSSS de l'Estrie-CHUS*)

- Sylvie Moreault (May 2019 until the end)

#### Government agency that helps increase the social participation of people with disabilities in Québec (free translation of *Office des personnes handicapées du Québec*)

- Emmanuelle Bailly (January 2019 to September 2019)
- Patricia Lamothe (September 2019 to January 2020)
- Agathe Richard-Richard (January 2020 until the end)

#### Students involved with the project

- Amélie Bernier-Girard, Bac social work (May to August 2019)
- Marie-Anne Genest-Roy, Bac. Psy. (October 2019 to June 2020)
- Maxime Hébert, Bac. Psy. (Since June 2020) – Ph.D. student in psychology at University of Québec in Trois-Rivières, research profile

## Advisory Committee

People representing seven organizations of Estrie : La Cordée, Handi Apte, Action Disability Estrie (free translation of *Action Handicap Estrie*), DIRA-Estrie, Disability Promotion Estrie (free translation of *Promotion Handicap Estrie*), Assistance and Accompaniment of Complaints Centre (free translation of *Centre d'assistance et d'accompagnement aux plaintes*), as well as the Laboratory of Innovations by and for Older Adults (free translation of *Laboratoire d'innovations par et pour les aînés (LIPPA)*) of the Research Centre on Ageing.

## **Annex 2 – Recommendations**

Our recommendations are divided in three sections. First, winning conditions are listed to make sure that mistreated older adults with disabilities feel well accompanied when undertaking procedures. Next, the recommendations are discussed based on the continuity of services to counter mistreatment of older adults. Finally, recommendations in order to continue research on the subject end this section.

### **1. Winning conditions for satisfying services in the context of mistreatment of older adults with disabilities**

To diminish the risk of mistreatment and promote a satisfactory follow-up in a mistreatment instance, certain conditions must be established. The accompaniment of older adults with disabilities who suffered mistreatment can, in public, private and community services, be optimised by a wellness care approach that notably translates into:

- Reception quality (listening, acknowledging the experience, empathy and availability);
- A quick and precise identification of the demand (or needs);
- A suitable answer to the specificity of each mistreatment instance;
- A partnership approach with the affected person (or their relatives) through the follow-up process (promote an approach centered on the strengths, empowerment and the service user as a partner);
- Accompaniment that takes into account the nature and the severity of the incapacity without it becoming overprotection;
- A support offer in the various procedures undertook, notably by assuring the transfer of personalised files toward other services;
- A follow-up with information on the undertaken procedures in the absence of the affected person.

Leaning on the identification of three groups of more significant actors in the services trajectory, it is highly recommended that in Québec:

- Each region be equipped of specialised community services on the subject of countering mistreatment, like DIRA-Estrie. This involves expertise development and adequate funding;
- Each team of the Service Quality and Complaints Commissioner acts with professionalism and celerity;
- Care providers of the RSSS (particularly social workers) be alert and involved in the follow-up of situations.

## 2. Recommendations based on the continuity of services to counter mistreatment of older adults

The Reference Guide to Counter Mistreatment of Older Adults (free translation of *Guide de référence pour contrer la maltraitance envers les personnes âgées*) has established a continuum of services to identify the different necessary steps to put an end to mistreatment of older adults in Québec. This continuum includes four steps, which are prevention, detection, intervention and coordination of the services (Government of Québec, 2016). Our recommendations are listed according to each step of this continuum, to integrate them harmoniously to the services in place.

### 2.1. Prevention

Considering that:

- Our conferences with the goal of recruiting participants were received as activities to raise awareness and training by the diverse public and community organizations and their members;
- The majority of participants knew little if not at all the public, private or community services that counters mistreatment of older adults that could help them (including the Elder Mistreatment Helpline who, when used, quickly transfers to regional and local services);
- Many participants had positive reactions when they were given a list of regional and provincial resources, even saying that they would have liked to possess this list when the mistreatment occurred;
- None of the participants spoke of the users' committee intended by the Act respecting health services and social services;
- The Assistance and Accompaniment of complaints Centre (free translation of *Centre d'assistance et d'accompagnement aux plaintes*) is not well known and the participants who contacted the local Service Quality and Complaints Commissioner did so after being directed there by care providers;
- Three participants suffered mistreatment in collective living environments where the State makes follow-ups of the quality (FTR and PSR);
- Many participants do not know well or not at all their rights;
- Documents of insurance, contractual, legal or financial nature are likely of causing comprehension challenges for everyone and even more for people with intellectual or memory disabilities;
- Almost all of the participants first revealed their mistreatment experiences to relatives before taking steps for help seeking from public, private or community services;
- The majority of participants were mistreated in a setting of public, private or community service delivery, or even by a relative;
- Many situations perpetrated by service providers revealed communicational and relational shortcomings;
- The defense of one's rights represent an important form of social participation and, therefore, contributes to active aging as it is put forward by the government.

It is recommended to:

- Develop communication strategies enhancing knowledge about the role of users' committees, assistance centres and accompaniment to complaints and the local Service Quality and Complaints Commissioner;
- Incorporate to the programming of organization who work with people with disabilities a series of awareness activities to the recurring and diversify mistreatment for older adults with disabilities, their relatives and the affected staff members (provide adequate funding);
- Continue the advertisement of the Elder Mistreatment Helpline so it is better known;
- Deliver in each region, especially with the collaboration of organizations working with people with disabilities or who are defending their rights, a list of available resources (assignment, target audience and services) that people can keep and consult if a mistreatment instance occurs;
- Ensure that this available resources' list is adapted to be properly read by people with specific disabilities (visual, intellectual, etc.);
- Following the same train of thought, create widely distributed awareness material about the different rights: of RSSS' users, of tenants, of consumers, etc.;
- Ensure that this information on rights is adapted to be properly read by people with specific disabilities (visual, intellectual, etc.);
- Make accessible a unified list of resources on the Government agency that helps increase the social participation of people with disabilities in Québec (free translation of *Office des personnes handicapées du Québec*)'s website, on the Elder Mistreatment Helpline's website or on other governmental websites to make sure that a wide audience can access it;
- Reinforce governmental control (accreditation rules, inspections, etc.) in different collective environment where vulnerable people are more likely to be (FTR, PSR, LTCC, etc.);
- Favor activities that allow improvement of insurance, contractual, legal or financial literacy of older adults with disabilities taking into account their comprehension ability (create a training program);
- Create awareness activities where the rights of people with disabilities are put to the forefront, rights that they will be able to promote and claim;
- Continue to inform the general public, so relatives are able to identify mistreatment and prepare them more adequately to welcome help seeking (or unveiling), if applicable (a possible angle to touch on the upcoming campaigns of provincial awareness);
- Make sure that the training programs allow to expand best practices on the matter of rights defense and the people with disabilities' exercise of citizenship;
- Coordinate with the ministry of Education and of Advanced Education and the different Professional Orders so that each training program of future care providers have a reflexive and practical component on the communicational strategies and the right attitude and behavior with their clientele or the users with disabilities;
- Coordinate with the ministry of Education and of Advanced Education and the different Professional Orders so that each training program of future care providers working with people with disabilities addresses ableism, ageism, sexism, racism and the effects of their intersectionality;
- Ensure that the training on the subject of mistreatment, especially as part of the great deployment of the Act to combat maltreatment of seniors and other people of full age in vulnerable situations (L-6.3), reaches care providers of the public and community network and that it is broaden to the private sector.



## 2.2. Detection

Considering that:

- The hints of mistreatment of an older adult are often subtle;
- In the two instances where the participants had cognitive impairment (intellectual disability and memory deficit), care providers of the public network or relatives were the ones who detected mistreatment;
- In the other instances, it was the older adults themselves (alone or with the support of a relative) which asked for help or denounced the situation.

It is recommended to ensure that:

- Each training program for future care providers working with people with disabilities addresses the recognition of mistreatment, its hints and indicators;
- Each continual training program of public, community and private network care providers more likely to interact with older adults with disabilities addresses the recognition of mistreatment, its hints and indicators;
- The organizations that accompany older adults with disabilities' relatives offer awareness activities to equip them in the identification of mistreatment, its hints and indicators and ensure that they know which services to use.

## 2.3. Intervention

Considering that:

- Many mistreatment instances occurred in the context of caregiving and public, community or private services, which involve the responsibility of concerned organizations;
- The organizations of people with disabilities or of defense of their rights were not really committed in the follow-ups (very little participants turned to them);
- The case of mistreatment of one participant living in a LTCC and one under protective supervision did not lead to the exercise of the Act L-6.3;
- All the participants had short-term consequences and, for many, these became long-term consequences;
- The relatives of these people also suffered consequences of the mistreatment, without having any support.

It is recommended to ensure that:

- The organizations acquire clear intervention rules allowing to react with haste to any reporting, denunciation or complaint involving one of their employees;
- The organizations of people with disabilities or of defense of their rights develop an expertise in the accompaniment of their members who suffered mistreatment;
- The Act L-6.3 be more widely publicised in every public, community or private organizations offering care or services to older adults living with disabilities or adults living with accelerated aging, with the purpose to ensure its exercise in a unified way;
- A psychosocial accompaniment service be not only offered to all older adults with disabilities who suffered mistreatment, but also to their relatives, if they want, in order to compensate for the short- and long-term consequences of mistreatment.

## 2.4. Coordination

Considering that:

- For many participants, evolving through their services trajectory has required a lot of important procedures;
- Coordination, when it happened, came either from social service workers of the RSSS or the community organization specialised in the matter of countering mistreatment;
- The organizations of people with disabilities or of defense of their rights were not really committed in the follow-ups (very little participants turned to them).

It is recommended that:

- Each region of Québec, with the collaboration of the regional coordinators that counters mistreatment of older adults, with their partnership and collaborative acts, have a trajectory of services that is clear, known and shared to facilitate intersectoral collaboration;
- This approach of services trajectory construction clearly states the offered services to the population for each public, private or community organizations who could be involved, to limit as much as possible the “revolving door” phenomenon during help seeking;
- The organizations of people with disabilities or of defense of their rights occupy a place in this trajectory development approach;
- The local and regional structures that counter mistreatment conduct the sharing of inspiring practice and a strategical watch to counter mistreatment of older adults with disabilities and that this information be shared on the provincial level.

## 3. Recommendations for research

Considering that:

- This research is the first in Québec to consider disability not as a vulnerability factor for mistreatment of older adults, but as a condition of certain people that deserve our full attention;
- This research is the first to explore summarily the intersectional challenges of ableism, ageism, sexism (only racism has not been studied, because the sample makeup did not allow it – all the participants were French speaking Caucasians);
- This research is the first in Québec to give a voice to older adults with disabilities on their experiences and their services trajectory;
- This research focused on psychological mistreatment and material and financial mistreatment has allowed to slightly touch other types of mistreatment suffered by the participants;
- Certain people with disabilities could not participate to the research because of their disabilities, which states the question of third-party respondents in research;
- Participating to the project was facilitated by an accompanying person for two participants (we could consider three if we take into account one of the participant’s son);
- In spite of the deployment of many strategies, recruiting for this research project was challenging;
- Almost half of the participants link their mistreatment instance to their disability;
- The majority of documented instances occurred at home and in a context of care or services provision;
- No specific intervention program was created or adapted in Québec, so there has been no research allowing to evaluate the contents, implementation of programs and its effects;

- This research will lead in the upcoming months to the creation of a training pod (podcast) and the production of flyers.

It is recommended to:

- Plan with partners – such as the Elder Mistreatment Helpline, support organizations for mistreated people, support organizations for people with disabilities or of defense of their rights – to continue the documentation of help seeking in mistreatment instances of older adults with disabilities;
- Keep up to date a scientific watch that regroups all national and international writings that document mistreatment of older adults with disabilities;
- Provide and plan a collection of data that allows to document other types of mistreatment than psychological mistreatment and material and financial mistreatment suffered by older adults with disabilities;
- Consider realizing a study that would take into account the voice of mistreatment witnesses or of third respondent, especially when the people with disabilities have a hard time to recount their mistreatment experience;
- With an emancipatory and empowerment goal and in the wake of LIPPA's activities, create an awareness program to counter mistreatment by and for older adults with disabilities (with a steering committee formed of older adults with disabilities) and evaluate their experience;
- Create, in partnership with one or many organizations, an awareness program to counter mistreatment of older adults with disabilities, implement it and evaluate the implementation and its effects (pilot-project);
- Depending on the results of the pilot-project, evaluate the possibility of deploying the program more widely in Québec;
- Finance an implementation study of the material from the training pod (podcast) and the flyers coming from this project;
- Create a program of advanced scholarship (social work, psychology, other relevant disciplines) which would allow to support one or many research projects on mistreatment of older adults with disabilities.