CANADA AT A CROSSROADS: RECOMMENDATIONS ON MEDICAL ASSISTANCE IN DYING AND PERSONS WITH A MENTAL DISORDER

AN EVIDENCE-BASED CRITIQUE
OF THE HALIFAX GROUP IRPP REPORT

EXPERT ADVISORY GROUP
ON MEDICAL ASSISTANCE IN DYING

February 13, 2020



Expert Advisory Group on MAiD

Recommendations on MAiD and Persons with a Mental Disorder An Evidence-Based Critique of the Halifax Group IRPP Report

About the Expert Advisory Group on MAiD

The Expert Advisory Group (EAG) on Medical Assistance in Dying (MAiD) where a Mental Disorder is the Sole Underlying Medical Condition (MD-SUMC) consists of individuals with an extensive range of experience related to Canadian and international MAiD policy and practices, and mental health and illness issues. The group was coordinated by K. Sonu Gaind in February 2020 initially to provide a balanced, evidence-based response to the Halifax Group's report "MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition", and to continue to provide expert advice to stakeholders as MAiD policies continue to evolve in Canada and beyond. The EAG is comprised of several members of the Council of Canadian Academies (CCA) expert panel working groups charged with reviewing the state of knowledge on MAiD, as identified below. Unlike the Halifax Group, the EAG additionally includes experts outside of only CCA panel members, including pre-eminent international experts and those with relevant lived experience with mental disorders. The EAG is particularly appreciative of those fellow EAG members, colleagues and patients with lived experience of mental illness who had the courage to share their experiences and insights.

Members of the Expert Advisory Group on MAiD

Allison Crawford, MD, PhD, FRCP(C)

- Associate Professor of Psychiatry, University of Toronto
- Medical Director, Ontario Psychiatric Outreach Program
- Clinician Scientist, Centre for Addiction and Mental Health, with research in Indigenous health, particularly circumpolar contexts and patient- and community- oriented suicide prevention

K. Sonu Gaind, MD, FRCP(C), DFCPA, FAPA

- Governor and Associate Professor of Psychiatry, University of Toronto
- Chief of Psychiatry/Medical Director of Mental Health, Humber River Hospital
- Member, CCA Expert Panel on MAiD MD-SUMC
- Past Chair, time-limited Canadian Psychiatric Association Task Force on Assisted Dying

Rose Geist, MD, FRCP(C)

- Associate Professor of Psychiatry, University of Toronto
- Director, Collaborative Care Medical Psychiatry Alliance
- Board Member, Consent and Capacity Board of Ontario

Mark Henick

- Mental Health Advocate, Strategist, and Speaker
- With lived experience/expertise of mental illness

Scott Y H Kim, MD, PhD

- Adjunct Professor of Psychiatry, University of Michigan
- Senior Investigator, Department of Bioethics, National Institutes of Health, USA
- Member, CCA Expert Panel on MAiD MD-SUMC

Trudo Lemmens, CandJur, LicJur, LLM (bioethics), DCL

- Professor and Scholl Chair in Health Law and Policy, Faculty of Law and Dalla Lana School of Public Health, University of Toronto, and Joint Centre for Bioethics, University of Toronto
- Member, CCA Expert Panel on Advance Requests for MAiD

Brian Mishara, PhD

- Professor, Psychology Department, Université du Québec à Montréal
- Director, Centre for Research and Intervention on Suicide, Ethical Issues and End of Life Practices, Université du Québec à Montréal
- Member, CCA Expert Panel on MAiD MD-SUMC

Sandy Simpson, MBChB, BMedSci, FRANZCP

- Associate Professor of Psychiatry, University of Toronto
- Chief of Forensic Psychiatry, Centre for Addiction and Mental Health (CAMH)

Harvey Schipper, BASc, MD, FRCP(C)

- Professor of Medicine, University of Toronto
- Adjunct Professor of Law, University of Toronto
- Member, CCA Expert Panel on Advance Requests for MAiD

Tom Shakespeare, PhD, FBA

- Professor, International Centre for Evidence on Disability, London School of Hygiene and Tropical Medicine
- With lived experience/expertise of physical disability

Tim Stainton, MSW, PhD

- Professor, School of Social Work, and Director, Canadian Institute for Inclusion and Citizenship, University of British Columbia
- Member, CCA Expert Panel on Advance Requests for MAiD
- Past Co-Chair, Canadian Association for Community Living Task Force on MAiD

Georgia Vrakas, PhD

- Psychologue, Professeure agrégée, Département de psychoéducation Université du Québec à Trois-Rivières - Centre universitaire de Québec
- Chercheuse régulière au Centre de recherche et d'intervention sur le suicide, enjeux éthiques et pratiques de fin de vie
- With lived experience/expertise of mental illness

This report reflects the views of the individuals of the EAG, and should not be construed to represent views or endorsement of any group the respective individual's work with or for. All attempts have been made to ensure views articulated are based on expert interpretation of the best and fullest range of evidence to assist in guiding policy.

To cite this document:

Expert Advisory Group on MAiD. (2020). Canada at a Crossroads: Recommendations on Medical Assistance in Dying and Persons with a Mental Disorder - An Evidence-based Critique of the Halifax Group IRPP Report. Toronto (ON):EAG. doi: 10.13140/RG.2.2.36236.87687 or 10.13140/RG.2.2.36236.87687/1

Released February 13, 2020 French translation to be published in February 2020

Cover image: Dorasan Station, Paju, Gyeonggi-do, South Korea. © 2015 K.S.Gaind

For any feedback or to contact the EAG:

Email: EAGMAiD@gmail.com Website: www.eagmaid.org Follow Twitter @EAGMAiD

EXECUTIVE SUMMARY

Canada is at a crossroads as we strive to find the most appropriate balance of medical assistance in dying (MAiD) laws and policies. The crossroads we face is not simply about legislation or a theoretical legal framework - it is about the real world implications of whom we help to die, and who we see ourselves as, as a society.

Prior to 2015 MAiD was prohibited by the Criminal Code of Canada. As we look towards the imminent rescinding of the "reasonably foreseeable natural death" safeguard, we need to carefully consider who we believe should be provided MAiD, and who should be protected from it. As expected with an issue as profound as MAiD, there is a diverse range of opinion about who should and should not be provided assisted dying. One thing, however, is clear – Canadians deserve policy that is based on the best evidence available.

MAiD policies in Canada have developed on the premise of having an irremediable medical condition with irreversible decline and unresolvable suffering, with MAiD being provided to relieve otherwise inevitable suffering. This naturally requires a condition that can be deemed to be irremediable. Unlike other medical conditions with a known, predictable course, evidence shows that mental illnesses can never be predicted to be irremediable. As the Centre for Addiction and Mental Health has pointed out, "At any point in time it may appear that an individual is not responding to any interventions – that their illness is currently irremediable - but it is not possible to determine with any certainty the course of this individual's illness."

Despite the scientific evidence showing that irremediability of mental illnesses cannot be predicted, some health professionals would nonetheless claim they could assess a person with mental illness as being irremediable, leading to people receiving MAiD without ever knowing they would have gotten better.

Some argue that if MAiD is available to those with predictably declining medical illnesses, it must be made available to those with mental disorders or we risk discrimination. In fact, allowing MAiD for mental disorders that cannot actually be determined to be irremediable, while claiming it is being provided for an irremediable condition, would be the ultimate form of discrimination.

If Canada's MAiD laws fail to explicitly acknowledge that it is impossible to predict irremediability for mental illnesses, marginalized populations suffering from mental illness will be provided MAiD for all sorts of life suffering, even when their mental disorder could have gotten better. To avoid exposing those suffering from mental disorders to a discriminatory risk of premature death, Canada's MAiD laws should explicitly recognize that irremediability cannot be predicted for mental disorders.

Once the "reasonably foreseeable natural death" safeguard is rescinded, Canada will become the most permissive jurisdiction in the world for MAiD, with the fewest safeguards against unwanted deaths, unless additional safeguards are introduced. Other jurisdictions worldwide require a "lack of reasonable"

alternatives" prior to MAiD being offered. This safeguard is uniquely absent in Canada's MAiD framework. Canadians should expect that MAiD is provided only when there are no reasonable alternatives and a person's decision to pursue MAiD is truly well-considered. Thus a "lack of reasonable alternatives" safeguard should be introduced. Finally, ambivalence is recognized as a key feature of suicidal individuals whom suicide prevention initiatives aim to help stay alive to get better. A "non-ambivalence" safeguard should be introduced to prevent society from facilitating the suicides of these vulnerable persons.

CORE RECOMMENDATION

As outlined in detail below, based on a fulsome review of evidence and key differences between mental disorders and other progressive medical conditions informing evolving MAiD policy, as Canada envisions rescinding the "reasonably foreseeable natural death" criterion the EAG makes a single core recommendation regarding MAiD MD-SUMC, that:

MAiD policy and legislation should explicitly acknowledge that determinations of irremediability and irreversible decline cannot be made for mental illnesses at this time, and therefore applications for MAiD for the sole underlying medical condition of a mental disorder cannot fulfill MAiD eligibility requirements.

ANCILLARY RECOMMENDATIONS

Ancillary Recommendation 1:

A non-ambivalence criterion should be required for MAiD in situations when death is not reasonably foreseeable.

Ancillary Recommendation 2:

A "lack of reasonable alternative" criterion should be required prior to being eligible for MAiD in situations when death is not reasonably foreseeable.*

*NB: For reasons articulated in Section 3 (iv), the EAG supports a "lack of reasonable alternative" criterion for all MAiD applications, as is required elsewhere in the world except in Canada. However, this criterion is particularly essential to introduce as current policies change and the "reasonably foreseeable natural death" criterion is rescinded, which is the focus of this critique.

¹ Mishara, B. L., & Kerkhof, A. J. F. M. (2018). Canadian and Dutch doctors' roles in assistance in dying. Canadian journal of public health, 109(5-6), 726-728. doi:10.17269/s41997-018-0079-9.

BACKGROUND

This critique was borne out of the need to urgently respond to the Institute for Research on Public Policy (IRPP) Halifax Group's Report, "MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition", during a crucial time when national and provincial policies with profound social and ethical implications are being formed. As Canada envisions rescinding the "reasonably foreseeable natural death" criterion, Expert Advisory Group (EAG) members believe Canadians deserve policy based on the best and most complete evidence available. The EAG is deeply concerned that the conclusions and many recommendations reached in the Halifax Group's report are flawed, and based on incomplete or selective review and interpretation of existing evidence.

The Halifax Group report issues a disclaimer that views expressed in their report represent individual views, and not those of the Council of Canadian Academies (CCA) nor of the CCA Expert Panel Working Group on Medical Assistance in Dying (MAiD) where a Mental Disorder is the Sole Underlying Medical Condition (MD-SUMC). None of the members of the EAG were aware of the Halifax Group's work until it was publically released January 30, 2020. The EAG felt it important that evidence-based counter arguments be presented to ensure public policy not be informed by any misperception that the Halifax Group report reflects expert consensus. It should be made clear that there is significant dissent regarding the provision of MAiD for those with mental disorders. In fact, in terms of the overall underlying conclusion of the Halifax Group report, that MAiD should be provided for mental disorders, surveys of mental health providers show that while most (72%) do support MAiD in general, most do not support MAiD for mental illnesses (only 29% in support)². This is not a reflection of stigma or discrimination on the part of the very professionals who work in mental health. Instead it is a reflection of highly relevant differences between mental illnesses and other progressive medical conditions for which MAiD is envisioned, as will be detailed below.

The EAG also felt it important that this critique be informed by a broader range of perspectives than only of those who worked on the CCA MAiD MD-SUMC expert panel. The Halifax Group indicates its membership came together "on the basis of their expertise and experience serving as members of the CCA expert panel". As outlined below, a central message of the final report of the CCA MAiD MD-SUMC panel was that there was no agreement on whether MAiD MD-SUMC could be safely introduced without unduly risking the lives of vulnerable persons. While the 15 month process on the expert panel certainly contributed to levels of awareness and background knowledge of all panelists in the area of MAiD MD-SUMC, a key omission from the

² Rousseau, S., Turner, S., Chochinov, H. M., Enns, M. W., & Sareen, J. (2017). A national survey of Canadian psychiatrists' attitudes toward medical assistance in death. The Canadian Journal of Psychiatry, 62(11), 787-794.

CCA process was involvement on the panel of anyone identified or participating from the perspective of lived experience with mental illness. Likewise, none of the chosen independent reviewers of the CCA MAiD MD-SUMC report were selected for lived experience with mental illness. The EAG has attempted to correct this gap, which continues in the Halifax Group report, by broadening expert membership beyond simply those who are ex-CCA panelists and including those with lived experience/expertise.

This critique will not review the historical background that has led to the current state of MAiD policy in Canada, which forms approximately half of the Halifax Group report. The EAG assumes readers are aware of this relevant background. Instead the focus of this critique is on the "Foundations for Recommendations" and the "Recommendations and Conclusion" of the Halifax Group report, many of which the EAG views as being flawed.

Finally, in terms of the actual CCA reports, the internal discussions and deliberations of that process remain confidential as all participants agreed. However, members are able to comment on the final CCA public report. Notwithstanding disclaimers from both the Halifax Group and the EAG that the groups' respective reports reflect individual views and not views or endorsement of any other group, the EAG is aware that the fact that many members of both the EAG and all members of the Halifax Group served as CCA expert panelists may confer a degree of legitimacy to their views. In this regard, it is important to note that even after an extensive 15 month process and production of a 247 page report³ with 25 key findings, perhaps more telling than the key findings is that at the end of this exhaustive process there remained five large areas of disagreement on fundamental key issues. There was likewise no agreement on whether any of the explored potential "safeguards" would actually be effective as safeguards to mitigate risk of overinclusion in providing MAiD. It is for this reason that the EAG felt it necessary to issue this critique, to highlight three issues:

- The Halifax Group's report does not reflect expert consensus opinion
- The Halifax Group's report does not report the key scientific evidence that contradicts their conclusions
- The CCA MAiD MD-SUMC report did not provide consensus guidance on key issues regarding whether or how to expand MAiD policy for MD-SUMC

Prior to outlining the many critiques of the Halifax Group report, the EAG would like to agree strongly with many of the points raised in Section 5.6 and recommendations 8 through 10 in that

³ Council of Canadian Academies, 2018. The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition. Ottawa (ON):The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition. [CCA MAID MD-SUMC]

report. Specifically the EAG agrees with the importance of improving access to mental health services, and increasing resources and funding for mental health care in Canada. These recommendations are not novel nor unique to the EAG nor the Halifax Group. Many others have been making similar recommendations for years if not decades, yet access and resources for mental health care remain unacceptably poor in our country.^{4,5}

CRITIQUE OF KEY POINTS IN HALIFAX GROUP IRPP REPORT

1. Flawed Fundamental Premise

The Halifax Group's report is predicated on a flawed fundamental premise. The Group makes the assertion that "in specific cases, the eligibility criteria of enduring, intolerable and irremediable suffering, and advanced and irreversible decline in capability could be met." Based on this premise, the Group argues MAiD for mental illness should be permitted, that it would be discriminatory not to allow such applications, and makes a series of recommendations outlining processes that could be implemented for applications for mental illness.

However, the underlying premise that eligibility criteria could be met by identifying irremediability in any application for MAiD for mental illness is flawed. The Halifax Group may be citing its opinion, but that opinion is not evidence-based. Existing evidence demonstrates the opposite, that irremediability cannot be identified in individual cases of mental illness.

It is important to make the distinction between whether or not a condition may retrospectively be seen 'after the fact' as having been irremediable, versus whether or not future irremediability can prognostically be identified in any particular case. To fulfill eligibility criteria, MAiD assessments require a prognostic assessment in each individual application that "a person has a grievous and irremediable medical condition," which is currently defined if all the following are met:

- (a) they have a serious and incurable illness, disease or disability;
- (b) they are in an advanced state of irreversible decline in capability;

⁴ Kirby, M., Howlett, M. (2009). Out of the Shadows Forever, Annual Report 2008-2009. Mental Health Commission of Canada.

⁵ Mental Health Commission of Canada. (2012). Changing directions, changing lives: The mental health strategy for Canada. Calgary, AB.

⁶ The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy. Pg. 13.

- (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and
- (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining."⁷ [with (d) criterion being declared unconstitutional in the 2019 Truchon/Gladu ruling]⁸

Expert bodies reviewing the evidence regarding identifying irremediability in mental illnesses have reached consistent conclusions. The Canadian Psychiatric Association has stated that "there is no established standard of care in Canada, or as far as CPA is aware of in the world, for defining the threshold when typical psychiatric conditions should be considered irremediable." In its policy advice on MAiD, the Centre for Addiction and Mental Health (CAMH) has indicated it is impossible currently to identify irremediability in any individual case of mental illness, stating: "At any point in time it may appear that an individual is not responding to any interventions — that their illness is currently irremediable - but it is not possible to determine with any certainty the course of this individual's illness. There is simply not enough evidence available in the mental health field at this time for clinicians to ascertain whether a particular individual has an irremediable mental illness." 10

Similarly, after careful review other professional bodies have also stated psychiatric illnesses should not be the basis for assisted dying given they cannot be considered terminal or irremediable. The American Psychiatric Association "holds that a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death", ¹¹ and the Royal Australian and New Zealand College of Psychiatrists "does not believe that psychiatric illness should ever be the basis for physician assisted suicide". ¹²

Even advocates for expansion of MAiD for mental illnesses have agreed it is not possible to identify irremediability in mental illnesses.

⁸ Truchon v. Attorney General of Canada, 2019 QCCS 3792 (CanLII).

⁷ RSC 1985, c C-46.

⁹ Gaind, K.S. (2016). Canadian Psychiatric Association interim response to Report of the Special Joint Committee on physician assisted dving.

¹⁰ Centre for Addiction and Mental Health (CAMH). (2017). Policy Advice on Medical Assistance in Dying for Mental Illness. Toronto (ON): CAMH.

¹¹ American Psychiatric Association. (2016). Position statement on medical euthanasia. APA.

¹² Royal Australian & New Zealand College of Psychiatrists. (2016). Position Statement 67: physician assisted suicide. Royal Australian and New Zealand College of Psychiatrists. RANZCP.

While arguing for allowing MAiD for mental illnesses, Dembo, Schuklenk and Reggler state: "With respect to irremediability, *although it is impossible to predict response or remission with certainty,* capable patients should have the right to make their own judgments based on the best evidence available at the time of decision making [emphasis added]." The EAG agrees capable patients should have the right to make decisions with the best available evidence, however the key issue regarding irremediability is neither about autonomy nor about capacity of decision-making. MAiD applications require predicting irremediability, and that is not knowable in mental illnesses. Even capable patients cannot know what is unknowable.

The risk of providing MAiD for mental illnesses, while being unable to predict irremediability of mental illnesses, is obvious. Non-dying people who would have improved will be assisted to die prematurely.

This is strikingly illustrated in another piece by Dembo (who also testified in Truchon/Gladu that MAiD should be allowed for mental illnesses). In an earlier published case study Dembo describes "Patient 1" as a "38-year-old woman with schizophrenia and obsessive-compulsive disorder, with both illnesses proving resistant to multiple medications and psychotherapies" who "attempted suicide three times after nearly 10 years of chronic, severe distress." When Dembo and the medical psychiatry service was consulted to see Patient 1, Dembo and the team "believed that there was almost no likelihood that she could recover", and Dembo indicates "a detailed review of the literature also indicated that her prognosis was extremely poor." However, Dembo writes that after another treatment attempt, "her [Patient 1's] symptoms vanished, and she has now remained well for 2 years. She is once again engaged in academic and advocacy work, as well as with friends and family, and grateful to be alive", and concludes the vignette with "I recall feeling conflicted that we were dissembling when we told her that she was likely to recover. Now, in hindsight, it seems that we did the right thing, but, at the time, we could not possibly have known." [emphasis added throughout]

The focus of the above piece was the health care provider's moral struggle with providing hope in a situation of mental illness that they and the team, after careful review, thought was hopeless. While the above case was not a MAiD assessment since it was prior to MAiD being permitted in Canada, it is clear that Dembo and the team thought the case was irremediable. The patient was also seeking death, as evidenced by her repeat suicide attempts, and there is no suggestion in the case study that the patient lacked capacity. If MAiD for mental illness had been allowed, Patient 1 would almost certainly have met all criteria, including (incorrect)

EAG Report on MAiD and Persons with a Mental Disorder

11

¹³ Dembo, J., Schuklenk, U., & Reggler, J. (2018). "For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying where Mental Illness Is the Sole Underlying Condition. Can J Psych, 63(7):451-456.

¹⁴ Dembo, J. & Clemens, N. (2013). The Ethics of Providing Hope in Psychotherapy. J Psychiatric Practice, 19(4):316-322.

determination of irremediability, and would have been assisted to die. Yet Patient 1 did improve and was "grateful to be alive", and Dembo acknowledges the team "could not possibly have known" this future course.

The EAG notes with some irony that, had MAiD for mental illness been provided for this non-dying 38 year old woman, rather than moral distress at conveying hope in a situation the health care provider thought was hopeless, the health care provider would likely have felt professional satisfaction that they compassionately helped the patient avoid further suffering, and would have never known their mistake.

Being unable to predict irremediability of mental illnesses should not be wrongly equated with the expected uncertainty in predicting the course of various other medical conditions with known pathophysiology and course, such as neurodegenerative conditions that were before the courts in Carter and Truchon. Unlike mental illnesses, illnesses like advanced cancer or neurodegenerative conditions do have predictable courses, notwithstanding the rare 'miracle cure'. This is simply not true for mental illnesses. Even untreated, clinical depression is estimated to spontaneously remit in over 50% of cases. ^{15, 16} And even in an illness such as schizophrenia, which at one time was assumed to lead to a potentially unremitting or progressive course, recent reviews suggest that "around 50% of people with the illness meet objective criteria for recovery for periods of time during their lives, with the periods increasing in frequency and duration once past middle age". ¹⁷

The issue of the inability to predict irremediability is minimally acknowledged in the Halifax Group report, yet it is fundamental to the question of whether MAiD should be permitted for mental illnesses. The Halifax Group acknowledges that "it can also be very difficult or impossible to provide with confidence the prognosis of the condition and predictions of treatment effectiveness", but goes on to state that "in some cases, however, the required assessment of capacity, prognosis, or treatment effectiveness will not be difficult, and it will be clear whether a person meets or does not meet the eligibility criteria". There is no evidence supporting the italicized assertions insofar as the predictability of irremediability of mental illnesses. In fact, after extensive review of this issue, the CCA expert panel which all Halifax Group members also sat on could not find evidence from anywhere in the world that supports being able to identify irremediability in individual cases of mental illness.

EAG Report on MAiD and Persons with a Mental Disorder

1.

¹⁵ Whiteford, H.A., Harris, M.G., McKeon, G., Baxter, A., Pennell, C., Barendregt, J.J., & Wang, J. (2013). Estimating remission from untreated major depression: a systematic review and meta-analysis. Psychol Med, 43(8):1569-85.

¹⁶ Chin, W.Y., Chan, K.T., Lam, C.L., Wan, E.Y., & Lam, T.P. (2015). 12-Month naturalistic outcomes of depressive disorders in Hong Kong's primary care. Fam Pract, 32(3):288-96.

¹⁷ Bellack, A.S. (2006). Scientific and Consumer Models of Recovery in Schizophrenia: Concordance, Contrasts, and Implications. Schizophr Bull,32(3):432-42.

The Halifax Group report's assertion that assessing prognosis in some cases of mental illness "will not be difficult", and determining irremediability criteria "will be clear", may reflect the Group members' personal views, but it does not reflect any evidence or fact. Similarly, any assessments of irremediability or irreversible decline would be based on an individual assessor's own personal value system and beliefs, rather than on any scientific or evidence-based determination of irremediability (the latter of which does not exist for mental illnesses). The unfounded belief of the Halifax Group that irremediability requirements can nonetheless be met illustrates the risk that some practitioners will, wrongly, think they can make determinations of irremediability of mental illnesses, when in fact such determinations cannot be made.

The Halifax Group suggests the requirement of two medical or nurse practitioners being of the opinion that eligibility criteria are met would somehow be protective. As above, given the impossibility of identifying irremediability in mental illnesses, the EAG and existing evidence does not support that this is an effective safeguard. Having two practitioners guess about something that is not knowable does not make it knowable or predictable.

In its recommendations, the Halifax Group itself advises that the "default position in cases of *uncertainty about* decision-making capacity, *prognosis*, and treatment efficacy is that the person is ineligible for MAiD [emphasis added]". The EAG agrees. As the chair of the CCA MAID MD-SUMC expert panel correctly pointed out last year after the extensive CCA review process was complete, while cautioning that 'much more study and research must be done before Parliament makes any change to the law.....no one can be completely certain that a mentally ill patient is never going to get better: "It's not clear that we have ways of measuring peoples' capacity to make decisions that are robust enough so that we wouldn't make mistakes one way or the other." No new clinical or scientific evidence has emerged in the past year to change that viewpoint.

While the Halifax Group suggests two practitioners should be able to make a determination of irremediability of mental illness, this is unfounded; actual evidence shows that at this time, all cases of mental illness have significant uncertainty of prognosis. Determinations of irremediability and being in an "advanced state of irreversible decline in capability" cannot be made in cases of mental illness. However, as evidenced by the Halifax Group's assertions, some practitioners would nonetheless assess some cases of mental illness to be irremediable based on personal values and judgement, despite not being able to truly make such a determination.

EAG Report on MAiD and Persons with a Mental Disorder

¹⁸ The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy. Pg. 21.

¹⁹ CBC News, January 3, 2019, accessed at https://www.cbc.ca/news/politics/maid-assisted-death-minors-mental-illness-1.4956388 February 9, 2020.

For this reason, the EAG's core recommendation, given proper review of evidence, is that MAiD policies must acknowledge that determinations of irremediability cannot be made for mental illnesses at this time.

Core Recommendation:

MAiD policy and legislation should explicitly acknowledge that determinations of irremediability and irreversible decline cannot be made for mental illnesses at this time, and therefore applications for MAiD for the sole underlying medical condition of a mental disorder cannot fulfill MAiD eligibility requirements.

2. Stigmatization and Discrimination

The Halifax group makes several comments regarding risk of stigmatization of those with mental disorder. It is unfortunately true that those with mental disorders have been and continue to be subject to significant stigmatization and discrimination.²⁰

The Halifax group suggests that if applications for MAiD MD-SUMC were not permitted, this would reflect or result in either "the misperception that the suffering caused by mental disorders is trivial or that mental disorder is a result of individual character failure", "the misperception that all people with mental disorders have diminished capacity to make major decisions", or would "imply that people with mental disorders need to be protected from themselves...[and] be seen as stigmatizing persons with mental disorders (suggesting that they lack the capacity for self-determination)". ²¹

None of these assertions are valid since they ignore the fundamental reason MAiD MD-SUMC should not be allowed at this time.

To be clear, the EAG is recommending MAiD not be expanded to allow for MAiD MD-SUMC because, in reality, eligibility requirements of irremediability could never actually be met, yet some practitioners would still opine on irremediability and patients would improperly receive MAiD.

In the view of the EAG, improperly suggesting that any restriction on MAiD MD-SUMC must reflect trivialization of mental disorders, or undermining of capacity or self-determination, is itself stigmatizing. Such arguments imply the only potential reasons for restricting MAiD MD-SUMC are ones based on undermining the autonomy, agency or value of those with mental

²⁰ Canadian Mental Health Association. 2019. Stigma and Discrimination. https://ontario.cmha.ca/ documents/stigma-and-discrimination/

²¹ The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy. pp 19-20.

disorders, and distract from the basic fact that irremediability in mental disorders cannot be predicted and that policy should be guided by this reality.

Furthermore, policy that improperly allows faulty determinations of irremediability of mental illnesses, despite these determinations being impossible to make, would itself be discriminatory by exposing those with suffering and mental disorder to premature death.

Value of life and stigma

When MAID is offered outside the end-of-life context, it means a state endorsed system of life-ending procedures is made uniquely available to those individuals who have a disability or a chronic illness. It constitutes an endorsement in our legal system and health care practices of the idea that those who have such conditions have a valid reason to have their lives cut short actively by health care providers. The lives of others without these conditions are not given this stigmatizing endorsement, and receive more support and protection against premature death. This problem is exacerbated even more in relation to mental illness because we lack the basis to conclude that the condition is irremediable and that there is no alternative to relieve suffering in the long-term.

Access and discrimination

These issues are further compounded by continued lack of access to adequate treatment for mental disorders. The Mental Health Commission of Canada has estimated that only one in three Canadians experiencing a mental health problem or illness have received services and treatment. In addition to inadequate resources, stigma and self-stigma have been shown to be factors in not seeking help and avoiding treatment for mental illnesses. ²³

Canadian data further shows that already marginalized populations are particularly at risk. For example, in different reviews, individuals from households with total annual income under \$30,000 were more likely than those with higher annual incomes to have had accessibility barriers towards receiving mental health services, ²⁴ and for those with mood or anxiety disorders those with lower education (grade 8 or less) were less likely to access mental health services than those with higher education (graduate degree). ²⁵ And there is a difference between those who seek MAiD MD-SUMC where it is permitted, and those who seek MAiD for terminal

²² Mental Health Commission of Canada. (2012). Changing directions, changing lives: The mental health strategy for Canada. Calgary, AB.

²³ Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, SI, Bezborodovs, N., Morgan, C., Rusch, N., Brown, J.S.L., & Thornicroft, G. (2014). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med, 45(1):11-27.

²⁴ Slaunwhite, A. K. (2015). The role of gender and income in predicting barriers to mental health care in Canada. Community Mental Health Journal, 51(5), 621-627.

²⁵ Steele, L., Dewa, C., Lin, E., & Lee, K. L. K. (2007). Education level, income level and mental health services use in Canada. Healthcare Policy, 3(1), 96-106.

conditions. International work suggests patients who request euthanasia for psychiatric disorders lack socio-economic resources, ²⁶ while those seeking assisted dying for terminal conditions have comparatively higher social, economic and educational privilege.²⁷

In the combined context of inadequate treatment due to poor access to care, low rates of help seeking secondary to self-stigma, the cognitive impact of mental illnesses on decision making and responding to Total Life Suffering (see Section 3 (i)), and an already marginalized and vulnerable population suffering from mental illnesses, permitting MAiD MD-SUMC risks further stigmatizing and discriminating against those with mental illness, and risks MAiD becoming a proxy for lack of access to adequate treatment of mental illness and/or unresolved psychosocial stressors.

3. Additional Risks if MAiD MD-SUMC Were Permitted

While the EAG's recommendation that MAiD not be expanded to allow for MD-SUMC at this time is in the first place based on the impossibility of predicting irremediability of mental illnesses at this time, we would also highlight additional challenges related to permitting MAiD MD-SUMC.

(i) Nature of Suffering

Mental disorders continue to be associated with high levels of psychosocial suffering such as social isolation, poverty, inadequate housing, under or unemployment and stigma. People suffering from mental illness often say the stigma and discrimination they experience is worse than the symptoms of the illness itself. Suffering is not compartmentalized, and the intolerability of suffering results from the full range of suffering experienced, not solely from suffering from illness. This recognition that Total Life Suffering is what forms the person's

²⁶ Verhofstadt, M., Thienpont, L., and Peters, G.Y. (2017). When unbearable suffering incites psychiatric patients to request euthanasia: Qualitative study. The British Journal of Psychiatry, 211, 238-245.

²⁷ Battin, M. P., van der Heide, A., Ganzini, L., van der Wal, G., & Onwuteaka- Philipsen, B. D. (2007). Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on "vulnerable" groups. Journal of Medical Ethics, 33, 591-597.

²⁸ Kirby, M. (2006). Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada. Ottawa: Standing Senate Committee on Social Affairs, Science and Technology.

²⁹ U.S.Department of Health and Human Services. (1999). Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

³⁰ Kirby, M., Howlett, M. (2009). Out of the Shadows Forever, Annual Report 2008-2009. Mental Health Commission of Canada.

experience, rather than just illness suffering, is similar to the concept of total pain in palliative care as described by Dame Cicely Saunders³¹ and others.

Under Canada's current MAiD law, intolerability of suffering is acknowledged as being a subjective determination by the patient. The perception and tolerability of suffering can be affected in an individual when mental illness is present in a number of ways. Cognitive symptoms of mental illness often result in a person having lower emotional resilience, such that even regular life stresses that are perceived as mild or moderate when not ill can be perceived as overwhelming when ill.³² Due to cognitive symptoms, people are also more likely to be distressed by issues which at other times may not distress them at all. For example, people experience lower levels of self-esteem and self-worth when depressed, and are more likely to feel guilty that they are a burden to family or others around them even when reassured by others that they are not a burden.³³ In such situations the mental illness essentially creates suffering around an issue that does not reflect an actual problem in the person's life – their suffering is real since they are experiencing it, but the perceived reason for the suffering is not.

Stigmatizing attitudes and perceptions by health care providers of the quality of life of people with chronic mental illnesses also risk influencing the assessment of suffering and of the options to relieve it. Evidence suggests that the assessment of suffering by health care providers is influenced by their own perception of the quality of life of patients. 34, 35 There is further reason be concerned that some providers will use a very broad concept of unbearable suffering as warranting MAiD, including various social determinants of mental health. 36 Studies show that a wide variety of factors are accepted as a basis for unbearable suffering in MAiD MD-SUMC requests, including chronic fatigue, childhood trauma, loneliness, serious conflicts with others, loss of loved ones, unemployment, lack of income, and insurance problems related to medical care.³⁷ We know these factors can be addressed; yet we would enable some health care

³¹ Saunders, C.M. (1978). The management of terminal malignant disease, 1st ed. London: Edward Arnold.

³² Hawton K, Salkovskis P, Kirk J, & Clark D. (1989). Cognitive Behaviour Therapy for Psychiatric Problems. New York, NY: Oxford University Press.

³³ American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

³⁴ Tuffrey-Wijne I, Curfs L, Finlay I, Hollins S. (2018).Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012-2016). BMC Med Ethics. 19(1), 17. https://doi.org/10.1186/s12910-018-0257-6.

³⁵ Stainton, T. Disability, vulnerability and assisted death: commentary on Tuffrey-Wijne, Curfs, Finlay and Hollins. BMC Med Ethics 20, 89 (2019). https://doi.org/10.1186/s12910-019-0426-2.

³⁶ Lemmens, T. (2019). When a theoretical commitment to broad physician aid-in-dying faces the reality of its implementation. American Journal of Bioethics 19(10), 65-68.

³⁷ Verhofstadt, M., Thienpont, L., and Peters, G.Y. (2017). When unbearable suffering incites psychiatric patients to request euthanasia: Qualitative study. The British Journal of Psychiatry, 211, 238-245.

providers to support MAiD based on an overly subjective assessment of unbearable suffering and of its irremediability.

It would be deeply problematic to allow idiosyncratic views of unbearable suffering, including social determinants of mental health, to be the basis of an approval to end the life of patients struggling with mental illness. Yet allowing MAiD MD-SUMC when mental disorders cannot be predicted to be irremediable would risk assisting non-dying people, who would have remediated from their mental disorder, to die due to their Total Life Suffering and psychosocial stressors. The Halifax Group acknowledges this, recognizing that "these factors [social suffering] may thus form part of the motivation for a request for MAiD for persons with MD-SUMC". 39

(ii) Suicide

The Halifax Group points out that the CCA expert panel concluded "[t]here is no evidence of any association between the legal status of assisted dying in a country and its suicide rate: some jurisdictions where assisted dying is legal have higher suicide rates than jurisdictions where the practice is illegal, and vice-versa". However, population reported suicide rates do not reflect those who are provided MAiD MD-SUMC, they reflect those who take their lives outside of sanctioned societal processes such as MAiD. The real question is not about whether population suicide rates change, but about whether allowing MAiD MD-SUMC would lead to society condoning and participating in killing people who we traditionally try to help stay alive through suicide prevention initiatives.

In the specific context of decisions regarding ending life, it must be recognized that unique to mental illness, the wish to die can itself be a symptom of illness rather than a reaction to circumstance. As per the DSM 5, "Thoughts of death, suicidal ideation, or suicide attempts are common. They may range from a passive wish not to awaken in the morning or a belief that others would be better off if the individual were dead, to transient but recurrent thoughts of committing suicide, to a specific suicide plan.....Motivations for suicide may include a desire to give up in the face of perceived insurmountable obstacles, an intense wish to end what is perceived as an unending and excruciatingly painful emotional state, an inability to foresee any enjoyment in life, or the wish to not be a burden to others." No other medical (non-psychiatric)

³⁸ Ho, A., Norman J.S. (2019). Social determinants of mental health and physician aid-in-dying: The real moral crisis. American Journal of Bioethics 19(10), 52–54.

³⁹ The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy. Pg. 18.

⁴⁰ Council of Canadian Academies, 2018. The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition. Ottawa (ON):The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition. Pg. 96.

⁴¹ OECD. (2018). Suicide Rates. Retrieved July 2018, from https://data.oecd. org/healthstat/suicide-rates.htm.

illnesses have a wish to die as a recognized potential core symptom of the diagnostic criteria of the illness itself. And suicide prevention initiatives aim to prevent such suicides.

In this regard, the EAG notes that reviews in Belgium and the Netherlands have found that individuals who seek MAiD for sole criterion mental illness share features with those who attempt suicide, including ambivalence, demoralization and hopelessness regarding life being unbearable, and social isolation and loneliness. In reviewing this issue, the CCA raises concerns in another Key Finding about whether it is possible to distinguish between those seeking MAiD where a mental disorder is the sole underlying medical condition (MAID MD-SUMC) and individuals who are suicidal. The CCA concludes: "There is some evidence that some people who have sought psychiatric euthanasia and assisted suicide in jurisdictions that permit it share certain characteristics with people who attempt suicide. Working Group members have different views about the relationship between MAID MD-SUMC and suicide and whether it is possible to distinguish between them (Section 4.2)."

It should be noted that with respect to the "different views" referenced in the CCA report, the perspectives expressing concern about the inability to distinguish between those whose suicides society traditionally tries to help prevent, from those who seek MAiD MD-SUMC in jurisdictions where it is available, are referenced with multiple citations to evidence suggesting there is overlap between these groups. The views of those indicating they believe suicide can be differentiated from MAiD in these circumstances are not referenced with any evidence-based citations, the only citations are to the Canadian Centre for Suicide Prevention (which is based purely on MAiD as currently practiced in Canada where natural death is reasonably foreseeable, and is therefore not relevant for MAID MD-SUMC discussions), and the American Association of Suicidology (AAS) position statement which has been appropriately critiqued as not being evidence-based. The AAS statement also originates in and focuses on the United States, where MAiD is only available for patients with a terminal illness diagnosis.

(iii) Ambivalence, and need for a "non-ambivalence" criterion

The Halifax Group recommends that a "nonambivalent" decision criterion should not be added as an eligibility criterion. Their report cites a lay person (i.e. non-clinical) definition of ambivalence from the Merriam-Webster Dictionary, and claims that "there is nothing unique to

⁴² Thienpont, L., Verhofstadt, M., Van Loon, T., Distelmans, W., Audenaert, K., & De Deyn, P. (2015). Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study. BMJ Open, 5(7):e007454.

⁴³ Kim, S. Y. H., De Vries, R. G., & Peteet, J. R. (2016). Euthanasia and assisted suicide of patients with psychiatric disorders in the Netherlands 2011 to 2014. Journal of the American Medical Association Psychiatry, 73(4), 362-368. doi: 10.1001.

⁴⁴ Kim, S. Y. H., Conwell, Y., & Caine, E. D. (2018). Suicide and physician-assisted death for persons with psychiatric disorders. How much overlap? JAMA Psychiatry, 75(11):1099-1100.

MD-SUMC that would justify adding an eligibility criterion of a 'nonambivalent' decision for MAiD MD-SUMC". ⁴⁵ The EAG disagrees, and would point out that in reviewing the evidence the CCA expert panel, which all Halifax Group members also sat on, acknowledged in one of its Key Findings that "research demonstrates that most people who attempt suicide are ambivalent about wanting to die (Section 3.2.1)". ⁴⁶

The EAG disagrees with the Halifax Group that "there is nothing unique to MD-SUMC" regarding ambivalence and the wish to die. In the context of potentially increasing ease of access to means of suicide via MAiD for mental illness, the EAG is concerned that the negative cognitive distortions that often accompany depression, coupled with the ambivalence of suicidal thoughts risks people making permanent and fatal decisions about ending their lives during periods of ambivalence or vulnerability, if access to lethal means is made easy and readily available.

The Halifax Group further erroneously claims that "nor must any other health care decisions made by capable people be nonambivalent", and draws parallels to a limited selection of "high-stakes or even life-threatening decisions (e.g., stopping dialysis or not trying another round of chemotherapy)" to support its assertions. The narrowly selected examples provide a faulty analogy.

Abstract academic discussions aside, in the real world treatment refusal of a potentially life-saving treatment in someone who would die without treatment is simply not the same as actively taking the life of someone who would live without MAiD. Providing MAiD to a non-dying patient is an active intervention that permanently changes their course by ending the life of a person who is not otherwise dying.

As the Halifax Group points out, Justice Smith in Carter referred to "a fully-informed, non-ambivalent competent adult patient" and understood non-ambivalence as "persistently and consistently requesting". While current MAiD criteria do not include a criterion of non-ambivalence, current MAiD criteria do require that death be "reasonably foreseeable", hence the natural consequence of existing criteria is that, whether or not the person chooses MAiD, they are dying. Once the "reasonably foreseeable" criterion is removed, receiving MAiD cuts short a potentially much longer period of life. In another IRPP report, Downie and Chandler acknowledge that for mental illnesses this period of foreshortened life can be longer than a

⁴⁵ The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy. pg 26.

⁴⁶ Council of Canadian Academies, 2018. The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition. Ottawa (ON):The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition.

⁴⁷ Carter v. Canada (Attorney General), [2012] BCSC 886 at paragraph 1393.

⁴⁸ Carter v. Canada (Attorney General), [2012] BCSC 886 at paragraph 313.

decade.⁴⁹ While it is impossible to know what is consistently in someone else's mind over a long period of time (i.e. whether they are ambivalent), contrary to the Halifax Group's assertion there is precedent for mandating lengthy periods of time to ensure persistent and consistent wishes for active medical interventions that permanently alter the course of a person's life. For example, gender reassignment surgery requires a diagnosis of "persistent gender dysphoria", 12 continuous months of hormone therapy, plus living 12 continuous months in the identified gender role.⁵⁰

Based on a fuller review of evidence than the narrow scope presented in the Halifax Group report, the EAG disagrees with the Halifax Group's view that a non-ambivalence criterion is not needed for those seeking MAiD when death is not reasonably foreseeable. A non-ambivalence criterion is of particular importance once MAiD is offered in situations when death is not reasonably foreseeable to avoid society facilitating death in ambivalent suicidal people.

Ancillary Recommendation 1:

A non-ambivalence criterion should be required for MAiD in situations when death is not reasonably foreseeable.

(iv) Incomplete safeguard of "well-considered", and need for a "lack of reasonable alternatives" criterion

The Halifax Group's states they believe a criterion of "well-considered" as they define it "more properly takes into account aspects of decision-making that the law should be concerned about. It also achieves what most, if not all, people who are advocating for a criterion of non-ambivalence are actually seeking". The EAG disagrees.

The Halifax Group points out the key elements of a 'voluntary and well-considered request' in the Netherlands' Euthanasia Code⁵¹, and that Belgian legislation requires a request that is "well-considered and repeated"⁵². However the Halifax Group fails to point out the implications of a

⁴⁹ Downie, J., and J.A. Chandler. 2018. Interpreting Canada's Medical Assistance in Dying Legislation. IRPP Report. Montreal: Institute for Research on Public Policy. DOI: https://doi.org/10.26070/efpr-9034.

⁵⁰ https://www.ontario.ca/page/gender-confirming-surgery taken Feb 5, 2020.

Regional Euthanasia Review Committees. 2018. Euthanasia Code 2018: Review Procedures in Practice. Regional Euthanasia Review Committees, the Netherlands. https://english. euthanasiecommissie.nl/binaries/euthanasiecommissie-en/documents/publications/euthanasia-code/euthanasia-code-2018/euthanasia-code-2018/euthanasia-code-2018/Euthanasia-code-2018_ENGELS_def.pdf.

⁵² Nys, H. (2017). A Discussion of the Legal Rules on Euthanasia in Belgium Briefly Compared with the Rules in Luxembourg and the Netherlands. In D. A. Jones, C. Gastmans & C. MacKellar (Eds.), Euthanasia and Assisted Suicide: Lessons from Belgium. Cambridge, United Kingdom: Cambridge University Press.

key additional safeguard in both countries that in all cases there needs to be an absence of "reasonable alternatives" that could be tried prior to MAiD being provided.

In the Netherlands, there needs to be "no prospect of improvement" and "the physician must have come to the conclusion, together with the patient, that there is no reasonable alternative to the patient's situation". In Belgium, the physician must ensure that "the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident with no reasonable treatment alternatives or therapeutic perspectives". ^{53, 54} Current Canadian MAiD law and policy do not require the absence of "reasonable alternatives", but only the purely subjective requirement that a person's suffering "cannot be relieved under conditions that they consider acceptable". This means that in Canada patients can receive MAiD even when there are "reasonable alternatives" that have never been attempted. Unlike in Belgium and the Netherlands, under current MAiD Canadian law the patient can reject all options for relief of suffering at the end of life and still obtain MAiD. Simply informing people of reasonable alternatives, as the Halifax Group suggests, is not a safeguard.

The omission in the Halifax Group report of discussion of the implications of Canadian law not having a "lack of reasonable alternatives" criterion, unlike other countries where MAiD is practiced for non-terminal conditions, is puzzling. This was reviewed at length in the CCA report on which all Halifax Group members sat. Based on the CCA review, and the absence of a "lack of reasonable alternatives" requirement in Canada, one of the CCA explicit Key Findings was that "No other country permits MAID MD-SUMC where one of the eligibility criteria is based on an individual's personal assessment of what conditions for relief of their intolerable suffering they consider acceptable. If Canada were to expand MAID MD-SUMC using this criterion, it could become **the most permissive jurisdiction in the world** with respect to how relief of suffering is evaluated."55

In the view of the EAG, and based on the evidence, a "well-considered" criterion alone as the Halifax Group is suggesting is inadequate in the absence of a "lack of reasonable alternative" criterion in situations where death is not reasonably foreseeable. The EAG recognizes that the law allows patients to refuse all treatments. But this has, with regards to patients who are not close to their natural death, never been combined with the option to request from the health care system an active ending of their lives when they have various treatment options left. Allowing or even requiring health care providers to actively end the life of patients in those

⁵³ CCA MAiD MD-SUMC pp 113-114.

Lemmens, T. (2018). Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice (April 3, 2018). (2018) 85 Supreme Court Law Review (2nd Series) 459.

55 CCA MAID MD-SUMC pg. 148.

circumstances is allowing or even imposing an unprecedented duty to provide substandard care. As pointed out in further detail in Appendix 1 of this report, this runs counter to other areas of medical practice where physicians are not allowed to provide care or to do medical interventions that are not in line with professional standards, even when patients insist. The EAG would further point out that numerous medical services do require certain pre-conditions before they are potentially offered to a person, for example liver transplants.

Ancillary Recommendation 2:

A "lack of reasonable alternative" criterion should be required prior to being eligible for MAiD in situations when death is not reasonably foreseeable.*

*NB: Given the issues cited above, the EAG supports a "lack of reasonable alternative" criterion for all MAiD applications, as is required elsewhere in the world except in Canada. However, this criterion is particularly essential to introduce as current policies change and the "reasonably foreseeable natural death" criterion is rescinded, which is the focus of this critique.

(v) False Reassurance of "Safeguards"

The Halifax group suggests a number of safeguards that it views would confer adequate protection in potential cases of MAiD MD-SUMC. They suggest that "where the challenges with respect to capacity are too great, practitioners will not be able to reasonably form the relevant opinion and therefore individuals will not be eligible for MAiD". This falsely suggests that capacity can serve as safeguard against potential cognitive distortions associated with mental illnesses. This is not true, as many times people will remain capable, yet mental illness symptoms significantly impact their decision making. Even while capacity is maintained, decisions when one is suffering from mental illness can be influenced by illness symptoms of hopelessness, selective ruminations about potential negative outcomes and dismissal of potential positives, stigma, lack of sense of worth, feeling a burden to one's family, and other cognitive changes that can impact treatment and other decisions. ^{56, 57, 58, 59}

⁵⁶ Beck, A., Rush, J., Shaw, B., & Emery, G. (1987). Cognitive Therapy of Depression. Guilford Press.

⁵⁷ Greenberger, D., & Padesky, C. A. (2016). Mind over mood: change how you feel by changing the way you think. Second edition. New York, NY: The Guilford Press.

⁵⁸ Burns, D. D. (1999). The feeling good handbook, Rev. ed. New York, NY, US: Plume/Penguin Books.

⁵⁹ Ferreri, Fl, Lapp L.K., & Peretti C.C. (2011). Current research on cognitive aspects of anxiety disorders. Curr Opin Psychiatry, 24(1):49-54.

The Halifax Group suggests that criteria should "not require an assessment of the quality of the decision the person is making". Though they cite the "well considered" criterion, the Halifax Group fails to point out that in the Netherlands the RTE Code of Practice "well-considered" criterion also requires that "it must be ruled out that the patient's psychiatric disorder has impaired his ability to form judgments". The notion that a capacity safeguard alone would protect against such impaired decision making is incorrect. Most people with mental illness retain full capacity to make medico-legal decisions. Ignoring that decision-making can be impaired by mental illness even while capacity is maintained is itself discriminatory, as it fails to account for relevant challenges those with mental illness face.

The Halifax Group states that, rather than being evidence of an unsettled or poorly considered desire for MAiD, individuals who request MAiD and choose not to proceed could reflect "a desire for a backup or exit route, revealing that the option of MAiD is itself a form of palliation, enabling individuals to persevere through their suffering". ⁶⁰ This argument, and recognition that a psychological intervention could bring relief of suffering, undermines the notion that such individuals are in an irremediable state.

Indeed, the CCA found that international data on MAiD MD-SUMC show that 38% withdrew their requests and 11% postponed or cancelled the procedure after approval. Thus, despite the MAiD MD-SUMC applications being for suffering that was "chronic, constant and unbearable, without prospect of improvement, due to treatment resistance", half of those applying changed their minds and were still alive between 1 to 4 years later (depending on when the patient was evaluated during the study period). There is of course no way to know how many of those who received MAiD might have changed their minds in that time frame if they had not been assisted to die.

In many ways this goes to the heart of the issue of what MAiD MD-SUMC assessments would essentially falsely assert was irremediable, when in fact the person cannot be determined to be in an irremediable state. In the view of the EAG, the implication that offering MAiD to those who are *not* in an irremediable state as a psychological treatment, knowing that some would still proceed with MAiD and have their lives taken, is ethically, morally and clinically unsound.

In terms of potential safeguards for MAiD MD-SUMC, no safeguards could adequately address the reality that irremediability cannot be predicted in individual cases of mental disorder. This is reflected in the CCA report on MAiD MD-SUMC, which cites the view of some members that

⁶⁰ The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy. Pg. 21.

⁶¹ CCA MAID MD-SUMC pg. 92.

"even with safeguards in place, some of the previously identified risks of over-inclusion would still not be mitigated should MAID MD-SUMC be expanded". 62

Finally, the Halifax Group makes recommendations regarding oversight and a post hoc peer review process. The EAG agrees that such an oversight and review process would be important as MAiD is expanding to those for whom death is not reasonably foreseeable. However, the EAG would point out that such a review process would not be any form of safeguard for MAiD MD-SUMC applications. Once patients receive MAiD, they never have a chance to remediate. Any post hoc review will wrongly and permanently categorize all such cases as having been "irremediable", and wrongly contribute to the faulty initial premise that irremediability could be properly assessed in cases of mental disorder. A post hoc analysis of MAiD MD-SUMC cases would simply, and wrongly, reassure society that it is providing MAiD for conditions that are irremediable, when in fact evidence shows that some of those who received MAiD for MD-SUMC would have gotten better — we just will not know who.

4. Potentially Permitting MAiD MD-SUMC

Given that it is not possible to predict irremediability in cases of mental illness, the single EAG core recommendation is that MAiD policy and legislation should explicitly acknowledge that determinations of irremediability and irreversible decline cannot be made for mental illnesses at this time.

If MAiD MD-SUMC were to be considered at some future point, the EAG believes this should only occur after robust societal discourse and if MAiD policy and legislation openly indicated that MAiD could be provided for non-irremediable conditions. This public discourse and the development of policy should include engagement with diverse individuals who have lived experience of mental illness, particularly those from vulnerable, marginalized or underrepresented groups, such as those with disabilities, Indigenous people and communities, those living in poverty, and LGBTQ2S people.

As indicated at the outset, the EAG agrees that mental disorders can cause significant suffering; however, they cannot be deemed to be irremediable. There is significant risk in society falsely reassuring itself it is providing MAiD for irremediable psychiatric conditions, when in fact mental illness cannot be determined to be irremediable and MAiD is being provided for Total Life Suffering. If societal policy were to shift to allow MAiD for Total Life Suffering even without the requirement of an irremediable medical condition, then this should be done openly and transparently, with society being fully aware what MAiD is really being provided for. For

⁶² CCA MAID MD-SUMC pg. 177.

example, some in the Netherlands are openly advocating that people above the age of 70 who are tired of living should be provided assisted dying, even in the absence of an irremediable medical condition.⁶³

To be clear, the EAG does not support and is not recommending this.

However, allowing MAiD MD-SUMC under the false pretense that irremediability can be predicted in mental illnesses is dangerous, and discriminates against those with mental illness. It reassures society that MAiD is being provided for reasons it is not. If society thinks those suffering with a *remediable* medical condition should be provided MAiD, it should make that decision openly and transparently, rather than be falsely reassured that the "irremediable" and "irreversible decline" assessment criteria are met for those with MAiD MD-SUMC. Further, as indicated above, for any MAiD applications when death is not reasonably foreseeable, the EAG makes an ancillary recommendation that a "lack of reasonable alternative" criterion should be required prior to being eligible for MAiD in situations when death is not reasonably foreseeable.

CONCLUSION

The EAG hopes this critique of the Halifax Group report is helpful to policy makers and the public as MAiD policies evolve in Canada. We further hope that a fulsome review of evidence assists legislators in supporting our core recommendation, that:

MAiD policy and legislation should explicitly acknowledge that determinations of irremediability and irreversible decline cannot be made for mental illnesses at this time, and therefore applications for MAiD for the sole underlying medical condition of a mental disorder cannot fulfill MAiD eligibility requirements.

It is important to note that arguments that claim limiting MAiD MD-SUMC is stigmatizing, or suggesting that "excluding all persons with MD-SUMC from accessing MAiD is discriminatory on the basis of diagnosis rather than on the basis of real capabilities", as the Halifax Group suggests, are themselves stigmatizing and discriminatory. Such arguments fail to recognize the real differences between unpredictable mental disorders and other predictably progressive medical conditions informing MAiD policy. Failing to account for these differences, and for the reality that irremediability cannot be predicted in mental illnesses, would put highly vulnerable people at risk, and lead society to take lives of non-dying people with mental disorders who would have improved.

⁶³ Out of Free Will (uit vrije wil translated). (2010). Retrieved from http://www.uitvrijewil.nu/index.php?id=1000

APPENDIX 1 – Further discussion of patient choice/autonomy regarding treatment(s)

The Supreme Court's explicit confirmation in Carter that ""[i]rremediable" ... does not require the patient to undertake treatments that are not acceptable to the individual", 64 and the well-recognized right under Canadian law to refuse life-saving treatment, may incline some to suggest that MAiD would have to be available even in the context where patients not at the end-of-life refuse all forms of treatment.

The EAG believes that a charitable interpretation of the Supreme Court's statement in Carter, an interpretation that reconciles this statement with the need to protect the lives of people who are vulnerable, as well as respect for the integrity of professional medical practice and for the duty of care of health care providers, is warranted. The EAG is of the opinion that it cannot have been the intention of the Supreme Court to insist that people who have various treatment options which will likely relieve their suffering and allow them to continue living for years or decades can refuse all treatment options while at the same time expect a mobilization of state resources and medical services to end their lives. This would have serious consequences for the protection of vulnerable people and for the integrity of medical practice. It would impose an unprecedented ethical and psychological burden on health care providers. It is also at odds with current medical practice and policy and suicide prevention activities.

The EAG is of the opinion that MAiD remains a uniquely challenging procedure, and that the Supreme Court's Carter decision, with its recognition of the need for a strict regulatory regime and the need for strong safeguards, recognizes this unique status. It is not the same, and definitely not in all circumstances, as refusing life-saving treatment.

It is one thing to recognize that people in the circumstances of the plaintiffs in Carter can refuse all further treatment while also requesting that health care providers in those circumstances assist in ending their life; it is quite another to suggest that patients who will likely have years or decades to live with standard medical interventions that are likely to relieve their suffering can refuse all of them, and in addition insist that health care providers actively end their life. While the outcome of mere treatment refusal may for some forms of illness in the long run be the same outcome as an active life-ending intervention, it clearly is not the same for the health care providers who are asked to perform it, and for the medical system that is asked to endorse this practice (the EAG would note here again that in the context of mental illnesses, remission without treatment also occurs, which indicates the likelihood of a very different outcome of treatment refusal and requesting a life-terminating intervention).

_

⁶⁴ Carter v Canada (AG) 2015 1 SCR 331, par. 127.

Moreover, there is also a difference between these two issues related to their basis in law. Treatment refusal is not only based on the right to make one's own treatment decisions, but also reflects the right to bodily integrity. Invading the person's body with a medical intervention without clear and unambiguous consent constitutes assault, as the CCA MAiD panel on advance directives emphasized. Consent constitutes in this context a waiver of a right to be free from bodily invasion. In the case of MAiD, we have the opposite situation: without clear and unambiguous consent, we are dealing with the most serious form of bodily invasion resulting in death. It speaks for itself that we should expect the utmost clarity and rigour in the decision-making process for such a life-ending invasion of one's body.

Not enforcing unwanted treatment is required to respect the bodily integrity of patients and does not constitute a clear violation of the professional standard of care. However, a regulatory system that allows or even requires health care providers to actively end the life of patients who have several treatment options left is allowing or even imposing a duty to provide substandard care. In standard medical practice, health care providers are not permitted to do an intervention or to provide services that violate professional standards, even when patients insist. For example, physicians cannot prescribe experimental drugs that have not been approved outside the context of a permitted clinical trial. They cannot provide untested stem cell therapies, or other unproven treatments or surgeries, even when patients insist that they offer them a chance of survival.

Perhaps a more apt analogy related to mental illness is the example of Body Dysmorphic Disorder (BDD). Individuals with BDD are preoccupied and distressed by one or more nonexistent or minor defects in their physical appearance. Their preoccupation with these perceived flaws can lead them to seek out cosmetic treatments and surgery rather than psychiatric care. Reviews of individuals with BDD who have received surgery show that even with surgery BDD symptoms rarely resolve, and sometimes surgery makes the symptoms worse. The mental illness symptoms of those with BDD significantly influence these individuals' decision making processes, and cosmetic surgical treatments are not recommended in these situations despite these being individuals who typically retain formal capacity. Providers who simply agree to provide repeat surgical procedures, rather than mental health care, would be providing substandard care.

If a violation of the standard of care is not allowed even when patients request it on the basis of their hope to live, for example in the case of untested stem cell therapies or unapproved

⁶⁵ Council of Canadian Academies, 2018. The State of Knowledge on Advance Requests for Medical Assistance in Dying. Ottawa (ON):The Expert Panel Working Group on Advance Requests for MAID, 38.

⁶⁶ Kelly, M., Didie, E., & Hart, A. (2018). Cosmetic Treatments and Body Dysmorphic Disorder. International OCD Foundation. https://bdd.iocdf.org/expert-opinions/cosmetic-treatments-and-bdd/

pharmaceuticals, how could it be permissible in the context of patients' often ambiguous and ambivalent desires to die? As indicated previously, the EAG would further point out that numerous medical services do require certain pre-conditions before they are potentially offered to a person, for example liver transplants.

REFERENCES

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.

American Psychiatric Association. (2016). Position statement on medical euthanasia. APA.

Battin, M. P., van der Heide, A., Ganzini, L., van der Wal, G., & Onwuteaka- Philipsen, B. D. (2007). Legal physician-assisted dying in Oregon and the Netherlands: Evidence concerning the impact on "vulnerable" groups. Journal of Medical Ethics, 33, 591-597.

Beck, A., Rush, J., Shaw, B., & Emery, G. (1987). Cognitive Therapy of Depression. Guilford Press.

Bellack, A.S. (2006). Scientific and Consumer Models of Recovery in Schizophrenia: Concordance, Contrasts, and Implications. Schizophr Bull,32(3):432-42.

Burns, D. D. (1999). The feeling good handbook, Rev. ed. New York, NY, US: Plume/Penguin Books.

Canadian Mental Health Association. 2019. Stigma and Discrimination. https://ontario.cmha.ca/documents/stigma-and-discrimination/

Carter v. Canada (AG) 2015 1 SCR 331.

Carter v. Canada (Attorney General), [2012] BCSC 886.

CBC News, January 3, 2019, accessed at https://www.cbc.ca/news/politics/maid-assisted-death-minors-mental-illness-1.4956388 February 9, 2020.

Centre for Addiction and Mental Health (CAMH). (2017). Policy Advice on Medical Assistance in Dying for Mental Illness. Toronto (ON): CAMH.

Chin, W.Y., Chan, K.T., Lam, C.L., Wan, E.Y., & Lam, T.P. (2015). 12-Month naturalistic outcomes of depressive disorders in Hong Kong's primary care. Fam Pract, 32(3):288-96.

Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, Sl, Bezborodovs, N., Morgan, C., Rusch, N., Brown, J.S.L., & Thornicroft, G. (2014). What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. Psychol Med, 45(1):11-27.

Council of Canadian Academies, 2018. The State of Knowledge on Advance Requests for Medical Assistance in Dying. Ottawa (ON):The Expert Panel Working Group on Advance Requests for MAID.

Council of Canadian Academies, 2018. The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition. Ottawa (ON): The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition.

Dembo, J. & Clemens, N. (2013). The Ethics of Providing Hope in Psychotherapy. J Psychiatric Practice, 19(4):316-322.

Dembo, J., Schuklenk, U., & Reggler, J. (2018). "For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying where Mental Illness Is the Sole Underlying Condition. Can J Psych, 63(7):451-456.

Downie, J., and J.A. Chandler. 2018. Interpreting Canada's Medical Assistance in Dying Legislation. IRPP Report. Montreal: Institute for Research on Public Policy. DOI: https://doi.org/10.26070/efpr-9034.

Ferreri, Fl, Lapp L.K., & Peretti C.C. (2011). Current research on cognitive aspects of anxiety disorders. Curr Opin Psychiatry, 24(1):49-54.

Gaind, K.S. (2016). Canadian Psychiatric Association interim response to Report of the Special Joint Committee on physician assisted dying. CPA.

Greenberger, D., & Padesky, C. A. (2016). Mind over mood: change how you feel by changing the way you think. Second edition. New York, NY: The Guilford Press.

Hawton K, Salkovskis P, Kirk J, & Clark D. (1989). Cognitive Behaviour Therapy for Psychiatric Problems. New York, NY: Oxford University Press.

Ho, A., Norman J.S. (2019). Social determinants of mental health and physician aid-in-dying: The real moral crisis. American Journal of Bioethics 19(10), 52–54.

https://www.ontario.ca/page/gender-confirming-surgery taken Feb 5, 2020.

Kelly, M., Didie, E., & Hart, A. (2018). Cosmetic Treatments and Body Dysmorphic Disorder.

International OCD Foundation. https://bdd.iocdf.org/expert-opinions/cosmetic-treatments-and-bdd/

Kim, S. Y. H., Conwell, Y., & Caine, E. D. (2018). Suicide and physician-assisted death for persons with psychiatric disorders. How much overlap? JAMA Psychiatry, 75(11):1099-1100.

Kim, S. Y. H., De Vries, R. G., & Peteet, J. R. (2016). Euthanasia and assisted suicide of patients with psychiatric disorders in the Netherlands 2011 to 2014. Journal of the American Medical Association Psychiatry, 73(4), 362-368. doi: 10.1001.

Kirby, M. (2006). Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada. Ottawa: Standing Senate Committee on Social Affairs, Science and Technology.

Kirby, M., Howlett, M. (2009). Out of the Shadows Forever, Annual Report 2008-2009. Mental Health Commission of Canada.

Lemmens, T. (2019). When a theoretical commitment to broad physician aid-in-dying faces the reality of its implementation. American Journal of Bioethics 19(10), 65–68.

Lemmens, T. (2018). Charter Scrutiny of Canada's Medical Assistance in Dying Law and the Shifting Landscape of Belgian and Dutch Euthanasia Practice (April 3, 2018). (2018) 85 Supreme Court Law Review (2nd Series) 459.

Mental Health Commission of Canada. (2012). Changing directions, changing lives: The mental health strategy for Canada. Calgary, AB.

Mishara, B. L., & Kerkhof, A. J. F. M. (2018). Canadian and Dutch doctors' roles in assistance in dying. Canadian journal of public health, 109(5-6), 726-728. doi:10.17269/s41997-018-0079-9.

Nys, H. (2017). A Discussion of the Legal Rules on Euthanasia in Belgium Briefly Compared with the Rules in Luxembourg and the Netherlands. In D. A. Jones, C. Gastmans & C. MacKellar (Eds.), Euthanasia and Assisted Suicide: Lessons from Belgium. Cambridge, United Kingdom: Cambridge University Press.

OECD. (2018). Suicide Rates. Retrieved July 2018, from https://data.oecd. org/healthstat/suiciderates.htm.

Out of Free Will (uit vrije wil translated). (2010). Retrieved from http://www.uitvrijewil.nu/index.php?id=1000

Regional Euthanasia Review Committees. 2018. Euthanasia Code 2018: Review Procedures in Practice. Regional Euthanasia Review Committees, the Netherlands. https://english.euthanasiecommissie.nl/binaries/euthanasiecommissie-en/documents/publications/euthanasia-code/euthanasia-code-2018/euthanasia-code-2018/Euthanasie-code-2018 ENGELS def.pdf.

Rousseau, S., Turner, S., Chochinov, H. M., Enns, M. W., & Sareen, J. (2017). A national survey of Canadian psychiatrists' attitudes toward medical assistance in death. The Canadian Journal of Psychiatry, 62(11), 787-794.

Royal Australian & New Zealand College of Psychiatrists. (2016). Position Statement 67: physician assisted suicide. Royal Australian and New Zealand College of Psychiatrists. RANZCP.

RSC 1985, c C-46.

Saunders, C.M. (1978). The management of terminal malignant disease, 1st ed. London: Edward Arnold.

Slaunwhite, A. K. (2015). The role of gender and income in predicting barriers to mental health care in Canada. Community Mental Health Journal, 51(5), 621-627.

Stainton, T. Disability, vulnerability and assisted death: commentary on Tuffrey-Wijne, Curfs, Finlay and Hollins. BMC Med Ethics 20, 89 (2019). https://doi.org/10.1186/s12910-019-0426-2.

Steele, L., Dewa, C., Lin, E., & Lee, K. L. K. (2007). Education level, income level and mental health services use in Canada. Healthcare Policy, 3(1), 96-106.

The Halifax Group. 2019. MAiD Legislation at a Crossroads: Persons with Mental Disorders as Their Sole Underlying Medical Condition. IRPP Report (February). Montreal: Institute for Research on Public Policy.

Thienpont, L., Verhofstadt, M., Van Loon, T., Distelmans, W., Audenaert, K., & De Deyn, P. (2015). Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study. BMJ Open, 5(7):e007454.

Truchon v. Attorney General of Canada, 2019 QCCS 3792 (CanLII).

Tuffrey-Wijne I, Curfs L, Finlay I, Hollins S. (2018). Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant

euthanasia cases in the Netherlands (2012-2016). BMC Med Ethics. 19(1), 17. https://doi.org/10.1186/s12910-018-0257-6.

U.S.Department of Health and Human Services. (1999). Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

Verhofstadt, M., Thienpont, L., and Peters, G.Y. (2017). When unbearable suffering incites psychiatric patients to request euthanasia: Qualitative study. The British Journal of Psychiatry, 211, 238-245.

Whiteford, H.A., Harris, M.G., McKeon, G., Baxter, A., Pennell, C., Barendregt, J.J., & Wang, J. (2013). Estimating remission from untreated major depression: a systematic review and meta-analysis. Psychol Med, 43(8):1569-85.